

ABORIGINAL MATERNITY CARE Resourcebook



SIoux LOOKOUT
Meno Ya Win
HEALTH CENTRE



Northern Ontario
School of Medicine
École de médecine
du Nord de l'Ontario
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uOttawa



Len Kelly MD, MClIn Sci, FCFP; Professor,
Irwin Antone MD, FCFP; Assistant Professor,
Natalie St. Pierre-Hansen BA, LLB; Research Intern,
 Division of Clinical Sciences, Northern Ontario School of Medicine, Sioux Lookout ON

ABORIGINAL WOMEN'S CARE RESOURCEBOOK

This edited compilation is meant to gather together some of the best and most relevant research material around appropriate cross cultural Aboriginal women's care. The references arise from peer-reviewed research, including research initiatives in Sioux Lookout at the Meno Ya Win Health Centre, which has a mandate to become a Centre of Excellence for Aboriginal Health care.

During the course of cross-cultural studies in Northern Ontario, we have encountered many helpful and clarifying studies and references. We hope these articles serve as a practical orientation for healthcare personnel engaging in cross-cultural care with Aboriginal patients (including First Nations, Inuit and Metis Nations). Any omissions are an oversight. We attempted to cover the topics in an up to date manner. Maternity care is a challenging area of healthcare delivery. This resource material may lessen some of the cross-cultural challenges in caring for Aboriginal women, even though most of our learning will come from our patients and their communities.

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Cover: "The New Arrival" by Lloyd Kakepetum.

INTRODUCTION

The Northern Ontario School of Medicine in partnership with the University of Ottawa has initiated a residency program in Obstetrics and Gynecology. One of the program objectives is to provide appropriate cross-cultural care to Aboriginal women. In conjunction with the researchers at the Sioux lookout Meno Ya Win Health Centre, we have developed this resource book for residents and other clinicians involved in delivering health care to First Nations, Inuit and Metis women.

Canada's First Peoples comprise 4% of Canada's population and form the background of our nation. Each First Nation has its own tradition, language and history. Delivering care across cultures is different, often difficult and culture specific. Caregivers need to understand each patient individually and we need to know some of the history and research specific to the communities and peoples we serve.

We are pleased to present a resource that may act as a backdrop to this process. The listings are not complete, but are a good starting point to understand some of the cross-cultural research available in Canada. Authors and publishers have gratefully permitted this compilation for educational purposes. Additional suggested articles can be forwarded to the editors for inclusion in future editions.

Dr S Fairley
Northern Ontario School of Medicine

Dr G Posner
University of Ottawa

Aboriginal Health Status

Macaulay A. Improving aboriginal health: How can health care professionals contribute? *Canadian Family Physician* 2009;55:334-336.

In this commentary piece Macaulay describes the Aboriginal concept of health and well-being. She explains how this should be incorporated into patient care. Caregivers should also understand the effects of intergenerational trauma caused by colonialization and the residential school system. She also identifies the need for research and evaluation around health care programming as well as the need for increased Aboriginal healthcare professionals.

Smylie J. A Guide for Health Professionals Working with Aboriginal Peoples: Executive Summary. *Journal of Obstetricians and Gynecologists of Canada* 2000;100:1056-1060.

Smylie describes issues surrounding Aboriginal health. The Aboriginal definition of health is one that is holistic: the concept of the circle or cycle is fundamental and the individual is seen as connected to family, community and environment. Healthcare Practitioners should work with individuals and communities to improve health outcomes but avoid stereotyping when addressing key areas of morbidity and mortality. She outlines these key areas.

Additional References

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Smylie J. A Guide for Health Professionals Working with Aboriginal Peoples: Health Issues Affecting Aboriginal Peoples. *Journal of Obstetricians and Gynecologists of Canada* 2001;23(1):54-68.

Smylie J. A Guide for Health Professionals Working with Aboriginal Peoples: The Sociocultural Context of Aboriginal Peoples in Canada. *Journal of Obstetricians and Gynecologists of Canada* 2000;22(12):1070-1081.

Waldram JB, Herring DA, Young TK. *Aboriginal health in Canada: historical, cultural, and epidemiological perspectives*. 2nd ed. Toronto: University of Toronto Press; 2006.

Improving aboriginal health

How can health care professionals contribute?

Ann C. Macaulay CM MD FCFP

Health is a state of complete physical, mental and social well-being, not merely the absence of disease or infirmity.¹

Well-being is associated with high self-esteem, a feeling of being at peace and being happy. This includes education. It includes employment. It includes land claims. It includes resource management. All of these lead back to wellness and well-being.

Rhea Joseph²

Health and well-being are not isolated, but inexorably linked with all aspects of living. Within this large landscape, what contributing roles can health professionals play in promoting aboriginal health?

All health care professionals can promote improved aboriginal health in Canada. This can happen daily for those caring for patients of all ages in a wide variety of settings, including rural communities, urban environments, or tertiary care centres. We also need to advocate in key areas to promote aboriginal health. These include helping all Canadians to understand the history of aboriginal peoples, with the negative legacy of colonization and the residential school system; the role of the social determinants of health; and the urgent need for increased education and employment. We must also advocate for more aboriginal health care professionals; multidisciplinary teams; increased aboriginal self-government, with control of programs including health and education; improved care for patients, families, and communities through adequate funding and relevant programs that are developed with aboriginal input and are appropriately evaluated; and research directed by or undertaken in partnership with aboriginal peoples. This is a long list but all these issues are important, interrelated, and need to be championed.

In context

Today there are approximately 3.3 million aboriginal people living in Canada, of whom about 61% are First Nations, 34% are Metis, and 5% are Inuit. These are 3 separate groups, all with unique local geographic and linguistic heritages, cultural practices, and spiritual beliefs, and it is important to avoid generalizations. Currently 55% of aboriginal people live in urban areas, some with strong ties to their communities of origin and others identifying with urban communities.³

Cet article se trouve aussi en français à la page 337.

There are striking inequities in aboriginal health outcomes, including life expectancies for both men and women approximately 5 to 10 years lower than the general population.³ This reflects the effects of history combined with the social determinants of health. Aboriginal history includes past colonization and the 1876 Indian Act, with appropriation of land and loss of traditional livelihoods, and current colonization through negative stereotyping. It also includes the residential school system established in 1892 to "civilize" aboriginal people: children were removed from their homes and placed in boarding schools funded by the federal government and operated by the churches. Children were forbidden to speak their own languages, and most were emotionally, physically, and sexually abused. This left a legacy of lost language and traditions, destroyed self-esteem, and unestablished parenting skills. As adults, many turned to alcohol and drugs to relieve the mental pain, resulting in fragmented communities and multigenerational trauma. The last residential school closed in 1996, and only in the summer of 2008 did the Canadian government finally offer an apology.

The social determinants of health include poverty, overcrowding, and unemployment. In 2001, 41% of aboriginal children under the age of 14 were living in poverty, which was 3 times the national rate; 35% of children were being raised by a single parent; and 1 in 4 single mothers reported an annual income of less than \$10000. In 2006, 11% of aboriginal people lived in overcrowded conditions (defined as greater than 1 person per room), which is 4 times higher than the general population.⁴ At the time of writing, 100 aboriginal communities needed to boil their water owing to contaminated water supplies.³

In recognition of these issues, the federal government established the Royal Commission on Aboriginal Peoples (RCAP) in 1996. The extensive final report stated the following:

Aboriginal people endure ill health, run-down and overcrowded housing, polluted water, inadequate schools, poverty and family breakdown at rates found more often in developing countries than in Canada.²

The document made many important recommendations to address health, economic development, human resources, and institution building.² Ten years later the Assembly of First Nations graded the federal

government with letter grades *A* through *F* for action taken on each RCAP recommendation. Their "report card" stated that there was "no sustained investment in meeting the basic needs of First Nations communities or in addressing key determinants of health/well being."⁵

This is a lost decade when the federal government could have made fundamental changes recommended by their own commission. There was no recognition of the groundbreaking work of Chandler and Lalonde who have documented lower—or absent—suicide rates in aboriginal communities in British Columbia that have high rates of "cultural continuity." Cultural continuity factors include self-government; settled land claims; women in community government; and community control of education, health, police, child welfare, and fire departments,⁶ many factors that were recommended by RCAP. Others have hypothesized that cultural continuity might also explain varying rates of chronic disease across communities.⁷

Against this negative background, health care professionals—including, of course, family physicians—can play a positive role in patient care, research, and health education, and whenever possible use their influence to advocate for wider change.

Patient care

Nonaboriginal health care professionals do best by adopting a holistic approach in offering advice and care for their patients. They should practise cultural humility by respecting local traditions and by being careful not to impose their own values. They need to understand that health encompasses physical, emotional, intellectual, and spiritual well-being, as reflected in the 4 quadrants of the medicine wheel⁸; to recognize the multigenerational legacies of colonization, the residential school system, and importance of local history; to respect traditional beliefs and healing practices; and to acknowledge the role of the social determinants of health and, in many communities, expensive foods and inadequate resources. They should work in multidisciplinary teams and include community health representatives. They must be sensitive to cross-cultural care. For example, less eye contact might be normal and patients might be very comfortable with long silences and might not answer direct questions. In self-contained communities, what happens to one individual will not only affect his or her entire family, but also the entire community. Aboriginal patients might be operating in a second language, might need an interpreter, and might not be comfortable questioning someone who is perceived to have greater power and knowledge. There are now excellent publications authored by aboriginal health care professionals and aboriginal scientists. These individuals are well positioned to understand the key issues in aboriginal health and have the greatest knowledge, deep insights, and practical recommendations.⁹

Non-Aboriginal health care professionals need to understand how Aboriginal people interpret their illness experience and respond to treatment regimens, and to respect the logic and rationale of another system of thought. They need to adapt their treatment plans and education programs to the cultural, social and economic circumstances of their Aboriginal patients and to recognize that many communities are geographically remote, with little access to specialty services.¹⁰

Some of these points are clearly illustrated in the article by Elliott and de Leeuw¹¹ included in this issue of *Canadian Family Physician* (page 443), which relates the case of a resident who was unaware that in the past aboriginal people with tuberculosis were sent away for treatment and many died without seeing their families again. The authors also raise valid concerns that health care professionals might unconsciously internalize mainstream negative perceptions of aboriginal peoples. Perhaps the general population will gain greater understanding if leading authors continue to describe the many positive attributes of aboriginal people, their many contributions to Canadian society, and the need for land claim settlements.¹²

Research

All those engaged in research—or collecting data for researchers—should ensure that the research meets high standards, uses a participatory approach in which researchers are in full partnership with aboriginal peoples and organizations,¹³ and follows the ethical guidelines of the Canadian Institutes of Health Research¹⁴ and National Aboriginal Health Organization.¹⁵ All results must be shared with communities and organizations in such a way as to benefit aboriginal peoples. In the past too much research focused on disease and dysfunction, which only served to emphasize the negative and did not add useful information to develop practical solutions. Today more research is focusing on resilience and is seeking answers to improve health. The 2 research articles in this issue of *Canadian Family Physician* are both excellent examples of positive research to investigate problems and use the results to improve future programs. The study by Kelly and colleagues¹⁶ (page 394) uses qualitative methods to better understand the needs of aboriginal patients receiving palliative care in a northern hospital; the results are being used to further improve end-of-life care in that environment. Other health care professionals can ask their aboriginal patients if the results are relevant for other locations. The SLICK study¹⁷ (page 386) uses quantitative research to evaluate many levels of diabetes care in Alberta and clearly documents that aboriginal patients are not receiving the care recommended by the Canadian Diabetes Association. The results show a reduced level

of care, inadequate screening for complications, and a lack of education from teams that include nutritionists and diabetes nurse educators. This is exactly the kind of evaluation that is needed for all programs. The results reinforce once again the glaring lack of appropriate programs needed by aboriginal peoples—in this case those with type 2 diabetes. I hope these results will have a real effect on care. The results should convince the federal government to immediately increase funding to improve programs for those with diabetes. It should also stimulate funding to develop the much needed research and health promotion programs aimed at reducing this epidemic of type 2 diabetes among aboriginal peoples.

Unraveling the mysteries of diabetes and why it is so prevalent among Aboriginal people in Canada and around the world requires a renewed exploration of indigenous "ways of knowing," with the integration of innovative ideas derived from ancient traditional practices of Aboriginal healers with the modern scientific methods of inquiry practiced by a new generation of researchers.¹⁰

Need for more aboriginal health care professionals

In 2002 aboriginal students represented 0.9% of all first-year medical students in Canada (18 aboriginal students of 2020 total). Given that aboriginal people (First Nations, Inuit, and Métis) comprise 3.3% of the Canadian population, the number of aboriginal students in medical schools is only one-quarter of the total needed to reflect the overall population.³ The same is true for all other aboriginal health professionals, including nurses, dentists, physiotherapists, occupational therapists, nutritionists, and pharmacists. Whenever possible health care professionals can encourage aboriginal youth to complete school and consider a future in health care. In addition all health professionals should receive training in aboriginal health to better equip them for the future. To this end the Indigenous Physicians Association of Canada and the Association of Faculties of Medicine of Canada are currently collaborating to make this a reality for all medical students. In 2008 they launched *First Nations, Inuit, Métis Health. Core Competencies. A Curriculum Framework for Undergraduate Medical Education*.¹⁸ Some medical schools already have extensive curricula in place—the challenge is now for all schools (medical, nursing, etc) to implement their own courses.

Conclusion

The vision of the Indigenous Physicians Association of Canada is to have "healthy and vibrant Indigenous nations, communities, families and individuals supported by an abundance of knowledgeable, well-educated, well-supported Indigenous physicians working together with

others who share this vision."¹⁹ This will take a concerted effort by all levels of government, working in partnership with aboriginal peoples, and support from the general public. Health care professionals—aboriginal and non-aboriginal—will be proud to contribute to this vision. ✪

Dr Macaulay is a Professor in the Department of Family Medicine at McGill University in Montreal, QC, and Director of Participatory Research at McGill. She has been a family physician in the Kanien'kehá:ka (Mohawk) community of Kahnawake, Que, since 1970.

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Correspondence

Dr Ann C. Macaulay, Department of Family Medicine, McGill University, 515 Pine Ave W, Montreal, QC H2W 1S4; e-mail ann.macaulay@mcgill.ca

The opinions expressed in commentaries are those of the authors. Publication does not imply endorsement by the College of Family Physicians of Canada.

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A Guide for Health Professionals Working with Aboriginal Peoples

EXECUTIVE SUMMARY

This Policy Statement has been reviewed by the Aboriginal Health Issues Committee and approved by Executive and Council of the Society of Obstetricians and Gynaecologists of Canada.

PRINCIPAL AUTHOR

Janet Smylie, BA, MD, CCFP, Ottawa, ON

ABORIGINAL HEALTH ISSUES COMMITTEE

Janet Smylie (Chair), BA, MD, CCFP, Ottawa, ON
 Pierre Lessard (Past Chair), MD, FRCSC, Yellowknife, NT
 Karen Bailey, MD, FRCSC, FACOG, Wetaskiwin, AB
 Carole Couchie, BHSc, RM (registered midwife), Toronto, ON
 Mary Driedger, RN, BScN, MN, CPM, Winnipeg, MB
 Erica Lise Eason, SM, MDCM, FRCSC, Ottawa, ON
 William J. Goldsmith, MD, FRCSC, Montreal, QC
 Roda Grey, RNA, SSW, Ottawa, ON
 Tracy O'Hearn, Ottawa, ON
 Kenneth Seethram, MD, FRCSC, Yellowknife, NT

SPECIAL CONTRIBUTORS

Avis Archambault, MA, Phoenix, AZ
 Howard Cohen, MD, Ottawa, ON
 Margaret Moyston Cummings, BSc, PHN, RN, MSW, Ottawa, ON
 Pascale Desautels, MD, Val d'Or, QC
 Bernice Downey, RN, Ottawa, ON
 Claudette Dumont-Smith, RN, BScN, MPA, Ottawa, ON
 Jessie Fiddler, Sioux Lookout, ON
 Margaret Horn, MA, Kahnawake, QC
 Elaine Johnston, BScN, Cutler, ON
 Mae Katt, RN, BScN, MEd, Thunder Bay, ON
 Lorraine Kenny, BA, Sioux Lookout, ON
 Dorothy LaPlante, RN (EC), BScN, Ottawa, ON
 Susan Maskill, BSc, Ottawa, ON
 Melanie Morningstar, Ottawa, ON
 Patricia Morris, MD, Ottawa, ON
 Ann Roberts, MD, Iqaluit, NU
 Elizabeth Roberts, MD, Ottawa, ON
 Marie Ross, BA, RN, CGPA(Dip.), Truro, NS
 Carol Terry, BA, Sioux Lookout, ON
 Vincent F. Tookenay, MD, Russell, ON
 Alan Waxman, MD, MPH, Gallup, NM
 Cornelia Wieman, MD, FRCPC, Hamilton, ON

SUPPORTING ORGANIZATIONS

Assembly of First Nations
 Canadian Institute of Child Health
 Canadian Paediatric Society
 College of Family Physicians of Canada
 Congress of Aboriginal Peoples
 Federation of Medical Women of Canada
 Inuit Tapirisat of Canada
 Metis National Council
 National Indian and Inuit Community Health Representatives Organization
 Pauktuutit Inuit Women's Association

These guidelines reflect emerging clinical and scientific advances as of the date issued and are subject to change. The information should not be construed as dictating an exclusive course of treatment or procedure to be followed. Local institutions can dictate amendments to these opinions. They should be well documented if modified at the local level. None of the contents may be reproduced in any form without prior written permission of SOGC.

FOR INFORMATION ON THE SELF-DIRECTED LEARNING EXERCISE SEE PAGE 1095.

Abstract

Objective: to provide Canadian health professionals with a network of information and recommendations regarding Aboriginal health.

Options: health professionals working with Aboriginal individuals and communities in the area of women's health care.

Outcomes: improved health status of Aboriginal peoples in Canada.

Appropriateness and accessibility of women's health services for Aboriginal peoples.

Improved communication and clinical skills of health professionals in the area of Aboriginal health.

Improved quality of relationship between health professionals and Aboriginal individuals and communities.

Improved quality of relationship between health care professionals and Aboriginal individuals and communities.

Evidence: recommendations are based on expert opinion and a review of the literature. Published references were identified by a Medline search of all review articles, randomized clinical control trials, meta-analyses, and practice guidelines from 1966 to February 1999, using the MeSH headings "Indians, North American or Eskimos" and "Health."* Subsequently published articles were brought to the attention of the authors in the process of writing and reviewing the document. Ancillary and unpublished references were recommended by members of the SOGC Aboriginal Health Issues Committee and the panel of expert reviewers.

Values: information collected was reviewed by the principal author. The social, cultural, political, and historic context of Aboriginal peoples in Canada, systemic barriers regarding the publication of information by Aboriginal authors, the diversity of Aboriginal peoples in Canada, and the need for a culturally appropriate and balanced presentation were carefully considered in addition to more traditional scientific evaluation. The majority of information collected consisted of descriptive health and social information and such evaluation tools as the evidence guidelines of the Canadian Task Force on the Periodic Health exam were not appropriate.

Benefits, costs, and harms: utilization of the information and recommendations by Canadian health professionals will enhance understanding, communication, and clinical skills in the area of Aboriginal health. The resulting enhancement of collaborative relationships between Aboriginal peoples and their women's health providers may contribute to health services that are more appropriate, effective, efficient, and accessible for Aboriginal peoples in Canada. The educational process may require an initial investment of time from the health professional.

Recommendations: Recommendations were grouped according to four themes: sociocultural context, health concerns, cross-cultural understanding, and Aboriginal health resources. Health professionals are encouraged to learn the appropriate names, demographics, and traditional geographic territories and language groups of the various Aboriginal groups in Canada. In addition, sensitivity to the impact of colonization and current socioeconomic challenges to the health status of Aboriginal peoples is warranted. Health services for Aboriginal peoples should take place as close to home as possible. Governmental obligations and policies regarding determination are recognized. With respect to health concerns, holistic

definitions of health, based on Aboriginal perspectives, are put forward. Aboriginal peoples continue to experience a disproportionate burden of health problems. Health professionals are encouraged to become familiar with several key areas of morbidity and mortality. Relationships between Aboriginal peoples and their care providers need to be based on a foundation of mutual respect. Gaps and barriers in the current health care system for Aboriginal peoples are identified. Health professionals are encouraged to work with Aboriginal individuals and communities to address these gaps and barriers. Aboriginal peoples require culturally appropriate health care, including treatment in their own languages when possible. This may require interpreters or Aboriginal health advocates. Health professionals are encouraged to recognize the importance of family and community roles, and to respect traditional medicines and healers. Health professionals can develop their sensitivities towards Aboriginal peoples by participating in workshops, making use of educational resources, and by spending time with Aboriginal peoples in their communities. Aboriginal communities and health professionals are encouraged to support community-based, community-directed health services and health research for Aboriginal peoples. In addition, the education of more Aboriginal health professionals is essential. The need for a preventative approach to health programming in Aboriginal communities is stressed.

Validation: recommendations were reviewed and revised by the SOGC Aboriginal Health Issues Committee, a panel of expert reviewers, and the SOGC Council. In addition, this document was also reviewed and supported by the Assembly of First Nations, Canadian Institute of Child Health, Canadian Paediatric Society, College of Family Physicians of Canada, Congress of Aboriginal Peoples, Federation of Medical Women of Canada, Inuit Tapirisat of Canada, Metis National Council, National Indian and Inuit Community Health Representatives Organization, and Pauktuutit Inuit Women's Association.

Sponsor: Society of Obstetricians and Gynaecologists of Canada.

EXECUTIVE SUMMARY

Aboriginal health is a highly relevant concern to the health care community. Aboriginal patients, whether identified as Aboriginal or not, will be encountered by most Canadian health care practitioners at some point in their practice. Such encounters may range from the daily to the infrequent; from the urban specialist who may be required to communicate the management of a complex disease process via translator to an Aboriginal patient flown in from a remote location, to the urban community health nurse who may be providing perinatal instruction to a young Aboriginal family, to the rural family physician who practices in or close to an Aboriginal community. In forging a balanced and positive health care practitioner-patient relationship, it is essential to understand the heritage context of the Aboriginal patient in order to negotiate chasms and find common ground.

History leaves a difficult contextual legacy. The adverse socioeconomic environment facing many Aboriginal

* As there was no MeSH heading for Metis, it was assumed to be included under "Indians, North American." "Eskimos" is the MeSH heading for Inuit people.

communities can be directly linked to the European appropriation of the traditional land of many Aboriginal nations: land that had been the basis of economic livelihood for Aboriginal communities prior to colonization. Additionally, the European colonists and their subsequent governments brought with them epidemics of disease, slavery, cultural suppression, imposed religious practices, family disruption and community relocation, and physical, emotional, and sexual violence:

Although Canada is often referred to as the ideal place to live because of its quality of life, there are two realities in the nation. One is for most Canadians; the other is for ... Aboriginal peoples. The statistics on the first inhabitants of what is now Canada are much like the statistics for most indigenous populations who have undergone colonization: inadequate nutrition; substandard housing and sanitation; unemployment and poverty; discrimination and racism; violence; inappropriate or absent services; high rates of physical, social and emotional illness and injury; disability; and premature death.¹

One predictable consequence of these socioeconomic inequities is that Aboriginal peoples have an overall health status that falls well below that of other Canadians. Aboriginal life expectancy is approximately seven to eight years less than that of the average Canadian. Chronic diseases, post neonatal mortality, accidental deaths, certain infectious diseases, and mental health problems continue to be disproportionately common among Aboriginal peoples.²⁻⁴ Although there have been some significant improvements in Aboriginal health over the past decades, the health care system has not yet been successful in rectifying this disparity.

The Royal Commission on Aboriginal Peoples (RCAP), whose purpose is to help restore justice to the relationship between Aboriginal and non-Aboriginal peoples in Canada by investigating the foundations of a fair and honourable relationship, has recognized the unacceptable level of health problems among Aboriginal peoples, the linkages of these health problems to larger social, economic, and emotional issues, and the inadequacy of the current health infrastructure to impact significant change.⁵ Its proposed new health strategy recommended long-term structural changes in government relations and economic development, as well as a reorganization of existing health and social service systems. Mainstream services were encouraged to "undertake a systematic assessment of their practices to see how they [could] improve their connections with Aboriginal peoples."⁵ This document is in keeping with previous recommendations by the Canadian Medical Association (CMA) which, in their submission to RCAP, recommended that the government of Canada "develop educational initiatives in cross-cultural awareness and other Aboriginal health issues for the Canadian population and in particular health care providers."² In a later (1996) CMA sponsored workshop on Aboriginal women's health issues, the participants, comprised mainly of Aboriginal women, recommended that:

The Canadian Medical Association, the Native Physicians Association in Canada or both should develop, or facilitate the development of, a series of publications outlining the historical concepts and approaches to health of Aboriginal peoples. The publications should also include information on variability and multiculturalism among the First Nations and Aboriginal peoples of Canada—even within individual communities. These publications should be distributed to all health service providers to heighten awareness and sensitize them to the present state of Aboriginal health."⁶

The Aboriginal Health Issues Committee of the Society of Obstetricians and Gynaecologists of Canada (SOGC), founded in 1994, is a multidisciplinary committee with Aboriginal and non-Aboriginal members, with representation from several Aboriginal organizations and backgrounds including First Nations, Inuit, and Metis. Its guiding principles, adopted at the first meeting, derive from the Keewatin Regional Health Board mission statement. The Committee additionally supports the recommendations and guiding principles in the CMA's *Bridging the Gap* document.²

This policy statement brings together concise information and specific recommendations regarding attitudes, knowledge base, and skills, to help the health professional build a more balanced two-way relationship with Aboriginal patients. Information and recommendations are grouped in four sections: sociodemographics, health definitions and issues, cross-cultural communication, and health resources. It is hoped that implementation of these recommendations and information will enhance understanding of Aboriginal cultures, approaches to health and healing, and worldviews.

A. METHODS

1. Social, cultural, and historical context

The creation of these evidence-based guidelines presented several challenges for the authors. For any such creation to be relevant, Aboriginal health issues should be framed in their social, cultural, and historical context. This adheres to RCAP findings regarding the causal connection between specific illnesses and "factors outside the boundaries of ordinary medicine—social, emotional, and economic conditions that in turn lead back to the corrupt, destabilizing, and demoralizing legacy of colonialism;"⁵ as well as the desire by Aboriginal peoples for their health issues to be understood holistically, summarized here by Henry Zoe of Dogrib Treaty 11 Council:

For a person to be healthy [he or she] must be adequately fed, be educated, have access to medical facilities, have access to spiritual comfort, live in a warm and comfortable house with clean water and safe sewage disposal, be secure in cultural identity, have an opportunity to excel in a meaningful endeavour, and so on. These are not separate needs; they are all aspects of a whole.⁵

The five volume RCAP report,⁷ the product of five years of extensive public hearings, community visits, expert consultation,

commissioned research studies, and literature review, is an important knowledge source for Aboriginal health needs.

2. Language, oral and written

Aboriginal cultures historically followed an "oral tradition" in which information was collected, conserved, and transmitted through carefully memorized verbal discourse often including stories and songs. Although there are examples of stories recorded through artwork prior to colonization, written information sources are of relatively recent European introduction into the Aboriginal community. For these reasons, a feeling of distrust regarding written information exists among some Aboriginal individuals, some of whom feel that important cultural information, such as traditional healing techniques, should only be transmitted orally and not be written down. Thus, at least some important information regarding Aboriginal health is unlikely to be found in a written format, and much data regarding Aboriginal peoples is not published in the standard accessible sources.

Additionally, lower rates of literacy and formal education achievement among Aboriginal peoples in Canada create systemic barriers to publication by Aboriginal authors; and those who do get published may decide that their information transmitted as a story, political organizational document, or other resource material is more consistent with their perspective than formal scientific literature. Using a comprehensive search strategy, LeMaster⁸ found only a limited number of published intervention studies in the health education literature which included "Native Americans." However, the author had encountered elsewhere numerous unpublished newsletters and other commissioned documents from governmental and Aboriginal organizations, none of which could be found in a literature search, although some of them contained relevant data. LeMaster concluded that "it is very likely ... that many health education interventions are conducted by and for Native Americans, but results are not disseminated in the published literature."⁵

3. Language groups

Aboriginal peoples in Canada represent over 50 culturally distinct language groups. Although often grouped together by non-Aboriginals, it is important to remember that First Nations, Metis, and Inuit peoples each have a unique cultural, social, and historical context, and are represented by separate political organizations. Increasingly, specific and focussed health programming is being called for by different Aboriginal groups. For example, at the May 2000 Forum on Aboriginal Health Services and Issues, Okalik Egeesiak, President of the Inuit Tapirisat of Canada, called for health programmes specifically for Inuit peoples, to be based on Inuit approaches to health issues. Another distinct set of health issues is raised by the historical exclusion of Metis people from health programmes administered by the federal government via the former Medical Services Branch. Although this policy statement presents one

set of recommendations intended to apply generally, the specific and distinct health concerns of First Nations, Inuit, and Metis peoples are detailed in the text where possible.

4. Culturally appropriate, balanced format

Finally, the Committee wished to present the information and recommendations in a culturally appropriate, balanced format. A careful, systematic documentation of the enormous health problems facing Aboriginal peoples in Canada could easily lead to a document that, while factual, is bleak and depressing. The personal cultural perspective of one author was that "bad news" needs to be balanced with "good news." This notion of "balance" is fundamental to Aboriginal concepts of health. The authors have therefore attempted to achieve a balanced presentation which communicates the inherent resources of Aboriginal individuals and communities at the same time as it identifies health issues.

5. Process

Just as this document attempts to bridge the perspectives of health professionals and Aboriginal clients, so the methodology has required a synthesis of the published, scientific knowledge base with a contextual, culturally-informed approach.

A framework for this policy statement was circulated to Committee members by the Committee chair in 1997. This framework was revised by Committee members who were then assigned different sections of the framework on which to work. Information on the different sections was brought back to the Committee and two Committee members organized and expanded upon this data to produce a poster presentation at the 1998 SOGC Annual Clinical Meeting (ACM) in Victoria.

A formal literature review was initiated in 1998, with a computerized Medline search conducted using the MeSH headings "Indians, North American or Eskimos" and "Health." The search included all review articles, randomized clinical control trials, meta-analyses, and practice guidelines after 1966 inclusive. Ninety-five review articles, ten randomized clinical control trials, no meta-analyses, and one practice guideline were identified for a total of 106 articles, many from public health and social science sources. Papers were reviewed by a single researcher (JKS), and the article deemed relevant if it contained information about Aboriginal peoples (preferably in the Canadian context) and the topic was health (including sociodemographic determinants of health, health policy, and health education). Eighty-six of these articles were deemed relevant for review and all 86 articles were retrieved. Data was extracted and organized according to the four major sections of the framework: sociological context, health concerns, cross-cultural understanding, and Aboriginal health resources. Ancillary and unpublished references were recommended by members of the SOGC Aboriginal Health Issues Committee and the panel of expert reviewers.

A draft series of recommendations incorporating the previously adopted guiding principles as well as recommendations

regarding Aboriginal health from other sources was produced and circulated to the Committee in early 1999. Members responded with their feedback and the recommendations were revised. Ongoing work by Committee members helped produce tools to educate health professionals in the areas of cross-cultural communication. A roleplaying session was piloted at the 1998 AGM of the Association of Professors of Obstetrics and Gynaecology and presented at the 1999 SOGC ACM in Ottawa. In the autumn of 1999, one of the Committee members was commissioned to finish the literature review and produce a draft document, which was circulated to Committee members and a panel of experts and then revised, before presentation for review by the SOGC Executive and Council.

RECOMMENDATIONS

A. SOCIOCULTURAL CONTEXT

1. Health professionals should have a basic understanding of the appropriate names with which to refer to the various groups of Aboriginal peoples in Canada.
2. Health professionals should have a basic understanding of the demographics of Aboriginal peoples in Canada.
3. Health professionals should familiarize themselves with the traditional geographic territories and language groups of Aboriginal peoples.
4. Health professionals should have a basic understanding of the disruptive impact of colonization on the health and well-being of Aboriginal peoples.
5. Health professionals should recognize that the current sociodemographic challenges facing many Aboriginal individuals and communities have a significant impact on health status.
6. Health professionals should recognize the need to provide health services for Aboriginal peoples as close to home as possible.
7. Health professionals should have a basic understanding of governmental obligations and policies regarding the health of Aboriginal peoples in Canada.
8. Health professionals should recognize the need to support Aboriginal individuals and communities in the process of self-determination.

B. HEALTH CONCERNS

1. Health professionals should appreciate holistic definitions of health as defined by Aboriginal peoples.
2. Health professionals should recognize that the degree of ill health in Aboriginal populations is unacceptable, and work with Aboriginal individuals and communities towards improved health outcomes.
3. Health professionals should recognize and respond to key areas of morbidity and mortality without stereotyping.

C. CROSS-CULTURAL UNDERSTANDING

1. Relationships between Aboriginal peoples and their health care providers should be based on a foundation of mutual respect.
2. Health professionals should recognize that the current health care system presents many gaps and barriers for Aboriginal individuals and communities seeking health care.
3. Health professionals should work proactively with Aboriginal individuals and communities to address these gaps and barriers.
4. Health professionals should work with Aboriginal individuals and communities to provide culturally appropriate health care.
5. Aboriginal peoples should receive treatment in their own languages, whenever possible.
6. Health care programmes and institutions providing service to significant numbers of Aboriginal peoples should have cultural interpreters and Aboriginal health advocates on staff.
7. Aboriginal peoples should have access to informed consent regarding their medical treatments.
8. Health services for Aboriginal peoples should recognize the importance of family and community roles and responsibilities when attempting to service Aboriginal individuals.
9. Health professionals should respect traditional medicines and work with Aboriginal healers to seek ways to integrate traditional and western medicine.
10. Health professionals should take advantage of workshops and other educational resources to become more sensitive to Aboriginal peoples.
11. Health professionals should get to know Aboriginal communities and the people in them.

D. ABORIGINAL HEALTH RESOURCES

1. Aboriginal communities and health professionals working with Aboriginal peoples should support the creation of community-directed health programmes and services for Aboriginal peoples.
2. Aboriginal communities and health professionals working with Aboriginal peoples should support the development of community-directed, participatory health research for Aboriginal peoples.
3. Aboriginal communities and health professionals working with Aboriginal peoples should encourage the education of Aboriginal health professionals committed to future work in Aboriginal communities.
4. Aboriginal communities and health professionals working with Aboriginal peoples should recognize the need for preventative health programming in Aboriginal communities.

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Front cover illustration: Jay Bell-Redbird, an Ojibwa artist from Wikwemikong First Nation, created the logo on the cover for the SOGC Committee on Aboriginal Health Issues.

The logo represents the diversity of Aboriginal peoples in Canada. The medicine wheel base, a symbol used by many indigenous communities, represents a paradigm of teaching and healing that promotes wholeness, harmony and balance. The four colours are significant in healing work and also represent the diversity of all humanity. The floral motif is very representative of beadwork designs done by women in the woodland and sub-arctic regions of Canada. The sash around the circle is a symbol of the Metis nation. The drum with a moon symbol is drawn in the style of the west coast peoples. The great white pine and the four roots of peace are important symbols of the Iroquois confederacy. The eagle, a sacred bird to many nations, represents freedom, honour, and respect. The Inuit woman with her baby in an amauti at the centre of the circle represents the importance of women as the bearers of life and the importance of children as the future hope of the people.

Cross-Cultural Communication

The following articles provide useful information for improving clinical encounters with First Nations patients. Respect is very important in Aboriginal philosophies these articles highlight this understanding of respect and the ways in which health care providers can show respect through their communication styles.

Brandt C. Native Ethics and Rules of Behaviour. *Can J of Psychiatry* 1990; 35:534-539

The article, written by a Mohawk psychiatrist, is intended for mental health professionals but is applicable to a wide range of clinical encounters with First Nations people from Ontario and Quebec (Brandt cautions against universal application beyond these provinces). Brandt describes the historical roots and manifestations of the common characteristic of conflict suppression. He details a number of behavioural norms around non-interference and conflict avoidance.

Deagle GL. The Art of Cross-Cultural Care. *Can Fam Physician* 1986;32:1315-1318.

Deagle describes the process of acculturation. He emphasizes that values are culturally determined. As such caregivers need to understand/transcend their own culture – which can be painful. Caregivers need to understand the relationship between culture and illness and examine incongruent beliefs or concepts surrounding a disease. The steps towards understanding involve: living or spending time in the community; learning gestures and non-verbal communication styles; and proceeding slowly.

Hagey, Rebecca. Anishnawbe Health Resources and the Indirect Approach. *Nutrition Newsletter* 1986;7:23-25.

Hagey discusses the common First Nations communication style of indirect communication. She provides a starting point for understanding a complex communication pattern that cannot easily be summarized. Her main points are: show respect by showing interest rather than putting someone on the spot to give an answer; caregivers must be alert to these indirect questions; show respect by allowing the question to be answered when the respondent wishes, such as later on in the conversation; First Nations often attempt to balance relations by ensuring not to come across as superior. This is done through both tone and content/meaning.

Kelly L and Brown JB. Listening to Native Patients: Changes in physicians' understanding and behaviour. *Can Fam Physician* 2002;48:1645-1652

Kelly's qualitative study of 10 non-Aboriginal physicians who provide care to First Nations patients and communities. The study examined how physicians have developed and improved their clinical encounters with First Nations patients. This involved process of change around learning to listen: becoming comfortable with silence, taking more time with patients and listening for information through indirect communication and the use of metaphors. This study highlights the need for orientation to community values and communication strategies and for ongoing feedback from community members.

Additional References

Brown AJ. The Meaning of Respect: a First Nations perspective. *Can J Nurs Res* 1995;27(4):95-109.

Elliot CT. and de Leeuw SN. Our aboriginal relations: When family doctors and aboriginal patients meet. *Canadian Family Physician* 2009;55:443-444.

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Native Ethics and Rules of Behaviour*

CLARE C. BRANT, M.D.¹

Psychiatrists assessing Native children and adolescents often find them passive, difficult to assess and not forthcoming. This behaviour, which actually reflects the influence of Native culture, is often misinterpreted by clinicians unfamiliar with that culture as evidence of psychopathology. Patterns of conflict suppression, conflict projection and the humiliating superego are described and placed in their historical and cultural perspective, where they originated as techniques of ensuring the group unity and cohesion essential for survival in a hostile environment. Failure to recognize and understand such cultural influences can lead to errors in diagnosis and treatment that can turn what was intended as a helpful encounter into a destructive one.

Many general psychiatrists see Native children and adolescents in assessment, and often find them passive, difficult to assess, and not forthcoming. This behaviour, which affects the individual Native child's attitude and performance in an assessment situation, is understandable in view of the child's cultural background. The psychiatrist may, at times, misinterpret the behaviour as resistance, passive-aggression, opposition, depression, or withdrawal. The general psychiatrist's failure to recognize the derivatives of the individual child's cultural heritage as they affect his behaviour in a clinical situation may result in unperceived errors in diagnosis, in formulation, and in treatment. For example, overuse of antidepressants and the all too frequent diagnosis of personality disorders may occur. This may turn what is intended to be a helpful encounter into one that is not useful or even traumatic for the patient. Such encounters will no doubt also be frustrating for the clinician.

For these reasons, this article is presented to discuss some features of the Native Canadian's cultural heritage, hoping that this might provide a context that will help mental health professionals understand and deal with Native patients with greater sensitivity and accuracy.

It has long been recognized that the culture of the North American Natives differs substantially from that of the dominant white (non Native) society. Variations in customs, beliefs, ideals and aspirations, as well as psychosocial differences, are well documented and generally accepted (1-7).

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¹Mohawks of the Bay of Quinte #14841; Assistant Professor of Psychiatry, University of Western Ontario, London, Ontario.

Address reprint request to: Dr. C.C. Brant, Box 89 York Road, Shannonsville, Ontario K0K 3A0

Well over one and a quarter centuries ago, for example, significant differences between the two cultures were alluded to by Susanna Moodie, writing about her own encounters with Native people:

I had heard and read much of savages, and have since seen, during my long residence in the bush, somewhat of uncivilized life; but the Indian is one of Nature's gentlemen — he never says or does a rude or vulgar thing. The vicious, uneducated barbarians who form the surplus of over-populous European countries, are far behind the wild man in delicacy of feeling or natural courtesy (8).

Why and how were this "delicacy of feeling" and "natural courtesy" established and maintained? What accounts for the often radical differences between Native and non Native society that were noted — albeit, a bit hyperbolically — by Ms. Moodie? Some of the differences have been recognized widely as being biological (9-12). However, the following is an attempt to identify and analyze certain of the North American Native ethics, values, and rules of behaviour which persist in disguised form as carryovers from the aboriginal culture and which strongly influence Native thinking and action even today. Some of the difficulties encountered by modern day Native people as they attempt to practise aboriginal ethics and rules of behaviour in the context of radically different social circumstances will also be discussed.

The direct observations on which this article is substantially based were compiled during 24 years of medical practice and other forms of association with the Iroquoian groups of southern Ontario and Quebec, the Ojibway of southern Ontario, and the Swampy Cree of James and Hudson's Bay. The last 12 years of this period were spent in service as a psychiatrist and psychotherapist. Additional data were obtained through extensive interaction with Native people across Canada and in the northern United States during service as a visiting consultant and lecturer. The limited material published on the subject was also reviewed.

Although the author believes the following ethics and rules of behaviour to be present in some form in all tribes of North America, his therapeutic contact was confined to Ontario and Quebec Native people, and the reader is cautioned against any indiscriminate or universal application.

The individual and group survival of this continent's aboriginal Plains, Bush, and Woodlands people required harmonious interpersonal relationships and cooperation among members of a group. It was not possible for an individual to survive alone in the harsh natural environment (13) but,

in order to survive as a group, individuals, living cheek by jowl throughout their lives, had to be continuously cooperative (14) and friendly. These conditions were established and maintained by the following.

Conflict Suppression

Conflict suppression was established among the members of an extended family, clan, band or tribe largely through the practice of non interference, non competitiveness, emotional restraint (including the suppression of anger), sharing, the Native concept of time, attitude toward gratitude and approval, Native protocol and the principle of teaching (shaping vs modelling). These first four principles are designated as the most important factors promoting harmony and the latter four are believed to be less influential. These practices, which are described in detail below, were enshrined as "ethics" or principles of behaviour. Over time they became embedded in Native culture as societal norms and continue to influence Native life today.

Non Interference

The ethic of non interference is a behavioural norm of North American Native tribes that promotes positive interpersonal relations by discouraging coercion of any kind, be it physical, verbal, or psychological (14). Manifestations of it have been observed and described by Rosalie Wax and Robert Thomas (15), among others. A high degree of respect for every human being's independence leads the Native to view instructing, coercing or attempting to persuade another person as undesirable behaviour. Accordingly, group goals are arrived at by consensus and achieved by reliance on voluntary cooperation. Wax's characterization of white society provides a stark counterpoint to the Native norm:

Thus, at a casual party, the (white) man who remarks that he plans to buy a pear tree may anticipate that someone will immediately suggest that he buy a peach tree instead. If he remarks that he is shopping for a new car, someone will be happy to tell him exactly what kind of car he ought to buy (15).

The white man who can out-advise another is "one up" and the individual over whom he has exerted influence is expected to take it all with good grace. In Native society by contrast, such an attempt to exert pressure by advising, instructing, coercing or persuading is always considered bad form or bad behaviour. The advisor is perceived to be "an interferer." His attempt to show that he knows more about a particular subject than the advisee would be seen as an attempt to establish dominance, however trivial, and he would be fastidiously avoided in future. The ethic of non interference, then, is an important social principle.

Indeed, it was even a principle of governance and group administration in aboriginal times. In aboriginal Native societies, the most talented and best qualified member would be selected leader by informal consensus. Among the Cree and Ojibway, leadership was task specific and fluid (16,17). Among the Iroquois, selection was vigorously democratic,

then bestowed for life upon those designated as sachems (18,19). But once the leadership had evolved, it would rely on voluntary cooperation for the attainment of group goals, whether with regard to hunting, warfare or economic decisions.

The ethic of non interference is one of the most widely accepted principles of behaviour among Native people (20). It even extends to adult relationships with children and manifests itself as permissiveness (21,22). A Native child may be allowed at the age of six, for example, to make the decision on whether or not he goes to school (15) even though he is required to do so by law. The child may be allowed to decide whether or not he will do his homework, have his assignments done on time, and even visit the dentist. Native parents will be reluctant to force the child into doing anything he does not choose to do.

Non Competitiveness

The practice of non competitiveness meanwhile, suppresses conflict by averting intragroup rivalry (14) and preventing any embarrassment that a less able member of the group might feel in an interpersonal situation. Members of a Native baseball team, for example, will rarely be heard to cheer team mates even if a home run is hit with the bases loaded. To do so might embarrass those who had struck out or managed only single base hits. This non competitiveness extends even into working life despite the fact that it is often seen by non Native employers as a lack of initiative and ambition.

Emotional Restraint

The exercise of emotional restraint (17) is a corollary and extension of non interference and non competitiveness. On the positive side, it promotes self-control and discourages the expression of strong or violent feelings (14). However, emotions such as joyfulness and enthusiasm are suppressed along with anger and impulses to destructiveness. Still more problematic is the fact that the suppression and repression of hostility give rise to a number of psychosocial disturbances currently experienced among Natives. Repressed hostility often explodes into the open under the influence of alcohol and is inappropriately visited upon innocent bystanders such as a spouse, child, or casual acquaintance. The present day cause of Native frustration, usually government bureaucracy, which interferes with even the basic aspirations of Native people, is controlled by oppressors too distant to be seen or wrestled with (23). Violence within the family and community by a person under the influence of intoxicants is a serious problem on reserves (13).

Emotional restraint in the Native also appears to give rise to a high incidence of grief reactions following separation or loss. Forty-four percent of the Native people who consulted a psychiatrist, according to one small study, were suffering from a grief reaction of one kind or another (24).

Sharing

Sharing, the exercise of generosity, is a behavioural norm that discourages the hoarding of material goods by an individual (14). In aboriginal times, when this principle

originated among Native peoples, group survival was more important than individual prosperity; consequently, individuals were expected to take no more than they needed from nature and to share it freely with others (25). Of course, this is somewhat akin to the central principle of Marxism and Christianity. Native people, however, regard it neither as a political ideology nor as a religious requirement. It was and still is simply a part of the Native way of life. Although the main function of this principle was to help ensure group survival in the face of the ever present threat of starvation, it also serves as a form of conflict suppression by reducing the likelihood of greed, envy, arrogance and pride within the tribe.

As an offshoot, however, it may also suppress individual ambition since one is not supposed to keep for himself the fruits of individual labour. In addition, the discouragement of the acquisition of material goods has been extended to education and the acquisition of other non tangible assets. Subtle disapproval of a Native student's plans to attend university may be enough to make him decide to stay on the reserve.

The ethic of sharing has its corollaries: equality and democracy. If one visits a Native village, one usually sees few people who are very rich or very poor. An economic and social homogeneity is promoted by the ethic and practice of sharing, and every member of the society is considered as valuable as any other. No one is given special favours except the elder. Everyone is expected to do his fair share of the work and to keep for himself only his part of what he has taken from nature.

This is in sharp contrast to white society's drive towards individual success, power and wealth. Consequently, there is pressure on Native society to adopt the white man's outlook, to relinquish the ethic of sharing for the sake of individual prosperity and success. But Native society has so far not been willing to do this, perhaps in part because it is contrary to the principle of sharing.

Talented young Native people, for example, are often encouraged by well intentioned whites to strive for individual success and thus escape the doldrums of poverty and lack of opportunity on their home reserves. Yet, even if the young, talented person is so inclined, often his peers and elders subtly, or not subtly, discourage it. They know that, more often than not, young Native people who are attractive, talented or have better than a Grade 12 education are taken away from the reserve, placed in the white society and disappear as far as the reserve society is concerned. They often marry non Natives and sometimes become embarrassed about their origins, never returning or sending their prosperity, knowledge or wisdom back to the village. They are essentially lost. Clearly, this runs contrary to the tradition and ethic of sharing and, partly as a result of this conflict between the values of the white world and the traditional ethic, Native society has tried to resist it. Still, this skimming of Native society has occurred consistently for over 400 years. Indeed, it is only recently, with new employment opportunities on the reserves, that young Native people have been willing or able to return and share their achievements with their home reserves.

The above four principles of conflict repression, in their various forms and expressions, constitute the basis for demystifying and understanding Native behaviour. To carry the process further, though, four more traditional influences on behaviour are described. These have been observed at work during clinical practice and reported in the literature, but their overall specific functioning is still incompletely understood. These influences are: the Native concept of time; the Native attitude toward gratitude and approval; Native protocol; and the practice of teaching by modelling.

The Native Concept of Time

Like others living in close harmony with nature, the Native person has an intuitive, personal and flexible concept of time (26-28). It may have had its origin in an age when the activities of Native people were regulated by the seasons — by the sun, the migratory patterns of birds and animals, and a changing food supply. The absence of electricity or any other form of energy meant that the Native people had to depend on the seasons and nature to supply food and light. Having to live in harmony with nature in mutual relevance to all these things, the Native people developed the concept of "doing things when the time is right" — that is, when the whole array of environmental factors converge to ensure success.

The concept remains in play today. The Native person who appears to be dragging his feet might appear incorrigibly lazy one moment, but possessed of energy and tenacity when all the complicated factors are in alignment. For example, Mohawk steelworkers are highly esteemed for their contribution to the building of skyscrapers in cities such as New York, Boston and Chicago. The Mohawk crews will work 16 and 18 hours a day, putting up structures well within the contract time when "the time is right." Sometimes, however, they may seriously imperil a project if they choose not to work, perhaps because the time is right for some other enterprise.

Today, the Native concept of time seems less a principle for living with nature and more of a manifestation of the need for harmonious interpersonal relationships. For example, Tom, Dick and Harry may not make it to an 8 pm meeting because they have other responsibilities they are unable to leave because the time is not right. If they have a particular interest in the matter under discussion, the meeting will not be started until they arrive or until some message is received that they are not coming. To start without them might offend these esteemed and influential members of the community, quite aside from the fact that the other members of the community may not be aware of the importance of their input into the discussion. In another, more social context, it might be rude and inconsiderate to start a dance at a wedding celebration without all the brothers and sisters of the bride and groom being able to take part in the first waltz. Given the universality of the concept of time in Native society, Native people never seem to be inconvenienced or annoyed if social functions and other meetings start hours after the scheduled time.

The Native Attitude toward Gratitude and Approval

Gratitude or approval among Native people is very rarely shown or even verbalized. One is not rewarded for being

a good teacher, doctor, nurse, farmer, fisherman or hunter because that is what one is supposed to be; conversely, to be less than adequate would be a great embarrassment for the person being assessed, and so is not pointed out either. One is not thanked for doing something good because gratitude is seen as superfluous. The intrinsic reward of doing the deed itself is considered sufficient. Consequently, Native people have a great deal of difficulty accepting praise, reward and reinforcement. Indeed, Native children who are praised by their teachers will often deliberately do something to reverse the teacher's opinion the next day. To be told in front of the class that they have done a good job may be construed by them as being lied to and humiliated if they themselves do not believe they have done things perfectly. They may become ashamed if the positive assessment is not shared by the group. For that matter, even if praise is warranted, it may embarrass their peers who have not done as well, thereby disrupting harmonious relationships in the peer group.

To non Natives who work among Native people, this attitude toward expressions of gratitude or approval can be disconcerting. Those who work in remote Native villages are often impatient with what they perceive as ingratitude. For their part, teachers are often puzzled by the failure of the "normal" reward system to motivate students.

As for Native people themselves, since excellence is expected all the time, they generally are reluctant to try new things. They often experience a great deal of performance anxiety about making mistakes and holding themselves up to public scrutiny, ridicule and teasing (15). This further reinforces the need to avoid risk taking behaviour.

Native Protocol

Protocol subsumes notions such as manners, ceremony and savoir faire. It may seem to a casual observer that Native society is rather loose and unstructured and that there are not many rules of behaviour or etiquette. This is not the case at all. Native society has highly structured and demanding rules of social behaviour. There are rules about everything. Many, however, are specific to individual villages, clans, tribes, and bands, a fact that can cause problems, given the ethic of non interference.

In keeping with the ethic of non interference, it is not possible to instruct a stranger regarding local practices or protocols. Rules can never be stated, for to do so would interfere with the individual's right to behave as he sees fit. The kinds of consequences that can result, even among Native people, are illustrated by the following anecdote.

Among the Native peoples of Ontario, there is one group composed of hunters and gatherers who did not develop many advanced food preservation techniques. They lived in an isolated setting which did not have electricity or refrigeration. When a moose was shot, everyone in the village would share. The moose would be skinned, gutted and laid on the floor in the hunter's kitchen. The people in the village would come in with pots and would carve a roast off for their own use. The proper behaviour in that situation was to eat as much as one possibly could — six or seven meals a day of roast moose, fried moose, baked moose, moose tongue, and boiled

moose. At the end of three days there would be nothing left of the moose except the antlers and the hooves. The hunter would walk among the eaters as they enjoyed the meat and get his thanks by watching them restore their nitrogen balance. In this circumstance, it was the appropriate protocol to eat as much as possible before the meat spoiled and was wasted.

Another group living in the south of Ontario had practised animal husbandry since the Europeans brought farm animals from Europe. They had also been engaged in agriculture for thousands of years, growing corn, beans, squash and potatoes. When the southern group had a feast or banquet, the women prepared five or six times as much food as was possible to eat, as a display of prosperity, generosity and sharing.

When the two groups got together for a bowling banquet, the farmers from the south put out a great deal more food than was actually needed, intending to take home whatever was left over to put in their freezers. The hunter tribe, who were the guests, thought the appropriate and polite thing to do was to eat all of the food before it was spoiled and wasted. The farmers were offended by what they perceived as the hunters' greed and gluttony, and the hunters were distressed because they thought they were expected to eat more than human beings could. It was only after several of these unhappy interactions that the farmers learned that they should prepare only as much food as could be easily and comfortably eaten in one sitting.

The Practice of Teaching by Modelling

In teaching their children, white people seem to use "shaping" — that is, rewarding learners for successive approximations of the behaviour that they have been instructed to carry out. Native tribes use modelling almost exclusively. One is *shown* how rather than *told* how. This can be seen as another form of *conflict repression* in that the teacher does not purport to know more than his student, but through his own actions conveys useful and practical information which the student then has a choice of adopting or rejecting. The student is never placed on the spot and required to perform before he has been adequately trained. This reduces his performance anxiety and increases his loyalty to his teachers, who usually are parents and older members of his extended family. Modelling seems to increase attachment to the older members of the group, promoting group cohesiveness and continuity.

Projection of Conflict

In order to reinforce and promote the above behaviours, which can be classified generally as forms of conflict repression, it was necessary from earliest times to develop a number of superego constructs that would prevent deviations from these principles without causing intense anxiety. These devices of social control can be generally categorized as "bogeymen" admonitions or teasing, shaming and ridicule.

The need to suppress anger is taught to young Native children as having its origins in the aboriginal society, in which

there purportedly were shamans and witches who could be dangerous to an individual or his or her family. Shamans and witches were said to retaliate by casting spells upon the perpetrators of insult and injury. They did not always reveal themselves, so it was not possible to tell at a glance who was the good witch and who was the bad. Anger provoked them, so children were taught from a very early age never to engage in angry behaviour. Angry behaviour was considered not only unworthy and unwise, but dangerous as well.

As an extension of this method of suppressing intragroup hostility, the concept of the bogeyman "who ate bad children" emerged to maintain harmonious interpersonal relationships by projecting responsibility for the child's frustration onto an unknown and unseeable outside force. The parents were never seen as the source of frustration and deprivation, so the child's good behaviour could be maintained without direct confrontation with the parents or other elders. As a result, responsibility for frustration nowadays is easily projected onto teachers, Children's Aid Society workers, police, family court judges and others who impose restrictions and demands from without. However, the notion that all frustration is due to causes outside the group generates feelings of powerlessness over and resignation to evil forces that, in reality, are merely the darker side of one's own nature and that of others. Projection relieves the individual and his society of responsibility. Thus, Native people feel continuously at the mercy of the bureaucratic white government, which now takes the place of shamans, witches, bogeymen and bad weather.

The Humiliating Superego

Teasing, shaming and ridiculing as means of social control maintains harmonious interpersonal relationships by placing the responsibility for the discrepancy between self and ego ideal only upon the child. Shaming and teasing as an alternative to loss of privileges and parental anger can serve to erode self-esteem and give rise to an overwhelming sense of humiliation when encountered later in life. This tends to promote blame avoidance, which shows up as further non interference, hesitancy to try anything new or unwillingness to apologize or otherwise admit error or defeat. Behaviour patterns such as these tend to persist often in the face of changing times and circumstances; escape behaviour, for example, is often seen in Native students and employees when they have made errors.

A humiliating superego often is produced by the child rearing practices of teasing, shaming and ridiculing, which produce social shyness that sometimes verges on terror. This is functional in that it keeps young people attached to the group, promoting group unity and survival. While Kagan (29) has demonstrated the inheritability of shyness which he has called the "behavioural inhibition response to the unfamiliar," Native child rearing practices tend to add a psychological and social component to this biological predisposition. If 15% of the children in an ancient aboriginal society inherited the shyness trait as part of a normal distribution of that trait, it would tend to become concentrated within

the ghetto established by the reserve system. Young Native people who were bold, reckless and curious would be motivated to move away and seek better opportunities for employment and adventure, having the nerve to do so. The prevalence of the shyness gene would then become amplified among the people left at home. Meanwhile, among bold, reckless, and curious Native men, there is a high incidence of death by misadventure, such as industrial accidents on the high steel, motor vehicle accidents and homicide. They also tend more frequently to marry non Natives who refuse to live within the reserve system. As a result of such factors the tribe is continually deprived of their genetic material.

Conclusions and Implications

To ensure survival in an often hostile environment, Native societies found it essential to maintain group unity and cohesiveness. Hence, every effort was made to avoid interpersonal conflict among members of the group, a tendency that has persisted even into modern times. Behavioural norms designed to suppress conflict and promote group unity and survival are encouraged and reinforced by child rearing practices. However, these often result in a humiliating superego and result in the projection of culpability. This thesis is suggested as a means of understanding modern Native behaviour.

The list of Native ethics and rules of behaviour outlined above is far from complete and would have to be expanded to promote the further demystification of Native behaviour. However, these are arguably the most important.

Native people have a reverence for and attachment to their land, even to the few acres left after the pillage of the forests and plains by the dominant culture. Natives are products and extensions of this land and the vestiges of Native ethics and rules of behaviour, which continue to promote group unity and survival on Native lands, will not easily or soon be relinquished, even if the consequence of persistence in the old forms of behaviour is to be removed from competitiveness and success in the dominant non Native culture. However, maintenance of traditional Native ethics and rules of behaviour, as manifested in Native child rearing practices will continue to have significant implications for Native mental health. These implications are the subject of a paper presently in preparation.

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Résumé

Les psychiatres qui examinent les enfants et les adolescents autochtones les trouvent souvent passifs, difficiles à évaluer et peu communicatifs. Les cliniciens qui connaissent mal la culture autochtone interprètent souvent à tort ce type de comportement, qui en réalité traduit l'influence de cette culture comme un signe de psychopathologie. On décrit les structures correspondant à la répression des conflits, à la projection des conflits et au superego humiliant, et on les replace dans leur contexte historique et culturel d'origine, à savoir celui de techniques destinées à assurer au groupe l'unité et la cohésion essentielles à la survie dans un milieu hostile. Le fait de ne pas reconnaître et comprendre de telles influences culturelles peut entraîner des erreurs de diagnostic et de traitement qui risquent de transformer une entrevue qu'on voulait bénéfique en expérience destructive.

George L. Deagle

The Art of Cross-Cultural Care

SUMMARY

The art of cross-cultural care concerns learning how to transcend one's own culture in order to form a positive therapeutic alliance with patients from other cultures. Since the illness experience varies between cultures, communication difficulties are common between doctors and patients from divergent cultures. Family physicians can minimize these difficulties by sharing in the community life of patients, by listening analytically to patients' use of language and metaphor, and by using problem-solving skills to learn cultural codes. Examination of other cultures leads to increased self-awareness, which may be painful. Understanding one's own culture is a prerequisite to providing effective cross-cultural care. (*Can Fam Physician* 1986; 32:1315-1318.)

SOMMAIRE

L'art des soins multi-ethniques implique l'apprentissage à transcender sa propre culture en vue de former une alliance thérapeutique positive avec les patients d'origine ethnique différente. L'expérience de la maladie variant d'une culture à l'autre, les difficultés de communication sont fréquentes entre les médecins et les patients de nationalités différentes. Les médecins de famille peuvent minimiser ces difficultés en partageant la vie communautaire des patients, en portant une attention analytique au langage et aux métaphores des patients et par l'usage de méthodes de solution de problèmes pour apprendre les codes ethniques. L'apprentissage des autres cultures favorise une meilleure connaissance de soi, ce qui s'avère parfois douloureux. La connaissance de sa propre culture est l'exigence de base pour offrir des soins multi-ethniques efficaces.

Key words: culture, Indians (North American), cross-cultural comparison

Dr. Deagle is an assistant professor in the Department of Family Medicine at the University of Western Ontario, London, Ont. Reprint requests to: Dr. George Deagle, Southwest Middlesex Health Centre, Box 219, Mt. Brydges, Ont. N0L 1W0

IN AN AGE of burgeoning medical technology, a "not-so-quiet" revolution has begun in the discipline of family medicine. This revolution is leading us to an increased awareness of the "whole person" who presents to the family-practice office and to an increased concern for the context of the patients' illness. In 1980, Professor Ian McWhinney discussed the meaning of holistic medicine in his address to an Assembly of the College

of Family Physicians of Canada meeting in Vancouver. He traced the renewal of interest in holistic medicine to the natural or descriptive school of medicine founded at Cos in ancient Greece, classically described in the Hippocratic writings. This school emphasizes that "When illness is seen in its context, we are struck not so much by what is common to each disease, but what is different in each patient".¹ In this spirit, this article will examine the art of cross-cultural care as an important component of providing whole-person oriented medical care.

A very large proportion of the content of modern Canadian biomedical education may be irrelevant to a family physician's subsequent experience of attempting to provide comprehen-

sive community-based care. It seems to me that anthropology, sociology and psychology should be recognized as important "basic sciences" for family practice; these areas of study may be far more important than neuro-anatomy or biomedical statistics. The past and present preoccupation of our profession with certification of this, that and the other skill belies our continued concern with technology and a reductionist, disease-oriented approach to sickness. Under the joint pressures of economic restraint and political constraint it would be easy to let society relegate family physicians to an impoverished role as medical technicians or practitioners in narrow fields of health care. In dealing with these transitions, family medicine needs to make a strong statement within the medical commu-

nity, and also to society at large, that we are first and foremost concerned with the study of "man as man"; we represent a humanistic discipline.² The division of family medicine into "organic" proponents and "psycho-social" proponents reveals an outmoded perception that there can be a clear distinction between mind and body, individual and family, or culture and environment.

One unique feature of practising family medicine in Canada is the opportunity most physicians have to deal with patients of different cultural and ethnic backgrounds. In Eastern Canada a physician may care for a large group of so-called "New Canadians" from Italy, Holland or other European countries. In British Columbia family physicians are more likely to have patients who immigrated to Canada from Japan, China or other Asian countries. All Canadian physicians are likely to have the opportunity to deal with at least a few patients who are aboriginal or Native Canadians, and it is important to recall that they may view *all* of us as immigrants or New Canadians. Patients from any of the component cultures in the Canadian mosaic may seek care from a family physician who is of a different cultural background, and so each of us is likely to have the opportunity to provide cross-cultural care.

My own experience as a family physician living and working with members of the Haida Nation on the Queen Charlotte Islands, from 1975 to 1985, taught me that there are special risks and hazards that can undermine or destroy a therapeutic or growth-promoting doctor-patient relationship in a cross-cultural setting. At the same time, I learned that such relationships can also provide special satisfaction and joy. The art of cross-cultural care concerns learning how to transcend our own culture in order to form a positive therapeutic alliance with patients who are different from us. In order to develop this art, one basic step is required. It is understanding one's own culture. To this end, it helps to examine three basic questions:

- What does "culture" mean?
- What is the relationship of culture to illness, and care-giving?
- How can we improve our effectiveness in cross-cultural settings?

Following Bateson's suggestion

that "Every science, like every person, has a duty toward its neighbors, not perhaps to love them as itself, but still to lend them its tools, to borrow tools from them, and generally keep the neighboring sciences straight,"³ let us borrow some concepts or tools from anthropology to help us understand the abstract idea of 'culture'.

Benedict, in 1932 stated, "Cultures . . . are individual psychology thrown large upon the screen, given gigantic proportions and a long time span."⁴ Kluckhohn and Kelly suggested that culture was "all the historically created designs for living, explicit and implicit, rational, irrational and non-rational, which exist at any given time as potential guides for the behavior of man."⁵ In his general review of the difficulties posed by imprecise use of the term 'culture', Keesing suggested an important and useful distinction. He noted that culture may refer to patterns of behaviour and, in addition, patterns for behaviour. He restricted the use of the term 'culture' to "systems of shared ideas, systems of concepts and rules and meanings that underlie and are expressed in the ways that humans live. Culture so defined refers to what humans learn not what they do and make."⁶

We all consider that our own patterns for behaviour are "normal", and we often describe people from another culture as "different", "strange", "weird", "primitive", "unsophisticated". Our use of such words often reveals an underlying attitude in us that our own culture is superior, more advanced and preferable; it is not just different, but *better*. Keesing has described a very useful metaphor which is helpful for understanding the difficulty in analysing cultural codes or values. He compared our own individual cultural codes and values to glasses with distorting lenses:

The things, events, and relationships we assume to be "out there" are, in fact, filtered through this perceptual screen.

To view other peoples' ways of life in terms of our own cultural glasses is called *ethnocentrism*. Becoming conscious of, and analytic about, our own cultural glasses is a painful business.⁶

In order to illustrate how culturally determined values differ, consider the

following story or vignette, and select which of the three choices you think is best.

There were three fishermen who had quite different ways of fishing.

- (1) One man went out in his boat, worked hard and also set himself to living in right and proper ways. He believed that it is the way a man works and tries to keep himself in harmony with the forces of nature that has the most effect on conditions and the way fishing turns out.
- (2) One man went out in his boat. He worked the fishing gear sufficiently, but did not do more than was necessary to keep things going along. He believed that the way things turned out depended mainly on tides or the weather conditions, and that nothing extra that people do could change things much.
- (3) One man went out in his boat, where he worked on his fishing gear a good deal of the time and made use of all the new scientific ideas he could find out about. He believed that by doing this he would, in most years, prevent many of the effects of bad conditions.

Which of these ways do you believe is usually best?

This item is designed to measure culturally determined values surrounding the relationship of Man to Nature. Recognizing the severe limitations of administering a single item from a much larger series of items similar to this vignette, it is possible, nonetheless, to make some general statements about your response.

The first choice represents a Man-in-Harmony-with-Nature position, or ecological orientation.

The second choice represents a Man-Subject-to-Nature position. This choice was the most popular among the aboriginal people I studied.⁷

The final choice suggests an underlying Man-in-Control-over-Nature value position. This choice was the outstanding favorite of 30 health-care workers to whom I presented this choice.⁷

Each of us, in deciding which of the three choices we think is preferable, chooses on the basis of subconscious values we possess. Many studies in anthropology, notably the work of Kluckhohn and Strodtbeck,

have established that these values are culturally determined.⁸ They become for us what Benedict has described as "unconscious canons of choice".⁹ Redfield pointed out that "neither chiefs nor anyone else in society sees how all phases of life are organized by and conform to this same motive,"¹⁰ the unconscious canons of choice. Hall, too, states, "What people say they do is their 'folklore' of culture. What they do may well be different."¹¹ We can conclude that culture is an exceedingly complex and dynamic phenomenon, as illustrated by Hall's analogy that "Internalized culture is mind."¹¹

What is the relationship of "culture" to illness and care-giving? Is it of any relevance at all that a Haida person coming in to my office comes from a culture different from mine?

Patients experience *illness* whereas biomedically trained doctors are trained to diagnose and treat *disease*.¹² Since patients learn ways of being ill, it is not surprising that the illness experience varies from one culture to another. Kleinman has described what he refers to as "explanatory models" which each person in a culture possesses, often at a subconscious level, to help him or her understand what to do in the situation of being ill.¹³ Thus it should not come as a surprise to realize that the *illness* experienced by the Haida patient may well differ from my own expectations, since my model of what is wrong with the patient and how she or he might recover may bear little resemblance to the patient's explanatory model of the illness. This disparity can lead to major communication difficulties. As Weidman has suggested:

It is very easy for the orthodox health care provider to make his diagnosis, to write out his prescriptions, and to assume that the recipient's dutiful compliance with his medical regimen is the only possible pathway to health and a recovered sense of well-being for the patient. In such an approach there is most certainly a silent, unintended but very real disdain for the patient's perception of his problem, and for the patient's understanding of causes and cures insofar as health and illness are concerned.¹⁴

Patients who do not comply with orthodox scientific programs are

usually castigated as ignorant, superstitious or prejudiced. Physicians are often unaware that non-compliance from patients is usually the result of physicians' failure to be certain that they and their patients share the same beliefs or concepts surrounding illness and disease. The climate of mistrust and misunderstanding that can occur in asymmetrical interactions all too often leads to paternalistic or even coercive behaviour on the part of the physician who is unable or unwilling to consider the patient's model of illness.

An illustrative case report will complete our consideration of the relationship of culture to illness and care-giving.

A twenty-two year old native patient delivered her third normal child after a long labour. The baby was large and required a difficult forceps extraction. Since the woman had two previous children, it was recommended to her, in the circumstances of this stressful delivery, that she should have a post-partum tubal ligation. This procedure was done.

Within one year the patient presented in the office stating that she now wished to have more children. Surgical reconstruction of her tubes was not possible, and the patient remains chronically depressed about her infertility.

In retrospect, one paramount feature can be identified which predisposed to the unfortunate outcome in this case. The physician showed great concern for the future welfare of his patient, but the Haida patient was not as concerned about or aware of the *future* implications of her action, since in her culture, the future is not as important as the *past*. In addition, the physician asked the young woman to make the decision on her own, as he considered that it was her *individual* responsibility to do this, while the Haida patient would have preferred to discuss the issue with her family and friends, since a *collateral* decision is often seen as more desirable in her culture. An insidious form of coercion can occur in cross-cultural transactions when conflicting cultural values or codes are not identified or are perhaps even ignored "in the patient's best interest".

The potential for problems is obviously great. How then can we improve our effectiveness in a cross-cultural setting?

The art of cross-cultural care concerns learning how to transcend one's own culture in order to form a positive therapeutic alliance with patients that are different from oneself. As Hall states, "Self-awareness and cultural awareness are inseparable, which means that transcending unconscious culture cannot be accomplished without some degree of self-awareness."¹⁵

There are some specific practical steps that one can take to learn effective cross-cultural care.

- Be prepared to live in the community of the other cultural group or, at the very least, make time to share in life situations with members of the group. Because a culture is so complex, it is virtually impossible to "get into another culture by applying the 'let's-fit-the-pieces-together' process."¹⁵ The familiar research role of anthropologists as participant-observers allows these social scientists to learn about the "ethos" of distinctive cultural groups. Community-based family physicians have an excellent opportunity to engage in the same sort of participant-observer learning or research activities. Berger's book, *A Fortunate Man*, best describes for me how we can forge a link with a community.¹⁶
- If possible, learn the gestures and language of the people in the group you are studying, or use the services of the most skilled and sensitive interpreter you can find. Since the subconscious mind deals in imagery, develop and use culturally-compatible metaphors. This can be accomplished by listening to the way that the people themselves use metaphors. One of my elderly patients who was depressed, for instance, said that he felt "like a salmon who hasn't got the energy to swim anymore, so the river is just carrying me backwards—I just can't seem to get ahead."
- Remember that cultures are dynamic, and that no one individual knows how all the "unconscious canons" work in a culture. Generalizations or labelling of entire groups as "superstitious" is unfair and inaccurate. It is more important to observe what people do in real-life situations than it is to listen to what they say they do. If members of a cultural group censure or comment

on an individual member's behaviour, be alert to the fact that such behaviour marks a boundary for normal codes or values in that culture.

- Be very patient and proceed very slowly. Initial mistakes, oversights or ignorance can permanently impair the chance of ever being accepted into anything but the most superficial relationship with members of the group. Cultural codes must be respected, even in such simple matters as dress, interpersonal space or physical contact. The same problem-solving skills we possess as family physicians—that is, careful observation of cues, formation of hypotheses, and careful testing—can be put to good use in this critical introductory period. Our ability to live with uncertainty and risks is equally valuable.
- Be prepared to experience some pain. There is pain in finding out things about oneself and in becoming aware that our own cultural "glasses" have, in fact, been a perceptual screen that distorted what we perceived as reality. The process of transcending one's own culture means discovering that we, too, have a folklore of culture, with myths and metaphors that are often no more valid or real than the folklore of other cultures. It is painful to acknowledge that other cultures are not better or worse, not richer or poorer than ours; they are just different.

Why engage in such ambitious and risky endeavours? The study of other cultures is a powerful tool to increase self-awareness. Such self-awareness will vastly improve the effectiveness of care-givers even *within their own cultural group*. Finally, the ability to transcend our own culture is not only a prerequisite to developing the art of cross-cultural care; I believe that it may also be a prerequisite for world peace and survival. ●

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ANISHNAWBE HEALTH RESOURCES AND THE INDIRECT APPROACH

By Rebecca Hagey, B.Sc.N., Ph.D.



There is power in self-help. There is power in all-Native problem solving. The Native Diabetes Project started in 1980 when an all-Native committee from four agencies in Toronto got together to plan a diabetes education program for Native people. Stella Johnston from Anduhyaun, Millie Redmond from Council Fire, Roger Obonsawin from the Friendship Centre and Joe Sylvester from Pedahbun-Lodge formed that first core group. The Native Diabetes Program

has since expanded and evolved into Anishnawbe Health Resource, an all-Native corporation devoted to health interests of Native people.

It was Joe Sylvester, the designated elder for the Toronto area who became the spiritual leader for the programs which developed. It was important to have a spiritual leader to maintain the balance in communication between the various Native groups and the health professionals who were mostly non-Native. Mr. Sylvester helped us to see that there were indeed two different styles of communication. The professional style he calls the "direct approach" and the Native style is the "indirect approach". He found out too, that many Native people taking higher education and becoming professionals pick up the direct approach because that is how they are trained. It is only after they have a chance to evaluate their own speech and actions that they begin to wonder whether the Native way of communication might get better results. If the indirect approach is more natural to the Native way of thinking and feeling, it may be less stressful, and potentially more positive for the individual patients who are already having a hard time coping with their illness and with life's difficulties.

What is the indirect approach?

According to Joe Sylvester there are many parts to the indirect approach. It is something that a Native person grows up with. It takes many years of formation so that it cannot be summarized in a few pages. It cannot even be cut down to so many words. If a tall tree is cut down to make pulp and paper, the tree is no longer living. So Native people cannot just hand a recipe for communication to non-Native health professionals and expect them to learn the etiquette overnight. In fact, it is because living communication patterns are so complex that there is really very little hope of short cuts in learning them, even if they could be spelled out. The following are some points made by Mr. Sylvester. It is hoped that they can serve as a starting place for respect and understanding, and a steadily growing and improving communication.

1. Indian people don't want to hurt or embarrass anyone. The way they try to avoid this is they don't use words to point to that person directly. They will not ask direct questions such as "where do you work?", "Are you married?", "How much do you drink in one week?". These questions put people on the spot. Part of their identity is being peeled off by each question. Indians show respect for the other person by showing interest rather than putting them on the spot by demanding answers to questions. So instead of the direct questions, someone could say: "Perhaps you have been working hard these days?", "Maybe your wife is finding it difficult too?". These expressions of interest are only acceptable if they follow along naturally in the conversation. If there are too many of them, and if the point is to extract answers rather than be in harmony with the person, the effect is bound to be discomfort and embarrassment.
2. Given that Native values require that somebody with a question always leaves it up to other if they want to hear that question or not, then everyone always has to be more alert in listening for indirect questions. Non-Natives tend not to hear indirect Native questions because the usual signals "Who . . .", "What . . .", "Why . . .", "Where . . .", "When . . .", are almost never used. People may instead say, "I wonder . . ." "Maybe . . ." The reference to the person being questioned is always diverted so he or she won't feel they are being pounced on. This is extremely important for the health educator since questions are hardly ever put directly. It is unfair to expect Native people to ask direct questions. Direct questioning does not exist in most North American languages, and has not been widely adopted by Indians who now speak English or French as their first language. This is a good example of how one's cultural values determine what is learned and practised.
3. Indian people have a more flexible sense of time when it comes to making replies to hints of questions. Non-Natives usually expect fairly immediate answers, or at least a reply such as "I can't tell you right now". Natives show respect for the person by leaving it up to them when they will respond, although some situations

do press for a response. The following example shows the Native concept of not interfering to point at a person or to pressure them time-wise: Joe Sylvester took some non-Native consultants to a workshop on an Indian reserve. After the workshop, one of the non-Natives packed up a flip chart belonging to the reservation health centre and put it in the trunk of the car. The Native nurse, not wanting to accuse anyone of stealing the flip chart, said, "I wonder where our flip chart is?". The non-Natives did not hear this as a polite form of saying "Did you take the flip chart?" So they meandered around keeping an eye open for it. After almost half an hour had gone by, the non-Natives finally realized everyone was waiting for them to produce the chart. The driver from the Tribal Council wanted to get on the road before sundown, yet the Native nurse just calmly repeated her indirect question, "I wonder where our flip chart is?". Finally, one of the non-Natives realized she had mistakenly put the reservation flip chart in the trunk of the car. But even though time pressure was present in this case, the Native nurse showed respect for the visitors by not directly confronting them, letting them take time to realize their mistake.

4. For Indian people, talk should be balanced. When talk is balanced, people themselves will be in balance. There are two aspects of speaking which work to keep people in balanced relations: the sound or tone of speech and the content or meaning of the words. Balanced relations mean nobody is being put down; nobody is making himself superior. Balanced relations also mean showing harmony with nature since nature always tends toward balance in the long run. Balancing relations is sacred to most Native people, and is an expression of the Native way, and an indication of their spirituality. Therefore, if it is not respected the Native person will feel contaminated or violated.

(a) An example of tone in speaking is as follows. In my first speech talking about diabetes at the Friendship Centre, I knew nothing about this balanced talk idea. I put a lot of thunder into my voice, trying to get across the idea that diabetes was a problem Indian people could no longer ignore, and that it was great that so many people had showed up who were interested. I must have sounded like one of those old-time preachers pounding the pulpit. Some young people I was close enough to that could be honest with me, took me aside at the end and said "Arrows were coming out of your mouth." "I had to duck or one of those arrows would have hit me," "I was worried I might get diabetes just by getting hit." I asked Joe Sylvester what this meant. I honestly didn't know what they meant by "arrows". Joe explained that the tone was too negative. People can show that they don't like something that is causing a problem a little bit, but they have to follow that up with positive tones to show they are really in control. "If it is something off-balance like diabetes then our culture can balance that." "I can

show my strength to balance it by keeping my language in balance.”

- (t) An example of words or images-of-meaning being in balance is as follows. In the slide show which Anishnawbe Health Resources uses in workshops about diabetes, there is a slide with a skinny man and a fat man. The slide comes in the part of the workshop telling about who can get diabetes. Using the direct approach, a professional would likely say something like “Obesity is the single most important causative factor in Type II diabetes. You have much more chance of having diabetes if you are obese.” For most Natives this is too direct (mentioning the word you), and too negative. The way Mr. Sylvester talks about this slide is a good example of the indirect approach. He may say, “Thin or fat can get diabetes, but more likely somebody (we don’t use the word you) could get it if they are overweight. If we balance our food and our exercise, we can control our weight and our blood sugar.” So the negative idea of someone getting diabetes must be balanced with the positive idea that they can control it. And nobody is pointed out or put on the spot for having diabetes, or for being overweight. Respect and balance are maintained, and yet the information about a very tense and difficult subject gets across.

Another sign of respect that Native people use in everyday relations is including all points of view. Traditionally, learning took place in a circle and all members of the circle contributed to the process. By this method it is unthinkable for the goal to be determined beforehand, because the goal has to be derived in the process. This is important for health educators because they usually plan what the goals for learning will be ahead of time. For example in diabetes education the goal is always the regulation of blood sugar since the body is not doing this automatically. However handing down the goal from on high in this way negates the sanctity of the circle for many Native people. They may get the feeling the information is being forced on them and the value of the information may be lost.

6. One final point of etiquette we found out in the Native Diabetes Program, is that the direct approach can make people feel like objects — less than human beings. People’s defense to this, as described by Joe Sylvester, is that they put up a wall. “So all you are doing is talking to that wall. What the indirect approach does, is gradually bring down that wall so they can take in what vis it that you are saying. You will not tell them what to do and how to do it; you may invite them to share with you what you have found out.” The POW WOW model is another example of the indirect approach. At the pow wow there are booths and each person can go around at his own pace, get individualized attention if need be, and learn by demonstration. Diabetes workshops using this model with Native groups have reported success.

Helping Native people to learn how to balance the sugar in the blood is meaningless and useless without first respecting their culture and autonomy. There are many more parts to the indirect approach. But it is hoped these brief examples can help frontline health workers be more aware of the complexity and importance of Native patterns in communication etiquette. Anishnawbe Health Resources would be glad to hear any example you might have that will further our understanding about the differences and strengths and weaknesses of various styles in communication. For questions or comments please write to ANISHNAWBE HEALTH RESOURCES, 16 SPADINA ROAD, TORONTO, ONTARIO M5R 2S8.

(Rebecca Hagey B.Sc., N., Ph.D., is a consultant to the Anishnawbe Health Resources. Rebecca is a clinical anthropologist and an associate professor in the Faculty of Nursing, University of Toronto. The Native Diabetes Program received the 1983 Praxis Award from the Washington Association of Professional Anthropologists for the synthesis of theory research and practice and the application of anthropological knowledge to real-world problem solving.)



Joe Sylvester and Rebecca Hagey

Listening to Native patients

Changes in physicians' understanding and behaviour

Len Kelly, MD, CCFP, MCLSC, FCFP Judith Belle Brown, PHD

ABSTRACT

OBJECTIVE To discover how physicians develop an understanding of Native* patients and communities that enables them to communicate better with these patients.

DESIGN Qualitative method of in-depth interviews.

SETTING Native communities across Canada.

PARTICIPANTS Ten non-Native physicians providing primary care to Native patients and communities.

METHOD In-depth, semistructured interviews explored communication strategies developed by primary care physicians working with Native patients. The audiotaped and transcribed interviews were analyzed by the investigators using the phenomenologic approach of immersion and crystallization.

MAIN FINDINGS Three main themes emerged. First was elements of communication: during patient-physician communication, physicians speak less, take more time with patients, and become comfortable with silence. Second was community context: patients' illnesses are not distinct from their community context; patient care and community relations, culture, and values are often inseparable. Third was the process of change in physicians: over time, participants increased understanding of Native culture, ways of communicating, and behaviour. Change comes about through long service, listening well, and participating in community events.

CONCLUSION Developing cross-cultural communication was difficult and took years, if not forever. Understanding Native communities changed physicians. They described a journey of self-examination, development of personal relationships, and rewards and frustrations.

RÉSUMÉ

OBJECTIF Découvrir de quelle façon les médecins développent une meilleure compréhension des patients et des communautés autochtones,* qui leur permet de mieux communiquer avec ces patients.

TYPE D'ÉTUDE Méthode qualitative d'entrevues en profondeur.

CONTEXTE Les communautés autochtones du Canada.

PARTICIPANTS Dix médecins non autochtones dispensant des soins de première ligne à des patients et des communautés autochtones.

MÉTHODE Des entrevues en profondeur semi-structurées ont été utilisées pour identifier les stratégies de communication développées par des médecins dispensant des soins primaires à des patients autochtones. La transcription de ces entrevues enregistrées sur bande magnétique a été analysée par les auteurs à l'aide d'une approche phénoménologique, celle de l'immersion et de la cristallisation.

PRINCIPALES OBSERVATIONS Trois thèmes principaux ont été identifiés. Le premier concerne les éléments de communication: durant la consultation, le médecin parle moins, consacre plus de temps au patient et devient plus à l'aise avec le silence. Le deuxième concerne le contexte propre à ces communautés: les maladies sont indissociables du contexte de la communauté à laquelle appartient le patient et les soins donnés aux malades sont souvent intimement liés aux relations, à la culture et aux valeurs de ces communautés. Le troisième thème concerne le processus de changement survenu chez les médecins: avec le temps, les participants ont amélioré leur compréhension de la culture autochtone, leur façon de communiquer et leur comportement. Ces changements exigent une longue période de service, une écoute attentive et une participation aux activités de la communauté.

CONCLUSION L'établissement d'une communication interculturelle est un processus difficile qui exige plusieurs années, sinon toute une vie. Une meilleure compréhension des communautés autochtones entraîne des changements chez les médecins. Ceux-ci décrivent un long processus d'introspection, le développement de relation interpersonnelles ainsi que diverses récompenses et frustrations.

*The terms Native and First Nations are used throughout this article to denote the original inhabitants of Canada and their descendants.

*Dans cet article, les termes Autochtone et Premières Nations désignent les premiers habitants du Canada et leurs descendants.

This article has been peer reviewed.

Cet article a fait l'objet d'une évaluation externe.

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Listening to Native patients

Canada's Native people have high rates of morbidity, mortality, and chronic disease.^{1,2} While determinants of health are multifactorial,³ there is little doubt that Canada's First Nations communities have great need of medical care.

Recently, the Canadian Medical Association and the Society of Obstetricians and Gynaecologists of Canada published documents outlining principles and recommendations for Native health care.^{4,5} These documents presented information on historical issues and demographics, and the results of an in-depth examination of the need for culturally relevant, community-based initiatives for First Nations health care. Other literature^{6,10} documents the burden of illness among Native people and issues in the structure of health care delivery systems.^{11,12}

Physicians enter cross-cultural situations with little or no preparation¹³⁻¹⁵ and bringing their own values,^{16,17} which often differ from the values prevalent in the communities they serve. First Nations people value sharing and non-interference,¹⁸ and have a tendency to live in the present.¹⁹ A survey of five Ontario medical schools in 1992¹³ showed that their undergraduate curriculums offered no formal training in cross-cultural issues. In 1997, a Canada-wide survey¹⁴ of family medicine residency programs had similar findings. International studies of cross-cultural care warn against stereotyping and encourage embracing the values inherent in Native culture¹⁵⁻¹⁹: respect, understanding, and open communication. What can we learn from physicians caring for Native patients that might inform practising physicians and help prepare medical students for patient-centred care in cross-cultural settings?

Several qualitative studies have concentrated on communication^{20,22} with nurses, patients, and interpreters.^{23,26} They have identified important cultural elements: tradition; acceptance; equal treatment; respect; the role of family; and the importance of silence, trust, and sincerity during consultations.^{23,25} Using medical interpreters and translators has been described^{27,28} as have its challenges: appropriate vocabulary,^{29,30} ongoing medical education,²⁸ advocacy,³¹ and conflict resolution.²⁶

Current evidence on patient-doctor communication documents the effect of communication on health

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Dr Kelly teaches at Family Medicine North in Sioux Lookout, Ont, and is an Associate Clinical Professor at McMaster University in Hamilton, Ont. Dr Brown is an Associate Professor in the Centre for Studies in Family Medicine at the University of Western Ontario in London.

outcomes. Nonjudgmental, patient-centred interviews result in patients being more satisfied with their care³² and physicians having a better understanding of patients' experience of illness.^{33,35} Attention to non-verbal communication^{21,36,38} can result in actions that improve patients' outcomes.³⁹

The seminal work of Brant,⁴⁰ a Native psychiatrist, highlights the core values of Native culture: noninterference, non-competitiveness, emotional restraint, sharing, and a different concept of time. Brant places verbal and nonverbal cross-cultural communication issues clearly within this context and warns us that failure to understand cultural influences can lead to errors in diagnosis and treatment.

This study describes how physicians working with First Nations patients and communities learned to understand and communicate appropriately with their patients. In describing this process, we hope to begin to fill the gap in this area in current literature. This is the first study to explore physicians' experiences of working in First Nations health care. It is also the first time the attitudes and experiences of physicians from across Canada with respect to providing health care to Native people have been explored. While organizations such as the Society of Obstetricians and Gynaecologists of Canada⁴ and the Canadian Medical Association⁵ have given a comprehensive overview of the macrocosm, we intend to explore the microcosm—to look at physicians' relationships with Native patients.

METHODS

Ten physicians working with Canadian First Nations communities were interviewed. We considered them key informants, people we thought would recount their experiences in an informed, thoughtful way. They gave written consent to a semistructured 1-hour interview. Ethics approval was obtained from the University of Western Ontario's Review Board for Health Science Research Involving Human Subjects.

Participants

Maximum variation sampling was achieved by recruiting through personal contact 10 non-Native family physicians who had worked with various First Nations (Ojibway, Cree, Mohawk, Peigan, Mi'kmaq, Inuit, Oneida, Sukanee, and Haida) across Canada. The six men and four women were interviewed at locations across Canada by one of the authors (L.K.).

Data gathering

Interviews were audiotaped and transcribed verbatim. Each interview continued until the researcher felt he had a good understanding of participants' experiences. Interviews continued until theme saturation was reached.⁴¹

Data analysis

Each author read and interpreted the data independently and then repeated the process jointly with the other author. Immersion and crystallization techniques were used to elaborate themes.^{41,42} This method of analysis allows researchers to involve themselves in the transcribed texts and experiences of participants. After repeated reflections and immersions, interpretation of themes arising from the interviews crystallized.⁴²

Trustworthiness of the data was ensured several ways.^{43,44} Independent and team analyses were both conducted. Experienced non-participants (Native and non-Native physicians and nurses) validated the findings. Field notes were taken during data collection, and reflection was undertaken to ensure bias had not influenced the interpretation. Member checking,⁴⁵ where participants read and critique researchers' interpretations of their interviews, further validated the data.

FINDINGS

Nine participants were family physicians; one was a specialist. Mean number of years' experience in Native health care was 14.4 years (range 3 to 30 years). Most physicians lived in non-Native communities and made daylong or week-long visits to Native communities. Participants had varied practice profiles, and all provided primary health care. Many were involved in secondary in-hospital care.

Three themes emerged from our findings: elements of communication, illnesses existing in a community context, and changes in behaviour and communication strategies. The first identified certain elements of communication: patient-physician communication in a First Nations setting involves physicians speaking less, taking more time with each patient, and becoming comfortable with silence. Second, patients and their illnesses are not distinct from their community context: patient care and community relations, culture, and values are interwoven. Finally, participants described changes in their communication strategies, behaviour, and understanding of Native culture (Figure 1). This gradual process

was described by one physician as: "a veil being lifted from my eyes." These changes are affected by duration of service, the quality of listening, and physicians' participation in community events.

Elements of communication

The first indicator of divergent cultural values was the difference in communication styles: a very different pace to the discussion, a need for physicians to become comfortable with silence, and learning how to speak less and listen more. The most striking new communication elements were nonverbal: "Developing the patience, accepting the pregnant pauses, and the loss, the lack of eye contact. Appreciating that it wasn't rude or uncooperative behaviour." Simply speaking less was a common discovery for many: "An elder told me the story that we were born with two ears, two eyes, and one mouth and should use them accordingly. We should use the mouth just half as much as the ears and the eyes."

The amount of patience required was woven into a communication style with nonthreatening body language.

I would be seeing a teenage girl, who is maybe in some kind of trouble.... My approach in that situation would be to sit down, sometimes on the footstool on the floor, so I don't appear to be this large, white guy looming over a small Native girl, and not say anything for a long time. So that silent thing and getting out of someone's face and avoiding direct eye contact and avoiding pressuring someone for the answers.

The verbal components of communication were rich areas for learning about other cultures. Participants universally described the novel experience of conducting consultations through an interpreter: "I was totally unprepared for how to deal with using an interpreter." Having an interpreter affected the pace, reliability, and content of patient-doctor interviews and altered physicians' way of thinking: "I had to learn how to take my thoughts and break them down into small pieces and leave enough time between the thoughts for the person to respond and the translator to process the information."

Physicians needed to use relevant concepts: "I understood that abstract concepts were sometimes not a part of the language, so [I] learned different approaches." Consultations became indirect: "I am more likely to begin with social, non-illness-related conversation, and I am more likely to talk about family and community events."

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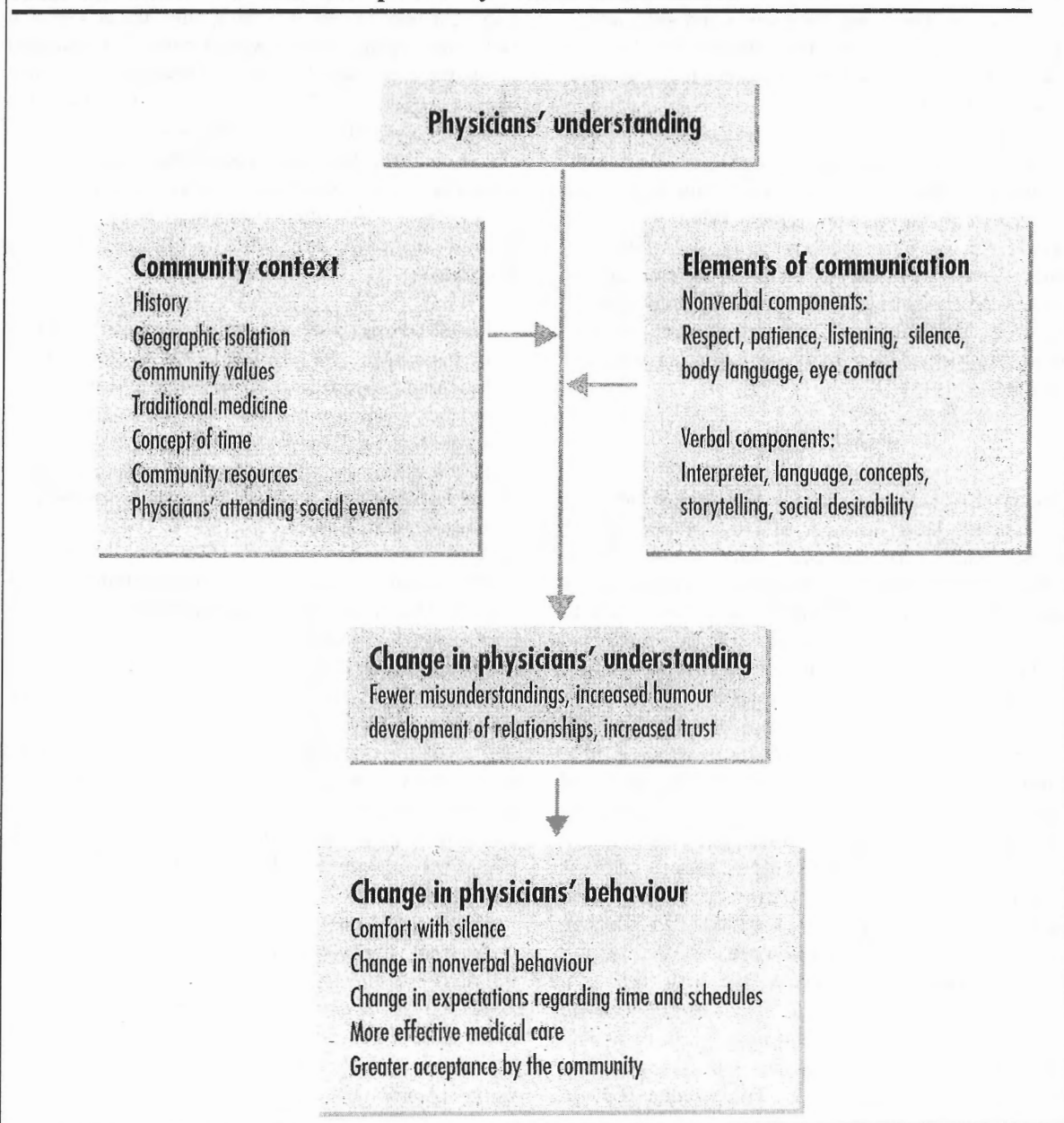
The most unfamiliar mode of verbal communication was the use of metaphor, story telling, and sense of humour, key elements of Native culture.

One elderly lady who was developing memory loss said to me: "I'm like an old cedar tree; the top is turning silver and grey and the wood is no good, but the bottom is still green." The history of storytelling is really prevalent and if you want to understand, you have to listen to the story.

Patients also answered questions in a manner they thought would please physicians or was socially desirable.

Well, there were the physical items: like in taking a history of whether you noticed blood mixed in with your stools. People said yes. I realized that they weren't noticing because they used outhouses. So in the context, people were giving me answers to make me happy.

Figure 1. Changes in physicians' understanding of Native culture lead to changes in their behaviour and their acceptance by Native communities



Participants pointed out how much patients varied: "Every person is an individual." They cautioned about stereotyping and identified a cross-generational aspect of nonverbal communication: "...less eye contact: again it's generational; the younger generation is changing."

Community context

Geographic and cultural isolation, history, and political events were part of the context within which patient-physician communication took place.

The other thing I had to learn, no matter how compassionate I thought I was and sincere in my reasons for being there, I had to prove myself really, largely by being there for a period of time because everybody came and went with all their compassion.

Community context and patients' illnesses were inseparable. Patient-physician communication was a microcosm of physicians' relationships with communities. Participants often thought there was a conflict in the balance between individual rights and more commonly held communal values. Patient confidentiality was often a poor fit.

Confidentiality is a big, big challenge. Particularly in the community, and I struggled with this, and I still do... [also] issues like abortion, birth control, or sexual abuse or social problems. If the individual's opinion or desires were at odds with the community's, they were really stuck and they were really uncomfortable in revealing that.

The concept of time varies among cultures. Participants experienced a different sense of time in Native communities that began in the waiting room and with booking patients.

I noted that people did not keep their appointments regularly. I asked "What's wrong, why don't people come on time for their appointments?"... and she [the translator, who was of Native descent] said, "Well, look at them; they are all visiting and laughing in there, they're okay with that, like, who has the problem here?"

Practice of traditional medicine and spirituality varied widely, was controversial, and piqued the curiosity of most participants.

Because I was quite interested in First Nations spirituality, I would often get a sense that I had said something

that was deeply disturbing for people. Some of the elders would recall the days when some of those things were considered devil worship;... then I would speak to typically younger people, who had been in other communities, who had discovered some of their traditional spirituality, and they would be talking to me almost in secret.

Topics difficult to discuss and sometimes steeped in stereotyping were abuse, addiction, anger, sexuality, abortion, and end-of-life directives: "Alcohol abuse was a difficult area because it's part of the stereotypic view that we have of Native patients, and they know it."

When they became familiar with community resources, physicians discovered something of its fabric. One physician spoke of seeking out caregivers, "women who look after the sick, the dying," and asking their advice.

Changes in behaviour and understanding

Participants experienced a process of learning to understand Native culture.

It took years of building relationships with people, with the culture, with the community, but it facilitated communication in a major way. It takes about a year for docs to feel like they have a handle on it, so that by their second year, they were feeling comfortable with their community... and by their third year, they're veterans; I mean they're almost getting efficient at it, if you can ever be efficient at it.

They described a collateral process of gaining acceptance in the community as their understanding grew. This not only engendered a sense of belonging and trust, but was thought to improve medical outcomes. One participant noted:

I think it was sort of like a veil that gradually gets lifted. It was like realizing that I didn't know the solutions because I certainly didn't know the problems. So in some ways that's the first hurdle.

The community's trust and acceptance of this physician increased with time and allowed discussion of important issues.

Many of us feel that if we stay for 1 year, 2 years, 5 years, it's an extraordinary length of time, but from a community standpoint, once a health care professional has been there for 2 years, it's when the community is starting to feel that they are beginning to know that person. There

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seems to be a sort of magic [at] 2 years when somehow the pieces of the jigsaw fall into place,... and I also think that's when the patients start to talk about more issues that are in their background.

Gaining acceptance from the community was facilitated by attending nonmedical community events.

I think it is a really important way to establish the community's trust in you and to develop the relationship between you and community members. You have to take part in life-cycle events, like going to funerals, attending baptisms and weddings.

First Nations health care involves managing a high burden of chronic illness and acute psychiatric and medical crises. This type of work creates an inherent physical and emotional drain: "My experience was one of perpetual fatigue, so the whole experience was coloured by that feeling of fatigue."

The communal burden of violence and the depth of grief carried by Native communities was hard to understand.

The most difficult thing for me is the cycle of violence and trying to break that. I try to understand it in an intellectual sense. I get so frustrated because it just seems to never end.

Participants unanimously identified the need for orientation to community values, communication strategies, and ongoing feedback from community members.

I really learned everything from the school of hard knocks, and so that took me quite a long time to realize where things were at. Like, my first reaction is to say, silence, were just like, "What's wrong with this person? How can I possibly help this person if they won't speak?"... I do think it would have been helpful if someone had given me a bit of the lay of the land and some directives about communication styles and so on.

With so many frustrations, why would physicians endure such cross-cultural medical practice? Participants identified personal growth, personal friendships, witnessing patient triumphs, and acceptance as rewards.

The biggest reward is establishing a relationship ... with elders; they'd show tenderness toward you. And seeing successful outcomes ... they will come and shake your

hand and smile, without saying anything. But you know that they're saying, "You know I know you. I remember you and thank you."

Participants acquired lifelong skills and greater self-awareness.

The skills that I learned by being patient, by listening, by understanding, by dropping or rethinking my assumptions, were skills and things that were to my benefit. When I look over, particularly the first 3 or 4 years, there were a lot of challenges to my values and it made me examine my values and I didn't always throw them out, but I certainly understood them better. So I think I became stronger, maybe more aware of myself.

DISCUSSION

Communication issues make cultural differences apparent. Our study explored cross-cultural communication issues and discovered a rich process of change in physicians' behaviour and cultural understanding. In describing the difficulties and rewards, participants showed how changes developed from a cross-cultural approach to patient care. Our study documents for the first time the 2- to 5-year time frame of this process of acculturation.

Deagle⁴⁶ identified the need for cross-cultural understanding and openness to nonverbal issues and the value of physicians' participating in non-medical First Nations' community events. The parallel process of community acceptance and understanding Deagle also described was noted by our participants. The process of change is often difficult: "Be prepared to experience some pain."⁴⁶ Brant⁴⁰ described the cultural background of many issues highlighted by our participants: non-interference, respect, and an alternative concept of time.

Participants recounted experiencing this alternative concept of time, which required adjustments in interview style and content. They described a need for patience during interviews, in patient management, and in community relations. Communicating appropriately, which was initially very challenging, became second nature.

Patient care and community context are inextricably linked. Physicians need to understand the social structure and value system of the communities they serve. Ultimately, physicians are treating both each patient and the whole community. All

participants mentioned the rewards of cultural acceptance and personal growth, the frustrations of cross-cultural communication, and the burden of a difficult workload. They suggested that formal orientation to community values and appropriate ways to communicate and continuous informed feedback could be helpful.

Our study takes its place in the literature on Native health care by documenting the cross-cultural experiences referred to in other qualitative studies.^{23,26} We have described the time frame for acculturation and the parallel process of change in physicians' behaviour and understanding that leads to acceptance by the community.

Implications

We recommend that agencies recruiting physicians for First Nations' communities make efforts to lessen the institutional and bureaucratic frustrations identified by our participants.⁴⁷ Such efforts might help retain physicians in Native communities. Most physicians recruited to a Manitoba agency over a 20-year period stayed less than 2 years in their placements,⁴⁷ mostly due to difficulties with the administration, which compounded the difficulties inherent in cross-cultural communication and led to a high turnover of physicians.

Second, we recommend orientation to cross-cultural communication and community values^{48,49} to increase physicians' effectiveness. Initial formal orientation to the history and politics of the community, followed by mentoring and feedback from other health care providers and First Nations' community members could help new physicians as they begin practice in Native communities.

Limitations and future study

Of the 600 000 First Nations people in Canada, only 30%⁵⁰ live on reserves. Contact with patients in this environment taught our participants how varied their patients and communities were, but would not necessarily have addressed issues among the 70% not living on reserves.

The study did not explore the experiences of physicians involved in First Nations health care for less than 3 years. This was intentional because the authors wished to explore communication experiences that had stood the test of time. Certainly, there is also a need to understand and document the experiences of physicians who leave practice in Native communities. Also, we explored the experience of only one party in the communication process. Future studies might explore the experiences of First Nations patients.

Editor's key points

- This qualitative study examines how physicians learn to communicate with Native people.
- Patient-physician communication with Native people involved speaking less, taking more time, and being comfortable with silence.
- Patients and their illnesses are not seen as distinct, but are perceived and described within the context of their communities. This complicates discussions of private issues where patient confidentiality conflicts with community values.
- A gradual process of acclimatization allows non-Native physicians to change their communication patterns and their understanding of Native people. Being patient with this process brings unique personal and professional rewards.

Points de repère du rédacteur

- Cette étude qualitative cherchait à établir comment les médecins apprennent à communiquer avec les Autochtones.
- Pour le médecin, communiquer avec les autochtones signifie parler moins, consacrer plus de temps et être à l'aise avec le silence.
- Les patients et leurs maladies ne sont pas vus comme distincts, mais sont plutôt perçus et décrits dans le contexte de leur communauté. Cela complique la discussion de sujets d'ordre privé, dans lesquels la confidentialité des patients vient en conflit avec les valeurs de la communauté.
- Un lent processus d'adaptation permet aux médecins non autochtones de modifier leurs stratégies de communication et de développer une meilleure compréhension des peuples autochtones. La patience au cours de ce processus est garante de récompenses personnelles et professionnelles uniques.

Conclusion

This study describes a common process of change experienced by physicians working with Canada's First Nations communities. Participants experienced a change in communication style, in their approach to First Nations patients, and in the level of trust and acceptance by the community. The changes in physicians' behaviour and understanding emphasize the unique quality and dynamic nature of physicians' interactions with First Nations patients. One physician recalled:

The sense of humility that comes with understanding your limitations, I could illustrate with a quick story: I saw a very elderly Native lady; her daughters brought

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her in, she was sort of a matriarch and they called me that night and asked would I come to the house and see her and I did. Normal pulse, normal blood pressure, chest was clear, everything seemed fine and I had no idea why they called me out at night, but I was pretty annoyed that they had done that ... when one of the daughters said to me: "Would you like a cup of tea?" and I said "Sure, that would be great," and that sort of diffused my little reprimand.

I went into the kitchen and sat down to have my cup of tea and while I was having the tea, the daughters went back into the bedroom, and then one of them walked out and said "Well, she's gone very peacefully now," and I said, "What?" and ran into the bedroom. She was lying there as dead as a doornail and they said: "Thank you very much for coming when mother died. You know we knew she was going to go and we really appreciate just you having been here."

I thought to myself, "Well, first of all am I ever glad that I didn't say what I had intended to say about the unnecessary visit and secondly, how the hell did they know she was dying?" I honestly did not have a clue. That injected in me a great sense of humility, like whoa, they know a lot that I don't know, about their mother but also just about death and dying and anyway I've held onto that sense of humility and that's pretty much where I remain. ✱

Acknowledgment

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Authors' contributions

Dr Kelly formulated the research question, designed the study, conducted the interviews, analyzed the data, and prepared the paper for publication. Dr Brown contributed to development of the research question and the design and participated in data analysis and preparing the paper for publication.

Competing interests

None declared

Correspondence to: Dr Len Kelly, Box 489, Sioux Lookout, ON P8T 1A3; telephone (807) 737-3803; fax (807) 737-1771; e-mail pogmor@voyageur.ca

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Cultural Competence

Birch J, Ruttan L, Muth T, Baydala L. Culturally Competent Care for Aboriginal Women: A Case for Culturally Competent Care for Aboriginal Women Giving Birth in Hospital Settings. *Journal of Aboriginal Health* 2009;4(2):24-34.

This literature review discusses the need for culturally competent care which involves an understanding of cultural, emotional, historical and spiritual aspects of health and healthcare. Birch's literature search revealed a paucity of research on the needs of Aboriginal women delivering in hospital settings.

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This fact sheet provides the key points regarding the development of the concept of cultural safety in healthcare. "Cultural safety moves beyond the concept of cultural sensitivity to analyzing power imbalances, institutional discrimination, colonization and relationships with colonizers, as they apply to health care." Cultural safety is predominantly applied to bicultural environments on post-colonialization. It focuses on respect and trust.

Walker R, Cromarty H, Kelly L, St Pierre-Hansen N. Achieving cultural safety in Aboriginal health services: implementation of a cross-cultural safety model in a hospital setting. *Diversity in Health and Care* 2009;6:11-22.

This article describes the Sioux Lookout Meno Ya Win Health Centre's (SLMHC) development and implementation of a *mino yawin* model of care. This model is based on a cultural safety approach which incorporates First Nations perspectives and worldviews into all levels of care in order to reduce barriers to care and improve health outcomes.

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Culturally Competent Care for Aboriginal Women:

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

June Birch, B.A., Research Assistant, Misericordia Child Health Clinic, Misericordia Community Hospital, Edmonton, Alberta .

Lia Ruttan, Ph.D., Research Associate, Misericordia Child Health Clinic, Misericordia Community Hospital, Edmonton, Alberta

Tracy Muth, M.Ed., Department of Educational Psychology, University of Alberta, Edmonton, Alberta

Lola Baydala, M.D., M.Sc., F.A.A.P., F.R.C.P., Associate Professor, Department of Pediatrics, University of Alberta, Edmonton, Alberta

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 Aboriginal¹ 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 Edgcombe (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-Wasekeesikaw, 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."



FACT SHEET: CULTURAL SAFETY

Origins and Background

- The term “cultural safety” was developed in the 1980s in New Zealand in response to the indigenous Maori people’s discontent with nursing care. Maori nursing students and Maori national organizations supported the theory of “cultural safety,” which upheld political ideas of self-determination and de-colonization of Maori people.
- Cultural safety was controversial when first introduced to public health and academic communities in the late 1980s and early 1990s. Criticisms voiced in the media claimed that nursing schools, by adopting mandatory cultural safety curriculum, were “force-feeding culture” and “indoctrinating nursing students” with specific political views.
- In 1990, the Nursing Council of New Zealand incorporated cultural safety in its curriculum assessment processes, and nursing school examinations began testing student comprehension of the concept. The Council’s current document outlining its position on cultural safety is entitled “Guidelines for Cultural Safety, the Treaty of Waitangi, and Maori Health in Nursing and Midwifery Education and Practice.”
- Cultural safety is based within a framework of dual cultures and is congruent with the tenets of Aotearoa/New Zealand’s founding document, the Treaty of Waitangi.
- “**Transcultural nursing**” is the most common theoretical approach to cultural skills education in Canadian nursing schools. It differs in a number of ways, including in origin, from the newer concept of cultural safety. Transcultural nursing was developed from the perspective of the dominant (European, white) culture, whereas cultural safety was developed by non-dominant Maori peoples reacting to negative experiences in the health and nursing system.
- The doctoral and other academic work of Irihapeti Ramsden, a Maori nurse, has served as this theory’s foundation. Her early work includes “Kawa Whakaruruhau: Cultural safety in nursing education in Aotearoa,” which was published for the Ministry of Education of New Zealand in 1990.

Key Concepts

- Cultural safety is an evolving term and a definition has not been finalized. However, the Nursing Council of New Zealand has defined culturally unsafe practice as “any actions that diminish, demean or disempower the cultural identity and well being of an individual.”
- Cultural safety moves beyond the concept of cultural sensitivity to analyzing power imbalances, institutional discrimination, colonization and relationships with colonizers, as they apply to health care.
- There is much confusion and ongoing debate about how cultural safety differs from other concepts like cultural competency, cultural awareness, cultural sensitivity and cultural appropriateness. Each of these terms has many definitions and it is difficult to gauge how they overlap.

- Ramsden is one of many health professionals who views these terms on a continuum of care. According to Ramsden, cultural awareness is the beginning step in the learning process, which involves understanding difference, while cultural sensitivity is an intermediate step where self-exploration of the student begins. Cultural safety is the final outcome of this learning process. A nurse who can practise safe care interacts with patients in such a way that those who receive care **define it**.
- Biculturalism is a key element of cultural safety theory and asserts the primary position of the original people of the land in relation to all subsequent arrivals (Polachek, 1998). This is in contrast to multicultural approaches that do not recognize power differences among various ethnic groups.
- Cultural safety has been referred to as "Critical Social Theory," because it is argued that "it is no different from teaching people to be aware of the socio-political, economic issues in society and to recognize the impact that these issues have on people" (Ramsden, 133).
- Cultural safety requires that nurses become **respectful** of nationality, culture, age, sex, political and religious beliefs. This notion is in contrast to transcultural/multi-cultural nursing care, which encourages nurses to deliver service **irrespective** of these aspects of a patient.
- A key element of culturally safe practice is establishing trust with the patient. Culturally safe care empowers people because it reinforces the idea that each person's knowledge and reality is valid and valuable. It facilitates open communication and allows the patient to voice concerns about nursing care that he or she may deem unsafe.
- Care may be deemed unsafe if the patient is humiliated, alienated, or directly or indirectly dissuaded from accessing necessary care.
- Cultural safety involves recognizing the nurse as the bearer of his or her own culture and attitudes, and that nurses consciously or unconsciously exercise power over patients. Cultural safety is a political idea because it attempts to change health professionals' attitudes about their power relationships with their patients.
- Many academics maintain that cultural safety in the mainstream health care system cannot be achieved by individual interactions. Rather, it depends on meaningful participation of Aboriginal people in decision-making processes that allow transfer of power to Aboriginal governments (Browne, Fiske, Thomas, 2001).

Cultural Safety Education

- Focuses on
 - teaching students about colonial history and its impact on Indigenous peoples, rather than on increasing knowledge about indigenous customs and health beliefs.
 - self-discovery: "Students need to learn to evaluate what they are bringing to the table in terms of their own invisible baggage; that is, attitudes, metaphors, beliefs and values" (Ramsden 1992: 23).
- Aims to
 - identify attitudes that may consciously or unconsciously exist towards cultural/ social differences in health care.
 - transform attitudes by tracing them to their origins and seeing their effects on practice through reflection and action.

Cultural safety education enables students to respect client diversity, e.g., asking permission of their patients before acting.

Cultural Safety Learning Objectives

Irihapeti Ramsden outlined the following learning objectives in her 2002 doctoral thesis, "Cultural Safety and Nursing Education in Aotearoa and Te Waipounamu":

- Educate student nurses and midwives not to blame victims of historical processes for current plights.
- Educate students to examine their own realities and attitudes that are brought to each new person they encounter in practice.
- Educate student nurses to be open minded and flexible in their attitudes toward people who are different from themselves, to whom they deliver service.
- To produce a workforce of well-educated, self-aware registered nurses who are culturally safe to practice, as defined by the people they serve.

Example of culturally safe care

A self-aware nurse recognizes homophobia in her own personality and chooses not to work in the H.I.V. ward of a hospital where there is a higher chance of encountering homosexuals. This reduces the likelihood of the nurse providing demeaning, humiliating or unsafe care to a patient (Ramsden, 2000).

Achieving Cultural Safety in Aboriginal Health Services: *Implementation of a cross-cultural safety model in a hospital setting*

Roger Walker, MPA, MHA, CHE; CEO and President, Sioux Lookout Meno Ya Win Health Centre
Helen Cromarty, BHScN; Special Advisor on First Nations Health, Sioux Lookout Meno Ya Win Health Centre
Len Kelly, MD, MClIn Sci, CCFP,FCFP Associate Professor, Northern Ontario School of Medicine
Natalie St Pierre-Hansen, BA, Research Intern, Northern Ontario School of Medicine, Sioux Lookout ON

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ABSTRACT

Genuine cross-cultural competency in health requires the effective integration of traditional and contemporary knowledge and practices.

This paper outlines an analytical framework that assists patients/clients, providers, administrators, and policy-makers with an enhanced ability to make appropriate choices, and to find pathways to true healing while ensuring that the required care is competently, safely and successfully provided.

Examples presented are primarily based on experience of the Sioux Lookout Meno Ya Win Health Centre (SLMHC), which serves a diverse, primarily Anishnabe population living in 32 northern Ontario communities spread over 85,000 sq. kms of Canada. SLMHC has a specific mandate, among Ontario hospitals, to provide a broad set of services that address the health and cultural needs of a largely First Nations population.

We will outline our journey to date to implement our comprehensive *minoyawin*¹ model of care, including an evaluation of the initial outcomes. This model focuses on cross-cultural integration in five key aspects of all of our services:

- Odabidamageg (governance and leadership)
- Wiichi'iwewin (patient and client supports)
- Andaw'iwewin (traditional healing practices)
- Mashkiki (traditional medicines)
- Miichim (traditional foods)

The paper outlines a continuum of program development and implementation that has allowed core elements of our programming to be effectively integrated into the fabric of all that we do. Outcomes to date are identified. Potentially transferable practices are identified.

Introduction

Genuine cross-cultural competency in health care seeks to provide patients with a safe and empowering environment in which to heal. In this context, the general concept of patient safety incorporates the constructs of cross-cultural patient safety. Cross-cultural patient safety in health care requires organizational values that are responsive to the values of the patients and communities receiving care. The perspectives and worldviews of the people represented must be integrated into all facets of service provision, from program development to service delivery. Canada's founding Aboriginal peoples comprise three distinct groups: Inuit, Metis, and First Nations (previously referred to as North American Indians). The Sioux Lookout Meno Ya Win Health Centre (SLMHC) is traveling a path towards cultural safety by integrating First Nation's values, knowledge and practices into the ethos of the organization.

The hospital is located in northern Ontario, Canada and serves a local population of 7,000 and a predominantly First Nations population of 18,000 in distant communities accessible by fixed wing aircraft. The Sioux Lookout

¹ "Minoyawin" is an Anishnabe term that connotes health, wellness, well-being – a state of wholeness in the spiritual, mental, emotional and physical makeup of the person.

Meno Ya Win Health Centre is Ontario's designated center of excellence for First Nations health. It is developing a comprehensive, integrated set of patient/client supports that can be adapted to other multicultural settings.

Meno Ya Win Health Centre

The Sioux Lookout MenoYa Win Health Centre provides services to a largely First Nations service population: eighty-five percent of our patients are predominantly First Nations, many of whom primarily speak one of the three Anishiniimowin languages: Ojibway, Oji-Cree and Swampy-Cree. There are 19 dialects within these languages. The majority of the twenty-eight northern First Nations communities are remote and accessible only by fixed wing air transportation. Patients who travel to Sioux Lookout for services are often far from family and community supports. They face navigation of an unfamiliar health care system in the midst of an environment and culture that is "foreign" to them. SLMHC has developed a model of care that provides optimal patient supports to navigate the health care system and its environment, and that ensures that care is competently, safely and successfully provided. This article will describe the SLMHC "menoyawin" model of care, its conceptual foundations, and its implementation through its Traditional Healing, Medicines, Foods and Supports program. This model may assist patients/clients, providers, administrators, and policy-makers with an enhanced ability to find local pathways to true healing while ensuring that the required care is competently, safely and successfully provided.

Culturally appropriate programming enables care

The international literature highlights the importance of traditional healing. (O'Neil *et al*, 2005; Waldram *et al*, 2006) The National Aboriginal Health Organization (NAHO) describes the correlation between healthcare systems and the cultural esteem of Aboriginal peoples. (NAHO, 2001) Integrating traditional healing with allopathic healing provides the client with choices enabling them to define their care. (Waldram *et al*, 2006) Acknowledging and preserving culture fosters relationships of trust and support self-efficacy and identity. (NAHO 2001) An assessment of South and Central American best practices in intercultural health found trusting relationships and the opportunity for two-way knowledge exchange, resulted in apparent increases in cultural pride, ownership and control. (O'Neil *et al*, 2005) The most demonstrable impact of these Latin American initiatives was increased access to both traditional and Western medicine, directly impacting people's health. (O'Neil *et al*, 2005) The Aboriginal Nurses Association notes that patients respond better to care and have better health outcomes when their care is culturally appropriate. (Aboriginal Nurses Association, 2005)

Cultural Safety

Building on concepts of transcultural care espoused by Leininger and others, the concept of 'cultural safety' was described by Ramsden in the 1980's and developed in the context of nursing education in New Zealand. (Ramsden 1989, 2001, NCNZ 2005, NAHO 2006) Unlike other cultural skills curriculums, which are developed by the dominant culture, the cultural safety approach was developed by the minority group, the Maoris. (NAHO 2006) This theoretical framework is most relevant in a bicultural environment, since program development incorporates cultural constructs in to program development which is possible when involving two cultures. It emerged alongside the developing political ideas of self-determination and de-colonization (NAHO 2006). The product is an approach that extends beyond cultural competence, examining power imbalances, marginalization and the relationships between colonizers and the colonized. Congruent with post-colonial theory, which examines cultural identity and relationships within colonized societies, the cultural safety framework uses a socio-historic lens to understand everyday interactions in health care settings.

There is a growing body of evidence that patients who are culturally or ethnically different from the mainstream are at higher risk of experiencing adverse events that might have been prevented except for the language or cultural difference. (Johnstone and Kanitsaki 2006) This is supported by the Joint Commission on the Accreditation of Hospitals. (Schyve 2002)

The First Nation traditional philosophy of health/healing is to use nature, natural products and natural life processes including culture, in a broad sense, as a primary healing approach. This encompasses the view of the human being as an organism with self-healing and strong recuperative powers. When these powers are maintained properly, a person is capable of on-going health and longevity.

Where disease does exist, a traditional healer seeks to correct internal and external imbalances between the four aspects of our personal wholeness: spirit, body, and mind (at both an emotional and mental health level). Bringing body, mind and spirit to a deeper inner level of knowing leads one toward integration and balance. The Sioux

Lookout model of care is built on these and related underlying traditional First Nations philosophies that are materially different from Euro-Canadian understanding. It is highly probable that this tradition will ultimately prove more successful at addressing some of the root causes of the profound health status issues facing First Nations.²

Cultural safety educators teach about the connection between socio-political processes and contemporary health and social issues. (Browne and Smye, 2002) Rather than focusing exclusively on increasing learners' knowledge of practices and traditions, educators raise awareness about colonial history and the continued injustices experienced by Indigenous peoples. (NAHO 2006) Understanding that power imbalances continue to exist, and that they are rooted in colonial processes helps learners examine their own attitudes and how they may impact the people to whom they provide care. The SLMHC approach is broadly based on both of these elements: expanding understanding of the "colonialization" processes and their impacts, and expanding knowledge and awareness of culture, practices, and traditions. This is the approach taken in Bimaadiziwin, our two day cultural orientation given to all hospital staff.

Beyond traditional risk factors

The SLMHC defines cross-cultural patient safety as the safe and successful delivery of health care services across cultural, linguistic and related barriers to the understanding and identification of client needs. It includes overcoming the obstacles to implementing prescribed remedial or supportive actions. Cultural safety encompasses a broader set of constructs than conventional contemporary constructs of patient safety, such as: infection control, medication errors, adverse events, and other typical health service safety issues. These cultural safety barriers are described in an analytical framework summarized in the following table.

Table 1. CROSS-CULTURAL PATIENT SAFETY RISK FACTORS

1. *linguistic*
potential for miscommunication, misunderstanding of descriptions of symptoms and therapeutic intervention; limitations in language, idiom, vernacular and non-verbal communication.
2. *cultural*
Potential for misunderstanding the cultural context of the presenting pathology, the challenge of implementing a prescribed course of action in the face of contradictory world views, values sets, norms and mores.
3. *medical literacy*
Varying levels of medical literacy among different populations, particularly where:
 - native languages do not include medical or related terminology - cultural or ethnic variations in access and use of medical services impact the effectiveness and outcomes of those services in reaching diverse populations
 - patients are unable to navigate the system due to lack of familiarity.
4. *program or practice*
Conventional services and practices contrast with traditional practices.
5. *contextual or structural*
potential for misunderstanding or mishap due to cultural habits and associated knowledge.
6. *systemic*
Disconnects between mainstream systems and specific population providers including territoriality, overlaps, gaps differing approaches, jurisdictional differences, etc. – these often involve access and availability issues.
7. *genetics*
Failure to take into account inherent issues in a population.
8. *racism/discrimination*
Manifestations of bigotry, prejudice or intolerance that result in the differential provision of services as the result of ethnic or racial factors.
9. *power, history and politicization of health*
Spotlight on individual issues at the risk of disrupting energy and resources from other priorities, often associated with treaty rights to health, historical issues and grievances, failure to consult,

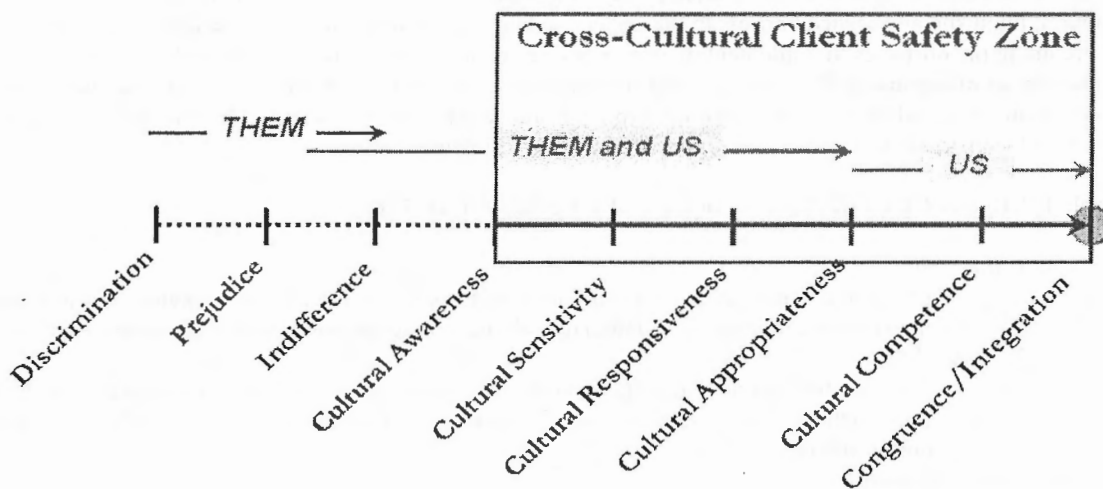
² Adapted from Cultural Program Overview, All Nations' Healing Hospital, 2005.

power and control issues, political agendas including: self-government, autonomy, self-reliance or community engagement.

Developing a zone of cultural safety

The SLMHC has developed a conceptual model to guide us in transitioning both the organization and individuals to a “zone of cultural safety”. It charts the path toward cultural integration at the organizational level and cultural congruence for the individual. It is primarily based on Guidelines for Cultural Safety, the Treaty of Waitangi and Maori Health. (Nursing Council of New Zealand 2005) It also draws upon the continuum of cultural competency for mental health care services developed by Cross (1989). His continuum sets forth six stages from cultural destructiveness to cultural proficiency. (Cross *et al*, 1989) Our developmental path identifies an institutional process of change from ‘them’ to ‘us’. We describe the cultural safety zone which begins with cultural awareness and ends at cultural integration at an institutional level.

Figure 1 THE CONTINUUM OF CROSS-CULTURAL CLIENT SAFETY



Achieving Cultural Safety in Health Services: Understanding and Responding to the Underlying Cultural Factors
 Walker and Coleman, 2006

In this model, marginalization or power imbalance positions are reduced or eliminated by moving the organization and component participants to progressively higher levels of equity, not necessarily equality, of health service access, service and quality. The development and deployment of sensitive remedial action and behavior requires an awareness of cultural diversity, inequity in service and treatment and their underlying causes and relationships. In turn, culturally-attuned responsiveness builds on a foundation of cultural sensitization and sensitivity. Cultural appropriateness depends on the ability and willingness of providers to respond with sensitivity, understanding and awareness. Cultural competence - the ability to provide services in a manner that succeeds in large measure because of the acceptability to the client of the type of service and the manner in which they are provided, likewise builds on these foundations. Cultural congruence, the individual internalization of diversity-based values and understanding, and the consistent externalization of equitable, value-based behaviors, is at the endpoint of the continuum. So are fully integrated practices and services at the organizational level.

Movement beyond marginalizing behaviors, allows the organization and individuals to engage in safer practice, and ultimately reduces the margin for error based on diversity and cultural factors as progressively higher levels on the continuum are reached. Organizational structures, programs, services, and processes can be built and resource allocation decisions made to advance the organization along this continuum. Staff orientation, training and development and staff supports can be established to facilitate behavior changes, and to enhance knowledge, skills and understanding. With the understanding that discrimination occurs at many different levels, caregivers can

engage in a process of critical reflection to examine how their own behaviors may consciously or unconsciously contribute to power imbalances and failure to overcome barriers to safe, quality care for their clients.

Similar concepts (cultural pre-competence, cultural competence, cultural appropriateness and cultural proficiency) have multiple definitions and can sometimes be difficult to distinguish from one another. (NAHO, 2006; Crampton *et al* 2006) Definitions are often dependant on the context in which the term has developed. Discourse in the United States is informed by a multicultural setting and therefore the framework of cultural competence is most often used. (Crampton *et al* 2006) Cultural competence is an openness and respect for diverse cultures and peoples. The bicultural environments of the cultural safety models are unique in that program design reflects the values and practices of the people receiving care.

For genuine cultural safety to occur, the minority group not only receives care that is culturally competent, but they themselves define a model of care that enriches and empowers their culture. Ultimately, the core foundation for cultural safety is rooted in patient-centric practice.

In 2003 SLMHC proceeded to build its organization based on these underlying values and concepts. It was recognized that a major redesign of values, structures and approaches was needed to move SLMHC beyond the modest approaches of the predecessor organizations to address the cross-cultural needs of the service population and to establish a firmly secure position for the new organization on the cultural safety continuum. The work began with the initiation of a planned organizational transition process.

The Process of Institutional Change

Background and Needs Assessment

SLMHC was founded in 2002 as a result of the 1997 Sioux Lookout Four Party Hospital Services Agreement between Canada, the province of Ontario, Nishnawbe Aski Nation and the Town of Sioux Lookout. The agreement is predicated on the need for culturally responsive health services programming at all levels; from foundational philosophies to definitions of service delivery.

A comprehensive needs assessment for culturally responsive care at SLMHC was undertaken in 2003 and 2004. It was informed by the following documents and processes:

- *Bi maa dizi win and Meno Ya Win: A Study of Development of Traditional Approaches to Health Care at Sioux Lookout Meno Ya Win Health Centre* – April, 2005
- SLMHC Population and Demographics Study – March, 2005
- Draft Traditional Medicine Program Proposal – October 2004
- A Sioux Lookout Meno Ya Win Health Centre *Backgrounder: First Nations Services* – July, 2004
- Cultural Requirements Report – July, 2004
- A Personal Journey to Health Care: Whitefish Bay to Sioux Lookout – Fall 2003
- SLMHC Functional Program, and other working documents

The *Bimaa diz win and Meno Ya Win* study included several research methodologies subsequently assessed by a First Nation-based program development team. Results were vetted through further elders' consultations prior to recommendations and program proposals going to Board and government levels for review and approval.

These research techniques included: extensive document review, review of health status and services data, development of a patient profile and an inventory of existing services. Active research methods included various outreach initiatives to stakeholders:

focus groups with elders, community leaders and members, medical and hospital staff, patients clergy and healers, and other stakeholders and northern community consultations. Health centre staff also visited to 16 culturally-defined, Aboriginal serving programs in other jurisdictions and performed an Ontario-wide hospital survey on Aboriginal services.

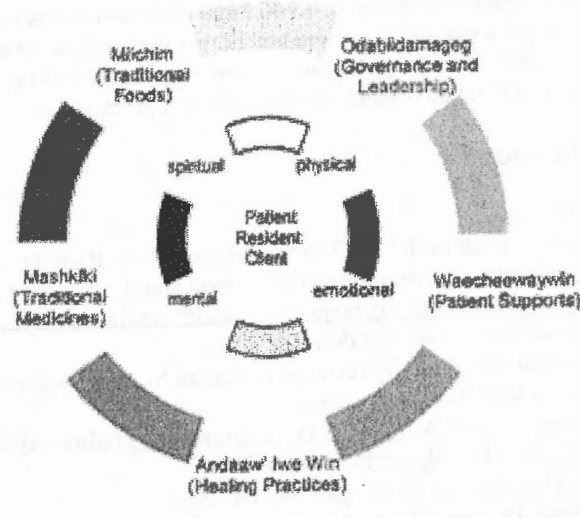
A step-wise rollout of a plan based on the data from this work was outlined in a proposed Traditional Healing, Medicines, Foods and Supports Program (THMFS). In reality, the program was intended to overlay everything else being done to advance SLMHC as new organization, and specifically, to establish SLMHC as a benchmark healthcare organization in the area of diversity programming.

Program Description

The *Traditional Healing, Medicines, Foods and Supports* (THMFS) program was designed as a model for integrated First Nations hospital-based services. The program was developed to create an environment that fosters culturally safe practices where the services that are provided are defined by the people who receive them. The THMFS program conforms to the principles of *integrative medicine* and is based on teachings and practices unique to the Anishnabe people of our area. The five components of the THMFS model are fully integrated into virtually all clinical programs, not as a separate, stand alone program.

Our very name, reflects this holistic approach to care: *menowayin* is an Anishnabe term that connotes health, wellness, well-being – a state of wholeness in the spiritual, mental, emotional and physical makeup of the person. The *medicine* wheel is based in part on incorporating these aspects of our being into all healing processes. The THMFS program, our *menowayin* model of care, was developed to be a core aspect of all SLMHC clinical and support services.

Figure 2. SIOUX LOOKOUT MENO YA WIN HEALTH CENTER MODEL OF CARE



This model of care is put into practice through the Traditional Healing, Medicines, Foods and Supports (THMFS) program. This program provides clients with an important range of *personal options* and the ability to *define* the care that they receive.

The program elements essential to effecting this organization-wide change are described below.

Traditional Healing, Medicine, Foods and Supports Program Elements

Odiidamageg (governance and leadership)

Board of Directors: 15 directors appointed on a “proportional representation” basis: 2/3 Anishnabe, 1/3 non-native.

Elders Council: An 8 person Elders Council advises on program development and management, strategic planning, board processes and other relevant issues.

Management and Leadership: The Senior Management Team includes a Special Advisor for First Nations Health, and an Advisor to the Board and CEO.

Wiichi’iwewin (patient, resident and client supports)

Wiichi’iwewin workers are available 24/7 to ensure complete bidirectional cultural and linguistic interpretation to optimize care planning and delivery. They provide the required comfort, support, community interfaces, navigation and non-clinical assistance to minimize cross-cultural, institutional, and health system barriers.

Wiichi’iwewin workers are supported by 2 Elders in Residence, a lexicon (under development), translated materials, Bimaadiziwin (cultural awareness training), and culturally-focused employment balance programs.

Andaw’iwewin (traditional healing practices)

Andaw'iwewin practices will be made available over time by adapting traditional healing programs available from community-based platforms (eg. Sioux Lookout First Nations Health Authority) to meet hospital and long term care-based needs. Traditional birth practices, smudging, healing circles, sweat lodge and other ceremonies, use of eagle feather, caring for medicine bundles, etc. are being introduced on-site.

Mashkiki (traditional medicines)

The use of traditional medicines will be introduced in conjunction with the development of appropriate mechanisms to prevent adverse reactions with other courses of treatment. A new facility now under construction to be completed in 2010 will house both preparation and storage areas for a broad variety of traditional medicines in addition to the regular hospital formulary.

Miichim (traditional foods)

Many of our clients are disadvantaged by the need to make a wholesale change in their eating practices and dietary content while they are hospitalized. A broad range of traditional foods is being added to the menu selections regularly available to patients and LTC residents. Regional variations and preferences in food items, menu selection, and cooking style are being provided to the extent possible.

Risk Management

The SLMHC risk management program will ensure that THMFS program leadership develop systems, skills and other resources necessary to successfully respond to areas of risk. Mitigation strategies have and continue to be developed to respond to potential areas of risk.

The identified areas of risk surrounding programming development and implementation include: conflict between traditional and mainstream approaches; failure to engage partners; heightened expectations that may lead to the loss of confidence in and support for SLMHC; limited use of THMFS program by First Nations clients; high utilization of SLMHC by First Nations non-residents of catchment area; inability to meet specialized staffing requirements; and perceived emphasis on meeting First Nation patient/client/staff/prospective employee needs that may lead to a sense of reverse discrimination. Mitigating strategies to respond to these areas of risk include: the development of good communication; consultation in program development and implementation; and planned, collaborative, incremental implementation.

Strategies to ensure availability and use of interpreters that respond to all area languages/dialects are in place to reduce risk surrounding communication and linguistic interpretation. Other risk management strategies have been developed to respond to areas of risk surrounding food, medicine and traditional practices: food contamination; adverse reaction to drugs and/or medicines; nutritional value of traditional foods; health impact of mainstream foods; infection/contamination issues as a result of non-sterile materials brought to support THMFS program; and congestion, noise, smoke, fire interferences that may occur with ceremonial practices.

In addition to monitoring these and other risk factors that may be identified in the future, it will also be necessary to review liability issues with the Health Insurance Reciprocal of Canada (HIROC) to ensure appropriate levels of financial protection are in place.

Obstacles to Implementation

Barriers to implementation fall into five broad categories: political (at the national or international level), health care system, cultural, organizational and individual. The deteriorating economics of care and society mean that the "financial imperative" often overrides the social good. In this context health services are commonly seen as a social utility weighed against all other social goods and services as distinct from ensuring the provision of healthcare services based on a view of them as a basic human right, particularly when a minority is involved where affirmative action fatigue may prevail. Politically, cultural issues are seen to be in the interest of a minority, while political and economic power is allocated to the majority. Health services in Ontario and other Canadian provinces has an increasing focus on accountability and showing direct benefits from investment decisions and has major focuses on infection control and targeted services (more cardiac/stroke, chronic disease management).

Consequently little interest develops in inequalities due to diversity. Cultural barriers include linguistics, patient medical literacy, power, history and politicization of health and racial discrimination. Organizations first need to understand the nature of the issues and potential responses, then act with appropriate resourcing at a time of competing demand for those same resources. Individuals may not be prepared or willing to invest the necessary effort to move forward to effect requisite changes in personal values, mindset or behavior.

Moving beyond cultural competency to cross-cultural integration at the individual, organizational or systematic level requires understanding and specific strategies to address and overcome these barriers.

Discussion

The SLMHC model of care may assist patients/clients, providers, administrators, and policy-makers with an enhanced ability to make appropriate choices, and to find pathways to true healing while ensuring that the required care is competently, safely and successfully provided.

At both an individual and collective level, this illness burden cannot be remedied solely by "fixing" the underlying causes rooted in determinant of health deficits. The persistent demoralizing effect of the twin legacies of "colonization" and "residential schools", and impacts of contemporary socio-economic deficiencies and multiple access-to-care barriers can be significantly addressed by traditional approaches.

International initiatives such as the US Office of Minority Health's *National Standards for Culturally and Linguistically Appropriate Services* (CLAS) and the EU's *Amsterdam Declaration Towards Migrant Friendly Hospitals* demonstrate frameworks developed in ethno-culturally diverse settings. Specifically the American CLAS standards provide a valuable model for building an organizational approach to cultural competency. Their suggested key areas for diversity initiatives could benefit Canada's increasingly diverse population (both Aboriginal and migrant). Similarly, forces that generated the Amsterdam Declaration are at play in Canada: significant permeability of borders and large scale immigration, vulnerability of migrant and minority populations and differential access and quality in health services. The Amsterdam Declaration recommendations directed at specific target groups are readily adaptable to the Canadian context, although specific adaptation to Aboriginal issues would be required. A developing global dialogue will contribute to better understanding of underlying barriers to successful cross-cultural delivery of health services.

Conclusion

Cultural safety encompasses a broader set of constructs than conventional contemporary patient safety theory and practice. In its essence it is rooted in difference and diversity, and hence based on awareness, understanding, acceptance, respect and empowerment of individuals within their personal, family or community cultural context. SLMHC is moving rapidly toward becoming an organization where mainstream Euro-Canadian and Aboriginal stakeholders are equally comfortable and fluent in any SLMHC context. There is a growing sense of identity and ownership. By following the path charted out, SLMHC hopes to reach a point where cultural diversity and fluency are embedded in the psyche of the organization and reflected in the behavior of the staff.

The net result will be safer, more accessible, more effective quality care.

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Rural Obstetrics

Dooley J, Kelly L, St Pierre-Hansen N, Antone I, Guilfoyle J, O'Driscoll T. Aboriginal Obstetrical Program: Sioux Lookout Meno Ya Win Health Centre obstetrics. *Canadian Journal of Rural Medicine* 2009;14(2):75-9.

Dooley details the Sioux Lookout Meno Ya Win Health Centre's (SLMHC) obstetrics program which provides a full range of safe obstetric care to 28 remote Aboriginal communities in Northern Ontario. The strengths of the program are: patient volume (300-350) which allows for continued competence interest and comfort level; remote location which makes for broad-scope and multiskilled physicians and nurses; organizational culture of collegiality and sense of commitment and ownership.

Kornelson J, Grzybowski S. The Reality of Resistance: The experience of rural parturient women. *Journal of Midwifery and Women's Health*. 2006;51(4):260-265

This qualitative study examines the delivery experiences of 44 women from four rural and communities in British Columbia. This study elicited four themes or what Kornelson calls realities: geographic location; health system resources; reality of parity and financial realities. Various "strategies of resistance" were employed by the participants to mitigate their feelings of anxiety: elective inductions to reduce amount of time away from their home, timing of conception to avoid winter travel, delayed presentation at hospital and unassisted homebirths.

Zelek B, Orrantia E, Poole H, Strike J. Home or Away? Factors affecting where women choose to give birth. *Canadian Family Physician* 2007;53(1):78-83

This qualitative study of 64 women living in Marathon, Ontario – where there is no c-section capabilities – examines the preference of staying in Marathon to deliver. They found that 77.8% of women choose to deliver in Marathon. There was a correlation between beliefs and choosing to deliver locally. Concerns included the belief that partner and/or coach could easily be present and beliefs around risks, convenience, involvement in decision making and doctor preferences.

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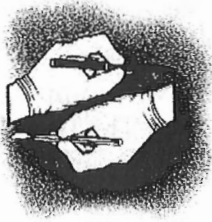
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DESCRIPTIVE ARTICLE ARTICLE DESCRIPTIF

Rural and remote obstetric care close to home: program description, evaluation and discussion of Sioux Lookout Meno Ya Win Health Centre obstetrics

J. Dooley, MD
Northern Ontario School of
Medicine, Sioux Lookout, Ont.

Len Kelly, MD
Northern Ontario School of
Medicine, Sioux Lookout, Ont.

N. St Pierre-Hansen, MD
Northern Ontario School of
Medicine, Sioux Lookout, Ont.

I. Antone, MD
Northern Ontario School of
Medicine, Sioux Lookout, Ont.

J. Guilfoyle, MD
Northern Ontario School of
Medicine, Sioux Lookout, Ont.

T. O'Driscoll, MD
Northern Ontario School of
Medicine, Sioux Lookout, Ont.

Correspondence to:
Dr. J. Dooley, Box 489,
Sioux Lookout ON P8T 1A8;
fax 807 737-1771;
jdooley@tbaytel.net

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Problem being addressed: Aboriginal and non-Aboriginal women in rural and remote settings struggle to access obstetric care close to home.

Objective of the program: To deliver a full range of modern and safe obstetric care to 28 remote Aboriginal communities served by rural-based health care.

Program description: Rural family physicians provide intrapartum, cesarean delivery and anesthesia services to 350 rural, primarily Aboriginal women in a collegial, supportive environment.

Conclusion: Rural and remote obstetric services need support before they fail. Patient volume, remote location and organizational culture are key elements. Evidence teaches us that outcomes are best when women deliver closer to home.

Problème abordé : Les femmes autochtones et non autochtones vivant en région rurale et éloignée ont du mal à obtenir des soins obstétricaux près de chez elles.

Objectif du programme : Offrir une gamme complète de soins obstétricaux modernes et sécuritaires à 28 communautés autochtones éloignées, desservies par des services de soins de santé ruraux.

Description du programme : Prestation de services intrapartum, de césariennes et d'anesthésie obstétricale par des médecins de famille exerçant en milieu rural, à 350 femmes, surtout autochtones, dans un contexte de collégialité et d'entraide.

Conclusion : Il faut soutenir les services obstétricaux en région rurale et éloignée, faute de quoi ils pourraient disparaître. Le volume de patientes, l'éloignement géographique et la culture organisationnelle sont des éléments clés dont on doit tenir compte. L'expérience nous enseigne que l'issue des grossesses est meilleure lorsque les femmes peuvent accoucher plus près de leur lieu de résidence.

INTRODUCTION

Delivery of obstetric services to remote communities in Canada will always be challenging. Despite decades of experience there are limited descriptions of successful models of care.

In 1997, the Joint Working Group of the Society of Rural Physicians of Canada, the College of Family Physicians of Canada and the Society of Obstetricians and Gynaecologists of Canada (SOGC) identified an "urgent need for Canadian research on the

maternal and neonatal outcomes of births ... in small hospitals."¹ A 2007 SOGC report identified a need for increased opportunities for Aboriginal women to deliver close to home in a familiar environment.²

BARRIERS

Rural women are increasingly required to travel for obstetric services.³ This need for travel results in poorer birth outcomes.⁴ For women from remote Aboriginal communities, the distance

travelled is even greater and the differences in cultural environments and language compound the stress of childbearing.

The geographical challenges that accompany a centralization of obstetric services are identified as one of multiple factors associated with Canada's rising induction rate.⁵ Travel for labour and delivery is associated with higher delivery complications and rates of prematurity,⁴ as well as increased financial, emotional and psychologic stress.^{6,7} Most women choose to deliver in their home community despite limited obstetric services.⁸⁻¹⁰ Zelek and colleagues¹⁰ documented that 77.8% of the eligible (nonprimigravida) women studied preferred to deliver at the rural hospital in Marathon, Ont., which had no cesarean delivery capabilities.

Most studies pertaining to the quality of maternal care by family physicians in rural hospitals indicate safe outcomes comparable to larger urban centres.¹¹⁻¹⁷ A 1984 study of rural obstetrics programs in northern Ontario found small rural hospitals that performed cesarean deliveries regularly had slightly better birth outcomes than urban centres.¹² Similar results from a recent study in Bella Coola, BC, support the conclusion that "low technology environments" are capable of providing excellent maternal outcomes even without cesarean delivery capabilities.¹⁶ A 2007 Canadian study that analyzed 5792 cesarean deliveries compared the outcomes of those performed by general practitioners to those performed by specialists and found similar outcomes.¹⁸

Closures and centralization of rural obstetrics programs in Canada because of physician shortages is not uncommon¹⁹⁻²¹ and is deemed part of the emerging maternity care crisis by the Ontario Women's Health Council.¹⁹ The council and others²²⁻²⁶ identify the need for health human resources and physician retention. Recently, the BC government has allocated funds to re-establish family physician involvement in obstetrics.²⁴

SOLUTIONS

Creative solutions that fit the environment and resources of a community can reduce women's need to travel for obstetric services and allow for the survival of small obstetrics programs. The Weenebayko Hospital in Moose Factory, Ont., services 6 remote, fly-in communities. The hospital's obstetrics program of 100 deliveries per year has closed at times because of physician shortages, requiring patients to travel to Timmins, Ont., to receive care. Now once again operational, the program has family

physicians performing deliveries, and the general surgeon doing cesarean deliveries with support from obstetricians on itinerant visits. The family physicians involved can access additional training in Timmins. The program, which reopened in 2004, allows women to stay "in zone" to deliver.²⁵

SIoux LOOKOUT MENO YA WIN HEALTH CENTRE PROGRAM

The obstetrics program at the Sioux Lookout Meno Ya Win Health Centre (SLMHC) has been in operation for 25 years and services 28 remote, fly-in Aboriginal communities and the town of Sioux Lookout, Ont., serving a total population of 25 000. The SLMHC has developed a model of care that incorporates Aboriginal values and promotes an environment of culturally sensitive care. The obstetrics program has cesarean delivery, ultrasonography and version capabilities, delivered by rural physicians with appropriate additional training. The program reduces the need for patients to travel more



Four generations pose for a picture in front of the Sioux Lookout Airport, as Beatrice (Ningewance) Kanate and her newborn son, Ethan, prepare to go home to North Caribou Lake First Nation. Ms. Kanate (centre) is pictured with (from far right, counter-clockwise) her grandmother, Agnes Ningewance; her father, Merv Ningewance; her brother, Pawn Ningewance; and her son, Ethan Kanate.

than 300 km to larger centres in Thunder Bay, Ont., or Winnipeg, Man. An average of 350 deliveries are performed at the centre each year.

Prenatal care

Currently there is one federally funded ultrasonography technician who travels to remote communities performing prenatal ultrasonography. In 2007, he made 55 community visits, performing 465 portable obstetric ultrasonography procedures in the local community nursing stations.

Routine prenatal care throughout the pregnancy is provided by visiting family physicians and by the community's expanded-role nurses with telephone access to on-call physicians.

Twice weekly prenatal clinics are held in Sioux Lookout with about 1000 patient visits per year. This allows patients referred for delivery to be followed up regularly after 38 weeks. It also allows for the review of patients referred for earlier complications.

Evaluation of referrals and case management

Multidisciplinary weekly rounds are held to ensure that the 350 pregnant women per year referred to the SLMHC obstetrics program are appropriate for our facility. This provides opportunity for risk assessment and further testing on specialty referrals.

Program coordination

A nurse coordinator facilitates consultations, liaises with nursing stations and ensures patients are oriented to our facility. This coordinator maintains contact with the patients and provides prenatal education while they are in Sioux Lookout. This allows us to ensure complete documentation is received and that the appropriateness of referrals and risk assessment for local delivery is developed.

Labour and delivery staff

The hospital continues to work to ensure that staff covering the labour floor have the appropriate experience. The SOGC ALARM (Advances in Labour and Risk Management) program has been run twice in the past 7 years in Sioux Lookout. The presence of an in-house registered nurse/neonatal resuscitation instructor also allows all care providers to maintain their competence. The continuing education of both the nursing and medical personnel attending deliveries is essential.

Availability of cesarean delivery

Surgical delivery is performed by 3 family physicians (2 local, 1 locum). Anesthesia services are provided by 4 general practitioner-anesthetists (2 local, 2 locum). Six other family physicians provide on-call services for the hospital-based prenatal clinic, labour and delivery.

Cultural supports

For many of our patients, English is a second language. We have Aboriginal interpreters available 16 hours a day for routine translation. Further cultural services are provided through the SLMHC Traditional Healing, Medicine, Foods and Supports Program, which includes a visit by an elder and access to traditional foods. In these ways the program tries to provide as culturally appropriate an environment as close to home as possible.²⁶

Tele-health evaluations

This component of the program commenced in September 2007 to decrease travel from communities for a broad scope of consultations, including mid-trimester assessments. Last year during a blizzard, 2 babies were born in remote communities, assisted by the on-call physician in Sioux Lookout via live video conferencing.

Evaluation

SLMHC is considered a level-1 obstetrics program (providing care to women who anticipate healthy nonemergent births and term newborns), but our patients often present unique cultural and geographic challenges. Both type 2 diabetes and gestational diabetes are becoming common complications. A 1997 study of Native women delivering in Sioux Lookout found the rate of gestational diabetes to be 8.4%, when the national average was 4%.²⁷ Data from 2005/06 showed that our region's rate of smoking during pregnancy and teenage mothers to be the highest in the province.²⁸

Outcomes

Our obstetric outcomes compare well with provincial averages. At 24%, our cesarean delivery rate, from 2005 to 2007, was lower than the provincial averages of 28% for all hospitals and 27% for all level 1 institutions.²⁹ Most of our cesarean deliveries (73%) were

urgent/emergent, and 27% were elective primary or repeats. Of the 627 deliveries, we had 10 failed attempts at vaginal birth after cesarean (VBAC) and 39 successful VBACs — a success rate of 80% versus a provincial success rate of 53%.²⁹ All 17 breech presentations were delivered by cesarean (10 happened to be elective repeat cesarean deliveries).

Complications

Our rate of gestational diabetes, combined with Aboriginal heritage, resulted in a 25.5% rate of large-for-gestational-age babies (> 4 kg), versus a provincial rate of 11%.³⁰ This is in keeping with information from other provinces which also demonstrates higher rates of macrosomia in Aboriginal offspring.³¹

Between 2006 and 2008 there was no intrapartum fetal or maternal death and only 1 readmission for postpartum infection. Six newborns weighing less than 2500 g were delivered in our facility, none of which were predicted or avoidable.

DISCUSSION

Key strengths

Three elements account for maintaining the ongoing success of our program: patient volume, remote location and organizational culture.

Patient volume

The volume of 300–350 deliveries per year ensures that physicians and nurses are busy enough to maintain competence, interest and a reasonable comfort level. The 75 or so annual cesarean deliveries provide enough operative workload to maintain expertise for at least 2 trained family physicians. Programs that do not sustain reasonable volumes need funding for physicians and nurses to regularly visit regional centres to maintain competence without experiencing financial penalties. We note the recent BC initiative to facilitate retraining of family physicians to rejoin obstetric service provision.⁹ Would pre-emptive funding and maintenance programs help obstetric service and prevent their closure?

Remote location

The remote location of our program is an asset. It ensures that broad-scope family physicians and multiskilled nurses will be the care providers. This allows for ownership of the service — including

stepping forward for advanced training where needed. In both anesthesia and cesarean delivery, we have support from a small number of trusted locum family physicians with these additional skills. In Sioux Lookout, such multiskilled locum physicians provide emergency department and family physician coverage as well as contributing to the obstetrics program.

Organizational culture

The organizational culture of a sustainable program needs champions, collegiality, coordination, safety and purpose. The ALARM courses we hosted were invaluable in identifying and supporting physicians and nurses keen to provide up-to-date and safe obstetric care. It contributed to a shared sense of commitment. Additionally, our largely Aboriginal population receives most of the rest of their medical care in Sioux Lookout. This contributes to the cultural competence and experience of care providers. There is a sense of teamwork among our local providers. We access collegial and appropriate telephone support from Winnipeg and Thunder Bay when required. Complex patients requiring more advanced care are air transferred to one of these centres as needed.

Needs and challenges

Travel from home communities to distant centres increases emotional stress and has the potential to have a negative impact on pregnancy outcomes. Although SLMHC ensures a more local and familiar facility for most of the patients, the women do have to spend time away from their families. One of the greatest limitations of the present program is inadequate federal funding support for escorts, to allow women the support of a family member during labour. This option is not funded despite evidence of improved delivery outcomes associated with labour support.^{32–33}

Our program's reliance on a small core group of family physicians to ensure anesthesia and cesarean delivery capabilities reveals both the strength of the program and a potential for difficulties in the future. There is a clear need to develop an employment package that would attract new physicians interested in providing this type of care, beyond present fee-for-service funding. Sustainability will need to be secured by achieving program-specific funding for service provision, mentoring and training. Such initiatives are in the planning stages.

In addition, rural and remote obstetric services need

- local, broadly skilled personnel: physicians, nurses, midwives, ultrasonography capability and the establishment of a critical mass of capable clinicians, including support for mentoring;
- regional support for specialist back-up, patient transfer, training, research, relationship-building, and locum nursing and physician support when needed.

CONCLUSION

It is crucial that regional and national funding bodies acknowledge the mandate to provide obstetric services close to the patient's home. This may involve identifying key regional programs and providing robust programming support and funding to enhance longevity.

Programs based on the goodwill and practice profiles of small groups of individual clinicians can carry us only so far. We have seen the closing of many rural obstetrics programs and the decline in family physicians involved in obstetrics in urban areas, where specialist obstetricians shoulder the workload. Such fallback positions are not available in rural and remote Canada. The time for a more committed approach is upon us.

Competing interests: None declared.

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The Reality of Resistance: The Experiences of Rural Parturient Women

Jude Kornelsen, PhD, and Stefan Grzybowski, MD, MCISc

The closure of many local maternity services has given rise to contemporary realities of care for many rural parturient women in Canada, which, in turn, determines their experience of birth. To date, we do not have an understanding of the realities influencing the birthing experiences of rural parturient women. This qualitative investigation explored these issues with women from four rural British Columbian communities through semistructured interviews and focus groups. Women in this study articulated four realities that influenced the nature of their experience of birth, including geographic realities, the availability of local health service resources, and the influence of parity and financial implications of leaving the community to give birth. When these realities were incongruent with participants' needs in birth, participants developed strategies of resistance to mitigate the dissonance. Strategies included trying to time the birth at the referral hospital by undergoing an elective induction and seasonal timing of pregnancies to minimize the risk of winter travel. Some women showed up at the local hospital in an advanced stage of labor to avoid transfer to a referral center, or in some instances, had an unassisted homebirth. *J Midwifery Womens Health* 2006; 51:260-265 © 2006 by the American College of Nurse-Midwives.

keywords: rural obstetrics, rural health services, access to maternity services

INTRODUCTION

There has been a significant decline in the number of rural communities in Canada offering local maternity care since 2000.¹⁻³ This has resulted from a confluence of factors, including the regionalization of health services delivery in many jurisdictions,^{4,5} physician recruitment and retention challenges,⁶ and diminishing access to midwives and nurses trained in obstetrics.⁷⁻⁹ In Ontario, for example, 11 small hospitals ceased providing obstetric care between the years 1988 and 1995.² A similar trend has been documented in Nova Scotia, where 32 of 42 hospitals closed their services between the years 1970 and 2002.¹⁰ This situation is not unique to Canada; it mirrors the reduction in services found in Australia, the United States,¹¹⁻¹³ New Zealand,¹⁴ and northern Europe.¹⁵

Although there is no consensus on the safety of small rural maternity services, the majority of studies record similar rates of perinatal mortality across all service levels, thus indicating that within a regionalized system, small rural services can provide safe care.^{13,14,16-18} In fact, with the dramatic decline of local maternity hospitals, the question of safety may be reframed to pose whether closing local services is safe. Literature from the United States offers some insight into this question. A study conducted in rural Florida found that infant mortality increased when local access to care providers was reduced.¹¹ Research undertaken in rural Washington State found that when women birthed away from their local community, they were more likely to experience premature birth and pregnancy complications, and their

newborns had longer and more expensive hospital stays than those born in local facilities.¹² These results suggest that newborn outcomes are better where there is access to even a limited local maternity service, rather than no local access. In addition, qualitative research about rural women's experiences have found that they, along with their families, incur significant psychosocial and financial costs due to travel to access obstetric care.¹⁹⁻²³

British Columbia, Canada's westernmost province, serves as an interesting case study. Since 2000, the province has experienced the effects of health care regionalization firsthand, as 17 small hospitals have closed their maternity services.²⁴ However, British Columbia is unique because of its topography; specifically, mountainous terrain and coastal communities, which may further contribute to the negative consequences experienced by women who need to travel for care. This study investigates the impact of service closures and other current realities of the rural maternity health services delivery context on the experiences of parturient women.

METHODS

This exploratory qualitative study is part of a program of research investigating women's experiences of obstetric care in rural and remote communities in British Columbia.^{22,23} The focus of this investigation was the realities of maternity care faced by rural women.

Data collection was carried out in four rural communities chosen to represent diversity in size (geographic boundaries, catchment areas for health care services, and population); distance to hospital with caesarean delivery capability and distance to secondary hospital; usual conditions of road and air access in winter months; and diversity of cultural and ethnic subpopulations within the

Address correspondence to Dr. Jude Kornelsen, 530-1501 West Broadway, Vancouver, BC, V6J 4Z6. E-mail: jude@saltspringwireless.com

communities. All communities were designated "high outflow" (i.e., more than two-thirds of low-risk births occurred outside the community). Prior to the onset of data collection, one of the research communities ceased providing local maternity care services.

Participants were recruited through 1) third-party recruitment through local maternity care providers and 2) a "snowball technique," where key informants and regular interviewees help identify other interviewees. In the former technique, letters describing the objectives of the study were sent to local physicians and other local care providers who interacted with women meeting our inclusion criteria, including public health nurses, doulas, La Leche League representatives, Head Start program leaders, prenatal educators, community health workers, and mother and infant group leaders. The letter included a poster advertising the dates we would be in town to interview. Interested potential participants were invited to contact the research coordinator for more information and to set up an interview time. As all four study sites were small, initial participants recruited through care providers or posters were often connected with other local women who had delivered a baby recently. Through the connections, we gained access to a broad range of study participants. Inclusion criteria included having given birth without significant complications in the past 18 to 24 months, and primary residence being one of the rural communities selected for this study. Achieving target numbers of participants to ensure saturation of data was easily accomplished in each community.

Unstructured interviews and focus groups were undertaken with women who had given birth up to 24 months prior to the onset of the study and whose primary residence during this time was in the research community. The interviews were guided by the following key probes: 1) "Tell us about your experience of birth." 2) "What maternity care services did you have access to in your community?" 3) "How satisfied were you with the services available in your community?" 4) "If you could change things to promote better maternity care in your community, what would they be?" 5) "What is a good birth?" and 6) "What is a safe birth?" Ethical approval for the study was sought and received from the University of British Columbia Behavioural Ethics Board, and consent was obtained from all women who participated in the interviews and focus groups before the onset of their involvement.

Jude Kornelsen, PhD, is a sociologist and Assistant Clinical Professor in the Department of Family Practice, at the University of British Columbia. For the past 3 years, Dr. Kornelsen's research has been focused on advancing the rural maternity care research agenda.

Stefan Grzybowski, MD, MCISc, FCFP, is Associate Professor and Director of Research for the Department of Family Practice, at the University of British Columbia. Dr. Grzybowski's current research focuses on rural maternity care and building primary care research capacity.

The study was undertaken by using a transdisciplinary approach²⁵ by a family physician who practiced obstetrics in a rural setting for 12 years and a sociologist whose research focus includes the study of conditions of child-birth for vulnerable populations.

All interviews and focus groups were undertaken by two members of the research team within a dyadic approach in which questions and probes were initiated by either researcher. The principal investigators' respective disciplines of medical sociology and clinical medicine led to a richness of data due to the complementary approach to the subject area. The combination of clinical and sociological perspectives gave rise to a more thorough interpretation of women's experiences than could be achieved by one perspective.

Analysis was carried out in two phases using a modified approach to grounded theory, which included the use of traditional procedures, such as coding emerging data, making connections between themes and sub-themes, and self-reflective memo writing.²⁶ Initially, five transcripts were individually coded by three members of the research team to ensure consistency and relevance of codes. Codes attributed to the text by the individual researchers exhibited a high level of congruence between them. A code book was developed on the basis of initial coding. A qualitative data analysis software program was used to apply codes to the transcripts, organize the data by themes, and link data to field notes and analytic memos. This allowed for multiple sorting of data as the analytic framework emerged.

The first phase of the analysis gave rise to a schema that revealed that women's experiences were determined by the congruence between their needs in childbirth and the realities of their geographic, health services, and social context. When there was dissonance between participants' needs and realities, many developed strategies to mitigate it. Because of space limitation, the focus of this discussion is limited to the realities rural parturient women face and the concomitant strategies they develop. Although the research sites for this study were chosen to represent diversity in key characteristics, direct transferability to other rural locations cannot be assumed because of the heterogeneity of rural communities. Further studies in diverse communities capturing varied geographic and sociodemographic variables (e.g., communities in the far north and religious communities) are warranted.

RESULTS

A total of 44 women were interviewed. Of these, 6 birthed within their local community and 38 birthed in a referral community. All data were included in the analysis. Seven women in three communities were videotaped.

Overview

Participants in this study recognized a set of circumstances, or “realities,” that affected their experience of labor and delivery. These realities included their geographic location (i.e., degree of isolation, proximity to the nearest referral community, and usual travel conditions), the health system resources available to them in both their local and referral community (i.e., access to care providers, tests, and diagnostics), and their parity. If these realities challenged participants’ ability to give birth in their home community, they developed strategies to overcome them. Strategies included elective induction of labor, seasonal timing of pregnancy, presenting at their local hospital at 10-cm dilation to avoid transport to a referral community, and having an unassisted home-birth. Each of the realities and strategies are described thematically in the following paragraphs.

Geography, Travel, and the Stress of “What If”

All of the women we interviewed conveyed an awareness of the logistic challenges involved in giving birth away from their community in relation to specific geographic circumstances. Common areas of concern were en route deliveries, the inconvenience brought by travel, and seasonal considerations, regardless of both the distance between the participant’s community and the referral center or anticipated mode of transportation. These concerns gave rise to anxiety for many participants:

“That was the only time I was a little concerned about being out here and being pregnant. The roads [are] bad. After the last ultrasound, I did come off the road in the snow, so that was a concern” (participant 9, community 2).

Concerns about driving in winter conditions led many women to compromise their course of prenatal care, often with reprisal. As one participant noted:

“So then you have to go to [the referral community] once a week. I chose not to go because it was winter. . . . So it was kind of tough because I got sort of flak for not going” (participant 1, community 1).

Anxiety over travel was not limited to getting to the referral hospital. Several participants noted concern about traveling back home with an infant, especially when the experience of motherhood was new.

Health System Resources

An awareness of lack of access to caregivers, whether in a participant’s home or referral community, was expressed by many participants in this study and often met with a sense of incredulity:

“I went in there and said, ‘I think I’m pregnant . . .’ Somebody said they weren’t seeing new patients and I said, ‘How can you not see new patients? Do you have to go out of town to see a doctor for a minor cold?’ He said ‘Yup’ . . .” (participant 9, community 3).

Most women in this study expressed a desire to access midwifery care or to have the choice to access such care. Although no registered midwives were practicing in any of the study communities, several participants arranged midwifery care by traveling outside their communities for prenatal visits and moving to their midwife’s community prior to labor and delivery—sometimes at significant personal costs.

Beyond securing a care provider, most participants from communities with no local services struggled with understanding why they were not able to deliver in their home community, especially when there was a history of local care. As one said:

“And it surprised me because . . . the nurses know how to do it because they’ve done it before. The doctors know how to deliver and like, to me, it’s like, why? You know they do deliveries here—they have no choice if somebody comes in and they’re having a baby . . . they’re going to have to deliver it” (participant 2, community 1).

The Reality of Parity

There were significant differences between the narratives of primiparous and multiparous participants in this study who had to leave their home communities to give birth. Differences stemmed from the stress incurred by both the logistic challenges of arranging care for other children, either in their own or referral communities, and the stress of separation for those who had to leave their children behind. As one participant noted:

“You know, the first time around, I think you’re prepared [to leave the community] because you don’t have any other responsibilities, but when it’s your second or third and you’ve got other children, that’s the hardest thing. . . . My family’s not here so I don’t have. . . . I can’t phone my mom and say, ‘Okay, can you come and watch the kids?’” (participant 2, community 1).

For some, the stress and anxiety of being away manifested in the form of depression (“I’ve had postpartum depression. . . and I knew it was just because of the situation of being away from [my son] and everything . . .” [participant 5, community 3]), whereas for others, it precipitated the desire to return home as quickly as possible.

Financial Realities

Almost all participants in this study expressed anxiety about the financial costs of leaving their community to give birth. Although status Aboriginal women had travel and accommodation costs reimbursed by their band councils, remuneration was often barely enough to cover the basic necessities and fell short if other children came to the referral community as well. The stress was highest for those with limited resources who, beyond food and lodging, had to contend with other miscellaneous costs such as parking and phone calls home.

Beyond explicit costs, many participants also acknowledged the cost of missed work their partners incurred to come with them to the referral community, even if only at the time of birth. One participant noted that her partner was off work for 12 days and went on to say, "That amount of time was hard because his was the only income coming in" (focus group participant, community 2).

Several participants noted that even a short trip to the referral community was difficult if the material means to do so were lacking. "I don't drive and we don't have our license, so it's hard to get from there back, and that's the one thing that frustrated me" (participant 7, community 2).

Strategies

As noted earlier, when the participants' psychosocial and physiologic needs were challenged by the realities of care in rural and remote communities, they developed strategies to mitigate the dissonance. These strategies included elective interventions to exert control over the timing of the birth, seasonal timing for birth, showing up in advanced stages of labor to preclude transport to a referral center (the "10-cm strategy"), and even unassisted homebirths.

Elective Interventions

To accommodate their need to plan time away from their home communities, several women in this study arranged elective inductions. As one said:

"So in the end, I phoned the doctor in [the referral community] and I said, 'I don't know what to do.' And we decided to get induced. So that is how we got to that stage, and I just felt like I did not have an option anymore. My options were all taken away from me" (participant 7, community 3).

Seasonal Timing of Conception

Several participants spoke of their awareness of seasons and the desire to avoid possible inclement weather at the time of birth, which might hamper their ability to leave

the community either before labor or if an intrapartum transfer was necessary. As one noted, "If you are planning a baby, don't plan it from like October to March, 'cause you never know [about the weather]. That was the scary part" (participant 1, community 1).

The 10-cm Strategy

In every research community, a small number of participants revealed either having delayed presenting at the local hospital for assessment or delayed leaving for the referral community until they were in advanced stages of labor to secure care in their local community. As one noted:

"I stayed here until noon and put up with the pain by myself and I walked around in here and kept quiet as long as possible because the contractions were really bad—they were really hard. . . . I said, 'There is no way I want to go to the referral community. It is a really long drive and I don't want to do that.' And that's why I stalled" (participant 4, community 1).

Although most participants did not alert their care providers that this was their plan, some did. "I kept telling [my doctor] I was going to deliver here, I just wasn't going to tell anyone when I was in labor" (participant 6, community 1).

Unassisted Homebirths

Although several participants talked about the possibility of having an unassisted homebirth for subsequent pregnancies as a way of avoiding the logistic stress and anxiety they faced when leaving their communities for previous births, only three women in this study had planned unassisted homebirths. The women who undertook these drastic measures did so out of a sense of lack of alternatives and may not have chosen to do this had there been adequate antenatal support within their community.

DISCUSSION

Parturient women in many small rural communities across Canada, the United States, and other jurisdictions face the challenge of securing maternity care within a context of diminishing access to local resources. In light of these structural constraints, many participants in this study developed strategies to mitigate the feelings of anxiety and stress caused by the dissonance between their needs in childbirth and the realities of accessing maternity care services when they were no longer available. These strategies may be understood as acts of resistance or, what Fogerty calls "reactance," which refers to the "motivational state aimed at recapturing the [perceived loss of] freedom."²⁷ (p. 1277) This reactance

can be manifested as conflict with local caregivers over what is the most appropriate and "safest" plan of management for the pregnancy. Local care providers may pressure women to leave the community as the due date approaches, not to be caught by a precipitate local delivery. This situation worsens over time as local care providers have less opportunity to practice and maintain their obstetric skills, and hence, feel even less confidence in their capacity to provide a "safe" local birth.²⁸ Care providers may become more rigid and inflexible, and the inherent inequity in power that can occur in the doctor-patient relationship may lead to a strengthening of a woman's resistance. As Fogerty states: "Those who have. . . greater amounts of social power than oneself can issue threats of relatively great magnitude to one's own free behaviours [thus] add to the possibility of arousing reactance and, as a result, noncompliance."²⁷ (p. 1282)

Ideally, the recourse to this is care providers' formation of a "social unit"²⁷ with the patient to engage in collaborative decision making marked by equal participation. The desire for enacting collaborative decision making regarding their care was articulated both by women in this study and rural maternity care providers who recognized the challenging circumstances of providing maternity care services in a community without local access to cesarean birth. Collaborative decision making is much more difficult to achieve in a community that no longer provides even limited local birthing services. For participants in this study, reactance—or resistance—was a product of the absence of such collaborative processes.

Reactance may further be understood as the result of differential interpretations of risk between care providers and birthing women, leading to participants' sense of distrust. This parallels Anthony Giddens's theory of the close links between risk and trust and an awareness that risks are socially constructed; trust is strongest within social groups, and distrust often prevails between one social group and another.²⁹

Support for acts of resistance was often garnered from other women in the community, reflecting what Cahill described as the supercedence of community values over medical directives: "Although medical science is powerful and doctors are respected members of society, patients are generally more influenced by their immediate communities."³⁰ Once one woman had successfully enacted a 10-cm strategy, or perhaps even an unassisted homebirth, the example is set for other women to emulate.

When the needs of rural parturient women were not supported by the local health care system, resistance to the medical model that mandated birthing away from the home community occurred. This led to situations in which mothers were unattended in labor and sometimes during the birth itself, and local care providers were forced to provide birthing services on an emergency basis with minimal preparation. As increasing numbers

of rural communities cease providing local maternity care, the phenomenon of resistance will only increase. It is ironic that in seeking to centralize birthing services to larger and perceived safer facilities, rural birthing women adopt strategies of resistance that include unsupported labor at home, and on occasion, unassisted homebirth. Perhaps this partially explains why Larimore and Davis documented increasing infant mortality in rural counties in Florida without local access to birthing services.¹¹ A further irony of this loss of local access to services is that multiparous women who would normally expect the least perinatal complications are placed at the greatest stress and risk. Given the struggle to deal with their older children and the uncertainty of a potentially precipitous delivery en route to a referral hospital, it is not surprising that they on occasion choose a 10-cm strategy or to stay at home and have an unassisted homebirth. When birth does occur at a referral hospital, women frequently advocate for early discharge and then face exhaustion, breastfeeding difficulties, and even postpartum depression in their home community.

CONCLUSION

Loss of local maternity services in small rural communities is associated with parturient women choosing to resist relocation to a referral community to birth; instead, they undergo unattended labor and in some cases delivery. To plan rural maternity health services effectively, we need a clear understanding of rural parturient women's needs, the health care realities they face, and the strategies parturient women will use to meet their needs. This discussion must take place within a context that balances our focus on the potential risks of birthing without immediate access to cesarean birth, the potential risks of closing services, denying access to care, and the sequela this precipitates.

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Home or away?

Factors affecting where women choose to give birth

Barbara Zelek, MD, CCFP Eliseo Orrantia, MSC, MD, CCFP Heather Poole, MSC Jessica Strike, MD

ABSTRACT

OBJECTIVE To investigate the factors that influence women to deliver their babies in small rural communities rather than in larger centres that have more comprehensive obstetric services, including cesarean section capability and epidural anesthesia.

DESIGN Self-administered survey.

SETTING Marathon, Ont, a rural community of 4500 in northwestern Ontario that offers low-risk obstetric services and has no local cesarean section capability. The closest referral centre, Thunder Bay, is 300 km away.

PARTICIPANTS Sixty-four women between 16 and 40 years old living in Marathon.

MAIN OUTCOME MEASURES The relative importance of personal and systemic factors and of beliefs that influence women to choose to give birth in Marathon rather than a larger centre. How well informed women are about local obstetric services. How likely women would be to choose to deliver in Marathon if they had low-risk pregnancies.

RESULTS Beliefs were more important than personal and systemic factors in influencing women's decisions. Respondents were moderately well informed about local obstetric services (mean proportion of correct responses was 66%). Most women with low-risk pregnancies would choose to deliver in Marathon (77.8%).

CONCLUSION For women in Marathon, beliefs are much more important than personal and systemic factors in influencing the decision to give birth in this small rural community.

EDITOR'S KEY POINTS

- Previous research has found that personal and systemic factors and women's beliefs influence whether they choose to deliver in rural settings close to home or in urban centres with specialist backup.
- This study in Marathon, Ont, looked at these factors to see how they influenced women's choice of place to give birth. It also tried to determine how well informed women were about the care available locally.
- Women were moderately well informed about the health care services available in Marathon, but this information did not seem to affect their choice of where to deliver.
- Women's sense of control influenced their decision making; they felt strongly that they would be more involved in decision making in Marathon than they would be in the city.

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Research | Home or away?

It is well documented that, if patients are selected carefully, low-risk pregnant women can give birth safely in rural settings.¹⁻³ In fact, it is sometimes safer to do so than to seek care in urban centres.^{4,5} Such findings are important for patients, as research has shown that women prefer to give birth close to home.^{6,7}

Marathon, Ont, is a rural community in northwestern Ontario with a population of 4500. The hospital in Marathon is designated a level 1 facility. Specialist support is not available on-site, and intrapartum obstetric care is provided only for women without major risk factors. As long as pregnancies are low-risk, residents of Marathon are allowed full say in the decision on whether to deliver locally or in Thunder Bay, the nearest referral centre, which is 300 km away.

Obstetric services in Marathon have undergone substantial changes. In the past, cesarean sections were done. More recently, the obstetric program was closed twice, once owing to a shortage of physicians in the community and again owing to a shortage of nursing staff in the hospital. Obstetric services have been available continuously since 1996, except for one short closure for about 6 months.

On-call obstetric care for low-risk women has changed also. Currently, physicians take 1 month of obstetric call duty in rotation. Since the obstetric program reopened, about 50% of all pregnant women in Marathon have given birth there. This rate is within the range seen in other rural communities without cesarean capability.^{2,3,8}

It is unclear what influences women's decisions about where they deliver. While the option is not offered to women with high-risk pregnancies, 25% of low-risk women in Marathon who do have the option still decide to give birth in a larger centre. Thus, it is important to determine how women who are allowed to make a decision regarding where they deliver go about making that decision.

Previous research has identified a range of personal and health care system factors that influence women's decisions around prenatal care in rural communities. Cost,^{7,9-11} support of family and friends,¹² and the atmosphere of services and attitudes of medical and non-medical workers¹¹ have been shown to be important for women accessing medical care. Some of these factors might have a role in women's decisions about where they choose to deliver.

Other research has investigated the importance of women's beliefs in their decisions on accessing maternity care resources.^{13,14} According to Johnson et al,¹⁵

beliefs are based on women's prior experiences and interactions with their health care providers. Beliefs are made up of both positive and negative experiences, attitudes, and values, as well as women's current perception of themselves and their concern for themselves and their infants.

No studies have focused on the personal and systemic factors that influence women's decisions to give birth in small rural hospitals rather than large urban facilities. Little is known about how their beliefs affect the decision. Although Omar and Schiffman¹⁶ found that inadequate information about prenatal services was the main barrier to use of these services among low-income pregnant women in rural areas, little is known about how well informed rural women are about such services.

Considering these gaps in the literature, we planned to determine some of the personal and systemic factors and beliefs that affect women's decisions on where to deliver their babies. We hoped to determine how well informed women living in Marathon were about the obstetric services offered in the community and how this knowledge influenced their decisions about the obstetric care they sought.

METHODS

Setting

The study was done in Marathon, a community of 4500 people. Marathon has a level 1 hospital. A group of family physicians provides obstetric services for women with low-risk pregnancies.

Participants

The survey was distributed to an opportunistic sample of women between the ages of 16 and 40 who came to the 2 local shopping centres during 4 days in August 2003 or who came to the local health clinic during a 2-week period in September 2003. All participants lived in Marathon or in the local hospital catchment area. Informed consent was obtained from each respondent; confidentiality and anonymity were assured.

Materials

The survey, devised by the authors (2 community family physicians and 2 summer students), had questions based on ideas from the literature that were identified as affecting women's choice of prenatal care. Input and feedback from local physicians was also sought during creation of the survey. The survey was pilot-tested on a small group of women to assess face and content validity.

Survey questions were divided into 3 sections: influences, how well informed women were about local services, and how likely they were to choose to deliver

Drs Zelek and Orrantia are family physicians at Marathon Family Practice in Ontario. Ms Poole is a doctoral candidate at McMaster University in Hamilton, Ont. Dr Strike is a family medicine resident at the University of Ottawa in Ontario.

in Marathon. The section on influences asked about the relative importance of various personal and systemic factors in women's decisions regarding obstetric care and how women's beliefs influenced their decisions. The relative importance of various influences was determined by calculating the mean scores of responses on a 4-point Likert scale. To assess how well informed women were, women were asked to check off on a list of obstetric services any they believed were offered in Marathon. Women's knowledge of local obstetric services was determined by calculating the number of correct answers on services offered and not offered divided by the total number of services listed. In the third section, respondents were asked how likely they would be to choose to deliver in Marathon.

Data were analyzed using the Statistical Package for the Social Sciences, version 10.0. Statistical significance ($P < .05$) was tested using Pearson χ^2 analysis. The study was approved by the Lakehead University Research Ethics Board.

RESULTS

Of all the women approached, two thirds agreed to participate in the study; 64 women completed the survey. Respondents ranged in age from 16 to 40 (mean age, 34). Women's age, marital status, and average family income were similar to those of women in the local population.

Personal and systemic factors and beliefs

The most important personal and systemic factors identified were being close to home, being where it was easy for a partner to be present, and being where it was easy for a coach to be present. Least important were the availability of epidural anesthesia, care in a place that did a high number of deliveries, and cost. With respect to beliefs, the strongest belief was in the convenience of delivering in Marathon. Participants most strongly disagreed that first babies should be delivered in the city and that their partners believed they should deliver in the city (Tables 1 and 2).

Knowledge of local obstetric services

Fifty-nine of the 64 respondents completed this section. How much women knew of local obstetric services (Table 3) ranged from 33% to 100%; mean number of correct answers was 66%.

Participants were best informed about the availability of emergency airlifts or ambulances to an urban care centre, pregnancy testing, ultrasound scans, and the availability of prenatal classes and prenatal care in Marathon. They knew least about the local availability of doulas, newborn resuscitation, vacuum extractors, maternal serum screening, and a whirlpool bath for use

Table 1. Relative importance of personal and systemic factors in decisions about where to give birth: Rated on a 4-point Likert scale where 1—not at all important, 2—somewhat important, 3—important, 4—very important.

FACTORS	MEAN SCORE
Closeness to home	3.42
Easy for partner to be present	3.41
Easy for coach to be present	3.21
Availability of neonatal intensive care unit	3.18
Availability of cesarean sections	3.12
Familiarity of health care workers	3.07
Time away from work and children	2.89
Availability of pediatricians	2.79
Availability of obstetricians	2.75
Expenses	2.60
Care in a centre with a high number of deliveries	2.59
Availability of epidural anesthesia in the city	2.41

Table 2. Relative importance of beliefs in decisions about where to give birth: Rated on a 4-point Likert scale where 1—strongly disagree, 2—disagree, 3—agree, 4—strongly agree.

BELIEFS	MEAN SCORE
It is more convenient to deliver in Marathon than in the city	3.26
Someone with previous complications should deliver in the city	3.13
I would be more involved in decisions in Marathon	2.95
It is safer to deliver in the city than in Marathon	2.58
My doctor would prefer that I deliver in the city	2.19
My partner would prefer that I deliver in the city	1.98
Women in their first pregnancies should deliver in the city	1.98

during labour. Twenty-seven women believed incorrectly that obstetricians were available locally.

Choosing Marathon

Participants were also asked whether they would choose to deliver their babies in Marathon, a city, or elsewhere if their pregnancies were uncomplicated. Responses indicated that 77.8% of the women would choose to deliver in Marathon. Their level of knowledge about the obstetric services available in Marathon did not influence their responses ($P = .166$).

Pearson χ^2 analysis was used to determine whether there was an association between how likely women

Table 3. Services offered and not offered in Marathon

OBSTETRIC SERVICES OFFERED IN MARATHON	
One-on-one nursing for mothers	
One-on-one nursing for babies	
Pain management	
Emergency airlift or ambulance to urban care centre	
Prenatal classes	
One-on-one doctor for mother	
One-on-one doctor for baby	
Same doctor for prenatal and delivery care	
Immediate postpartum breastfeeding support	
Baby and mother in same room postnatally	
Ultrasound	
Doulas	
Induction	
Newborn resuscitation	
HIV testing	
Private obstetric room	
Pregnancy testing	
Whirlpool bath during labour	
Prenatal care	
Vacuum extractor	
Maternal serum screening	
OBSTETRIC SERVICES NOT OFFERED IN MARATHON	
Obstetricians	
Midwives	
Cesarean sections	
Neonatal intensive care unit	
Forceps delivery	
Pediatricians	
Epidural anesthesia	
Water births	
Amniocentesis	

were to choose to deliver in Marathon and the relative importance of the various personal and systemic issues measured. No significant association between personal and systemic factors and women's choice of delivery location was found, except for a concern about time away from work or children (Table 4). On the other

Table 4. Significance of personal and systemic factors in decisions on where to give birth

FACTORS	P VALUE
Expenses	.730
Closeness to home	.694
Easy for partner to be present	.896
Easy for coach to be present	.864
Availability of neonatal intensive care unit	.347
Availability of cesarean sections	.734
Familiarity of health care workers	.451
Time away from work and children	.026
Availability of pediatricians	.237
Availability of obstetricians	.471
Care in a centre with a high number of deliveries	.368
Availability of epidural anesthesia in the city	.129

hand, responses to questions about women's beliefs indicated that they were significantly associated with the likelihood of choosing to deliver in Marathon (Table 5).

Table 5. Significance of beliefs in decisions about where to give birth

BELIEFS	P VALUE
It is safer to deliver in the city than in Marathon	.090
It is more convenient to deliver in Marathon than in the city	.008
Someone with previous complications should deliver in the city	.125
My partner would not prefer that I deliver in the city	.003
My doctor would not prefer that I deliver in the city	.064
Women in their first pregnancies should not deliver in the city	.034
I would be more involved in decisions in Marathon	.589

DISCUSSION

The key finding of this study is that the most important factors influencing where women choose to deliver are the most nebulous: beliefs. These are more important than personal and systemic factors and are not influenced by how well informed women are about local obstetric services.

The high proportion of women in our study who reported preferring to deliver in Marathon is consistent with results of other work that indicated that women believed it was important and convenient to deliver in their home towns.¹⁷ In line with the finding by Ridley et al,¹³ that women's sense of control influenced their decision making, the women in our study felt strongly that they would be more involved in decision making in Marathon than they would be in the city. This feeling might account for the reported preference for local delivery. Also in line with the finding by Ridley et al that women's perceived safety influences their decisions, our participants thought that women with complications in previous pregnancies should deliver in the city.

Other studies have shown that several personal and systemic factors influence women's choices regarding obstetric care.⁷⁻¹¹ Our study corroborates previous findings that being close to home and being where it is easy for partners and coaches to be present are of prime importance in the decision. Interestingly, expenses, which were found to be an important barrier to care in previous studies,⁹⁻¹¹ received one of the lowest scores in our study. This might be explained by the relatively high socioeconomic status of the community and the fact that the other studies were completed in the United States where lower socioeconomic status can limit access to the health care system.

Physicians currently practising in Marathon have tried to educate the community about recent changes in the provision of obstetric care so that women needing this care can make informed decisions.¹ Our study shows that women were moderately well informed about local obstetric services. This indicates that current methods of disseminating information (local newspaper, brochures at the clinic, and information distributed at prenatal visits) are adequate, but that there is certainly room for improvement. Even though women's decisions about where to give birth were not related to how much they knew about local obstetric services, it is important that they be informed in order to access these services appropriately.

Seventy-seven percent of women in our sample reported that they would choose to deliver in Marathon. This strong preference for local delivery could be explained by the recent stability of health care providers and of health care services in Marathon. In a case study that included patients from Marathon, Goldsmith¹⁸ found that patients reported great loyalty toward and faith in physicians with whom they had established positive relationships. The current obstetric care system in Marathon allows patients to get to know the physicians who will be present at their deliveries, and might, therefore, increase the likelihood of positive patient-physician relationships.

The number of women who would choose to deliver in Marathon would be similar to the 50% of women who actually deliver locally if all 25% of high-risk women also chose to deliver in Marathon. This study provides us with information as to why the remaining 25% of women would choose to give birth in a larger centre.

Our study indicates that personal and systemic factors are not the key element for women in Marathon making decisions about delivery. Instead, we have identified the importance of women's beliefs as the next area of research focus. If maternity care providers are better able to understand what informs women's beliefs and how best to positively influence them, they will be more apt to provide interventions to ensure that obstetric services are used appropriately. Ultimately, such understanding might lead to more healthy women and children in our rural community.

Limitations

As with any study in which participants are self-selected rather than randomly surveyed, selection bias is possible. As well, due to the small sample size, the power of this study might not have been strong enough to find the effects of some of the personal and systemic issues that have been found to be important in other studies. Finally, the health care environment in Marathon is unusual because, unlike many rural communities, it has had a stable physician base for most of the last decade. Therefore, the results of this study might not be transferable to other small, rural communities where there might be more fluctuation in health care providers.

Conclusion

In Marathon, we found that beliefs were much more important than personal and systemic factors in influencing women's decisions about where to give birth. The women were moderately well informed regarding local obstetric services. Most respondents living in this rural setting would choose to remain here for the duration of a low-risk pregnancy and delivery. ✱

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Contributors

Drs Zelek and Orrantia were involved in all aspects of the study. Ms Poole participated in designing the study, gathering and analyzing the data, and preparing the article for submission. Ms Strike participated in designing the study and gathering the data. All the authors reviewed and approved the final version of the manuscript.

Competing interests

None declared

Correspondence to: Dr Barbara Zelek, Box 353, Marathon, ON P0T 2E0; telephone 807 229-3243; fax 807 229-2672; e-mail bzelek@mfp.on.ca

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Aboriginal Obstetrics

Kronelsen J, Kotaska A, Waterfall P, Willie L, Wilson D. The geography of belonging: the experience of First Nations women. *Health and Place* 2010;16(4):638-45.

This mixed methods study highlights the impact of dwindling rural obstetrics programs on Aboriginal women. Particularly, the association of traditional territories with kinship ties, community and identity.

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These recommendations address key points surrounding community-based care: caregivers and decision makers should be well informed of the actual effects on women in remote communities; attempts to move birth closer to the community should be made and where this isn't possible existing programs need to be improved; caregivers should understand determinants of health and training should be provided for midwifery and community-based care.

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This 1995 qualitative study examined beliefs about pregnancy and prenatal care. Pregnancy was seen as a blessing and a natural process; family size was aligned with views of motherhood (tubal ligation and hysterectomy were seen as unacceptable). Beliefs around prenatal care included: having a well-balanced diet and positive thoughts; avoidance of strenuous activity, alcohol, drugs and smoking; exercises taught in prenatal classes were seen as affecting the baby adversely; technological interventions such as ultra-sound, induction, fetal monitoring and pelvic examination were seen as harmful to the baby.

O'Driscoll T, Kelly L, Payne L, Hansen-St Pierre N, Cromarty H, Terry C. Traditional First Nations Birthing Practices: interviews with elders in Northwestern Ontario

This qualitative study of 18 First Nations women described the beliefs and practices of traditional maternal and childcare. Knowledge of these practices was handed down by oral tradition and trans-generational apprenticeships at childbirthing. Health lifestyle and diet and breastfeeding supplemented with fish broth. Quiet demeanor during labour, saving the umbilical cord stump and use of the traditional cradle-board were referenced. There was a desire to see some traditional practices incorporated into hospital care.

Kelly L, O'Driscoll T, Payne L, St Pierre-Hansen, Cromarty H, Minty B, Linkewich B. Delivering away from home: perinatal experiences of First Nations women in NW Ontario.

This qualitative study and literature review documented the cultural and geographic distances traveled by First Nations women: cost, loneliness and the need for culturally-based hospital care.

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The geography of belonging: The experience of birthing at home for First Nations women[☆]

Jude Kornelsen^{a,b,*}, Andrew Kotaska^c, Pauline Waterfall^d, Louisa Willie^e, Dawn Wilson^d

^a Department of Family Practice, University of British Columbia, Canada

^b Centre for Rural Health Research, 530-1501 West Broadway, Vancouver, BC, Canada V6J 4Z6

^c Department of Obstetrics and Gynaecology, Stanton Territorial Hospital, Yellowknife, NT, Canada X1A 2N1

^d Heiltsuk College, Bella Bella, BC, Canada V0T 1Z0

^e Health Services, Hailika'as Heiltsuk Health Centre, Bella Bella, BC, Canada V0T 1Z0

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ABSTRACT

The number of rural hospitals offering maternity care in British Columbia has significantly declined since 2000, mirroring trends of closures and service reductions across Canada. The impact on Aboriginal women is significant, contributing to negative maternal and newborn health and social outcomes. The present qualitative case study explored the importance of local birth for Aboriginal women from a remote BC community after the closure of local maternity services. Data collection consisted of 12 interviews and 55 completed surveys. The average participant age was 32 years old at the time of the study. From the perspective of losing local services, participants expressed the importance of local birth in reinforcing the attributes that contributed to their identities, including the importance of community and kinship ties and the strength of ties to their traditional territory.

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1. Introduction

The number of rural hospitals offering maternity care in British Columbia has significantly declined since 2000, mirroring trends of closures and service reductions that are occurring across Canada (Allen et al., 2004; Hutten-Czapski, 1999, 2001; Peddle et al., 1983; Nesbitt et al., 1990; Rourke, 1998) and internationally (Larimore and Davis, 1995). A convergence of factors has influenced this crisis in rural maternity services including structural-economic changes in rural communities (Cameron and Cameron, 2001; Halseth and Sullivan 2003; Galvin, 2003), health care restructuring (Kornelsen and Grzybowksi, 2005a), a changing context of care that supervaluates access to technology and specialists (Kornelsen and Grzybowksi, 2005a), and health human resource issues (Grzybowksi et al., 2007; Kornelsen and Grzybowksi, 2008). These changes are taking place despite an emerging body of evidence on the safety of small volume maternity services (Chaska et al., 1998; Peddle et al., 1983; Rourke, 1998; Rosenblatt et al., 1985) and the impact of these

changing patterns of access on maternal and newborn health. The closures of small volume maternity services and subsequent evacuation of women to give birth have been linked to increased perinatal morbidity and mortality (Larimore and Davis, 1995; Nesbitt, 1996; Nesbitt et al., 1990), as well as heightened stress, anxiety, and social vulnerability on the part of birthing mothers (Chamberlain and Barclay, 2000; Greig, 1990; Jasen, 1997; Kornelsen and Grzybowksi, 2005b).

A review of recent policy literature indicates that these service changes in British Columbia have been made in an ad-hoc manner in response to a local or regional sense of crisis (Kornelsen and Grzybowksi, 2005c). In these instances, decisions have been reactive and not necessarily based on a broad range of health indicators, let alone cultural considerations.

Although all rural women experience the impact of reductions in local maternity services, qualitative evidence suggests that these impacts are felt more acutely in Aboriginal communities. This is due in part to the historical place of birth in Aboriginal life where it was a community event that strengthened ties within families and nations (Moffitt, 2004). In Canada's far north, the systematic evacuation of women from their communities due to shifting policy and practice has led to severe psychosocial consequences, including the loss of birth as a community event to birth becoming an isolating experience resulting in feelings of loss of control for women (Jasen, 1997; Voisey et al., 1990). When speaking of their evacuation experience, northern Aboriginal women themselves express regret at not having family close by to

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* Corresponding author. Tel.: +1250 653 4325; fax: +1250 653 4323.

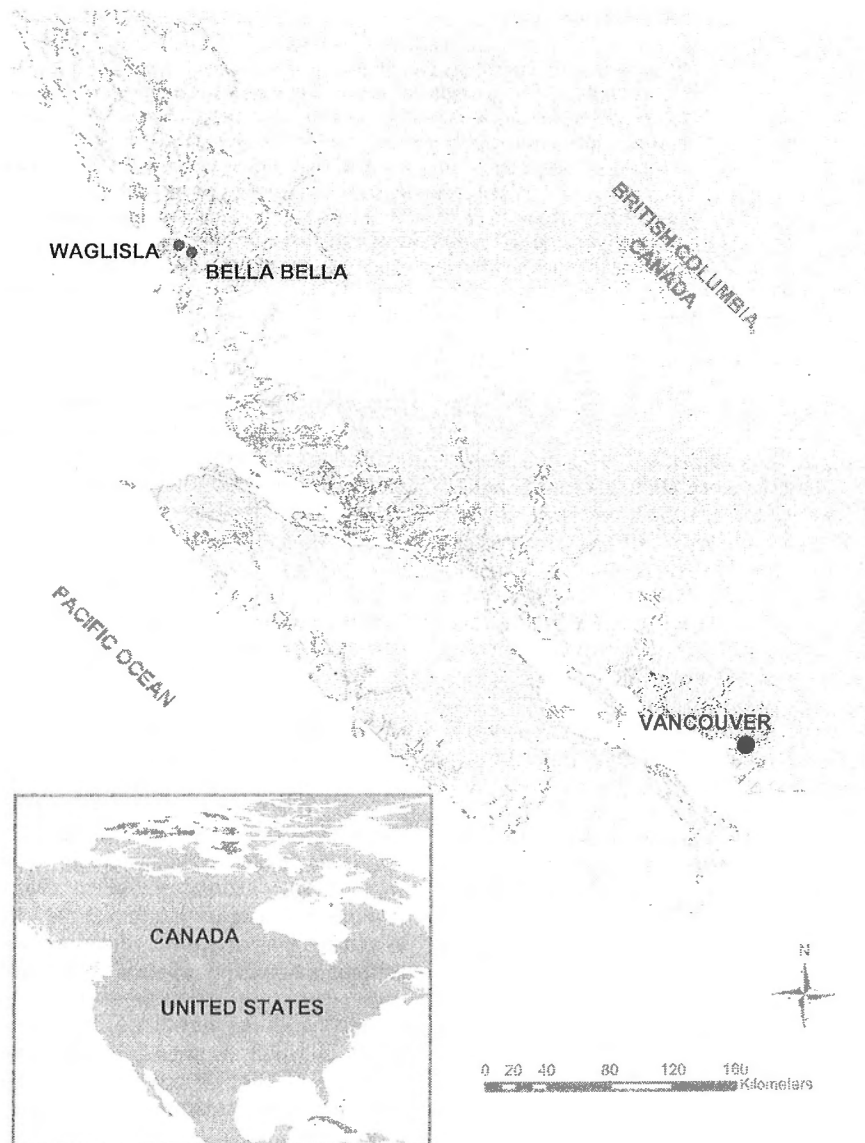
E-mail addresses: jude@saltspringwireless.com (J. Kornelsen), Andrew_Kotaska@gov.nt.ca (A. Kotaska), Pauline.Waterfall@gmail.com (P. Waterfall), louisaw@heiltsukhealth.com (L. Willie), cheryldawn12@hotmail.com (D. Wilson).

share their birthing experience and anxiety about being away from their homes and children for extended periods of time (Paulette, 1990). In a comprehensive overview of the unintended consequences of maternal evacuation from the far north, Jennifer Stonier lists the detrimental health effects on women (e.g., loneliness, worry, anxiety, loss of appetite, increased smoking behaviour) and those on the children and family left behind (increased rates of illness and school problems for other children of evacuated women and the loss of understanding of the birth process among men) (Stonier, 1990). Additionally, with increased energy, time, and money devoted to the immediate intrapartum period, fewer resources were available for care and education services within the community, contributing to the diminishment of prenatal preparation and postnatal support (Stonier, 1990).

This qualitative exploratory study considers the implications of closure of a local maternity service from perspective of local First Nation women. Findings focus on participants' perceptions of the importance of place and community in giving birth. The experiences of women who left the community have been recorded elsewhere (Kornelsen et al, forthcoming).

2. Background

A number of First Nations communities in British Columbia have lost local maternity services in recent years, forcing women to travel significant distances to access intrapartum care. The decisions leading to these closures have been ad-hoc and typically without community consultation. The community of Bella Bella, also called Waglisla, has a current population of 1250 residents, almost all of whom are from the Heiltsuk nation, and is located on Campbell Island on BC's Central Coast (Map 1). The hospital in Bella Bella/Waglisla is governed by the United Church Health Services and receives funding from Vancouver Coastal Health, while the Heiltsuk Band Council has taken responsibility for the management of insured health care benefits, received from First Nations and Inuit Health (FNIH), a division of Health Canada. Historically, the Heiltsuk Nation always birthed in their home community. However, in 2000, the provision of maternity care in Bella Bella/Waglisla began to atrophy, and since 2001 it has been the policy for all women to leave the community at approximately 36 weeks gestation to give birth elsewhere (usually BC Women's Hospital in Vancouver).



Map 1

Vancouver and Bella Bella/Waglisla are approximately 600 km apart, and women travel between the communities by either a 2 h long, weather-dependent flight or a 14 h trip by vehicle and ferry. Since 2001 a small number of local deliveries have taken place in the community due to precipitous labours, and between 2001 and 2005, 53 deliveries occurred in referral communities. This cessation of service was due to a confluence of factors, including recruitment and retention of practitioners with enhanced skills to provide local access to cesarean section and the reluctance of physicians to offer maternity care without the availability of such services.

A lack of local maternity services negatively affects a rural community's perinatal health and well-being (Chamberlain and Barclay, 2000; Klein et al., 2002; Nesbitt et al., 1990) and can lead to prenatal stress and preterm delivery (Heaman et al., 2005; Norbeck and Tilden, 1983; Rondo et al., 2003; Sable and Wilkinson, 2000; Wadhwa et al., 1993), as well as financial strain and decreased social support for birthing women (Chamberlain and Barclay, 2000; Kildea, 1999). Studies in Australia, Canada, and New Zealand indicate that there are significant disparities between Aboriginal and non-Aboriginal peoples' perinatal health (Chalmers and Wen, 2004; Craig et al., 2004; Luo et al., 2004; Muggah et al., 2003; Simmons et al., 2004; Vancouver Coast Health (VCH), 2004, 2005), in addition to finding that rural Aboriginal women are more likely to receive inadequate prenatal care compared to their urban and non-Aboriginal counterparts (Baldwin et al., 2002; Heaman et al., 2005). Perinatal health statistics for people living in the Central Coast of British Columbia, including Bella Bella/Waglisla, are dismal, with local preterm birth and infant mortality rates nearly 3 and 5 times the provincial average, respectively (Thommasen, 2003). Some Australian Aboriginal women believe that regional centre birth and separation from traditional territory are the cause of infant mortality (Kruske et al., 2006). Positive attributes of local birth include support and family involvement (Chamberlain and Barclay, 2000; Iglesias et al., 1998).

National efforts for improving rural perinatal outcomes for Aboriginal peoples in Canada emphasize the importance of keeping maternity services close to home, with community members playing a significant decision-making role in the service planning process (Couchie and Sanderson, 2007; Royal Commission on Aboriginal Peoples, 1996). Successful examples of rural Aboriginal maternity care include birthing centres in the Canadian north. The Inuit birth centres of Nunavik, Quebec are staffed by Aboriginal midwives and attempt to maintain Inuit mothers' connection to the land and community by keeping birth close to home and integrated with Inuit culture (Douglas, 2006). The birth centres provide primary care (without local access to cesarean section), which has led to a significant increase in the number of local births, a decrease in preterm birth rates, and contributed to low intervention rates for women who do leave the community to give birth (Houd et al., 2003; Van Wagner et al., 2007). Such birthing projects in Arctic communities produce many psychosocial benefits including decreased family disruption, greater parent satisfaction, and greater community involvement with the newborn baby (Chamberlain and Barclay, 2000).

Listening to Aboriginal women's birthing desires provides the foundational knowledge for building their maternity care programs, authenticates their knowledge, and ensures that programs are culturally appropriate (Moffitt, 2004; Molina, 2001; NAHO, 2006; Smylie, 2000; Smith, 2003). FNIH and the National Aboriginal Health Organization (NAHO) advocate for approaches to service development that are grounded in Aboriginal culture, build on community strengths, and require care providers to be sensitive to Aboriginal peoples' socio-cultural needs (FNIH, 2005; NAHO, 2006). The importance of community involvement in Aboriginal maternity care planning has been emphasized by health decision makers responsible for the area in which this research took place (Timbers, 2005).

For Aboriginal women, birth is an event tied to their traditional lands and identity (Douglas, 2006; INAC, 1996; Kruske et al., 2006; Wilson, 2003). The land is seen to shape cultural, spiritual, emotional, physical, and social aspects of the lives of Aboriginal peoples, and to provide plants and animals for food and medicine (Wilson, 2003). The land is seen as essential for maintaining good health and well-being; when Aboriginal peoples are separated from the land, they often experience isolation and dislocation. This has been demonstrated in studies on Aboriginal peoples' decision to access – or not to access – renal and palliative care outside of their communities (Anderson et al., 2009; McGrath, 2007). Chamberlain and Barclay (2000) found that the “research suggests that women are often aware of the physical risks [of childbirth] but they have an overriding need to have the support of their families and their communities at this time. The social consequences of major disruptions to family and community may, therefore, far out-weigh the risks.”

3. Methods

Results presented here are part of a larger case study on the implications of maternity service closures in Bella Bella/Waglisla. This paper presents findings from: (1) a written survey to document women's experiences of birth, locally or away; and (2) in-depth interviews to document women's stories of their experiences of birth.

Guidance for the study was provided by a community research advisory committee with representation from the Heiltsuk Cultural Education Centre, Hailika's Heiltsuk Health Centre, RW Large Memorial Hospital, and Heiltsuk College, as well as a community-based research assistant. As a participatory research approach is the most appropriate to ensure that the research questions and design are responsive to the needs and concerns of the community (CIHR, 2007), advisory and community consultation was held throughout the research process. All women in the study were from a confined catchment area, and their maternity services were closed in the recent collective memory of the community. All authors had prior relationships with the study community. The principal investigators are non-Aboriginal researchers who had practiced as a physician in the community (AK) and had undertaken research in the community since 2003 (JK). The other investigators (PW, LW, DW) are Heiltsuk women from the Bella Bella/Waglisla community. We sought and obtained ethics approval from the appropriate University Behavioral Research Ethics Board and from the Vancouver Coastal Health Authority.

3.1. Participants

Potential participants, women from Bella Bella/Waglisla who gave birth in the study time frame (1996–2005), were identified through existing records kept by one of the investigators (AK) while he provided care at RW Large Memorial Hospital from 1996 to 2001 and cross-referenced with a list of all women who gave birth in the study time frame based on the Hailika's Heiltsuk Health Centre Members List. The two lists were combined to give a comprehensive record of all the women from Bella Bella/Waglisla who gave birth between 1996 and 2005. Signed, written informed consent was obtained from all participants.

3.2. Written survey

The survey, designed to capture experiences of birth in and away from the community, was developed specifically for this

study and was based on the principal investigator's previous qualitative research conducted with First Nations birthing women in the province of British Columbia (Kornelsen and Grzybowski, 2005c). The survey was reviewed by the whole research team and amendments were made where suggested. Additionally, the survey was pilot tested with six community members for clarity of concepts and readability. All suggested changes were included. The 21 question survey included items on basic demographic information (i.e. age, ethnicity) and on participants' experience with receiving prenatal and intrapartum care rated on a 3-point Likert-type scale. We generated three separate forms: one for women who birthed locally prior to 2001, one for women who birthed away prior to 2001, and one for all women who gave birth from 2002 to 2005. Four themes informed the question groups: access to care, social support, sense of safety, and ideal visions of birth.

The community-based research assistant recruited potential survey participants by phone, from local phone book listings, or in person from the Health Centre day care program to ask them if they would agree to fill out an "Experiences of Childbirth" survey. The assistant hand delivered surveys to all women who had given birth within 2 years prior to data collection and retrieved the surveys upon their completion. The survey participation rate was one hundred per cent for those women approached to fill out the survey, with a total of 55 surveys returned. Once data saturation was met, the research team stopped approaching women in the community to complete the survey. Due to the high rate of illiteracy in the community, a member of the research team was available for women to assist in filling out the survey. We classified each survey into one of three categories: (1) birth away before and including 2000; (2) birth away after 2000; or (3) birth in Bella Bella/Waglisla.

3.3. Interviews

The women interviewed as part of this study were recruited by the community-based research assistant, who when distributing the surveys asked if women would be interested in participating in an interview. The research assistant then scheduled the interview to take place either at the community's Health Transfer House or in the board room at RW Large Memorial Hospital over the process of three days. Interviewees were recruited until data saturation was achieved (no new themes emerged from the data). The lead investigator and members of the research team conducted open-ended, hour-long interviews with 12 women from the community. The research team made efforts to minimize and neutralize potential power differentials between the team and First Nations interviewees and to establish safe interview environments in which women felt respected and their stories honoured (Meadows et al, 2003). Namely, interviewees were introduced to the study by a peer, the community-based research assistant; the study was accepted and supported by the community, as represented by the community research advisory committee; both the community-based research assistant and research advisory committee provided cultural guidance to the research team; interviews were open-ended to allow for women to express stories they felt were personally important, rather than to answer direct questions; interviews took place in locations familiar to the women; interview times were flexible to accommodate the women's needs; and interviewers positioned themselves in a physically non-threatening manner.

3.4. Data analysis: interview data

We tape recorded and transcribed all interviews into a word document. We used open coding methodology (Strauss and Corbin,

1998) to inform the four stages of our analysis: (1) immersion in the transcripts (reading and re-reading); (2) the development of themes and codes; (3) coding the transcripts; and (4) re-integrating the codes into an explanatory narrative. The principal investigator and project coordinator independently read and coded each transcript separately and developed code books (a list of derived themes and codes). We then compared the code books for congruency before coding the entire collection of transcripts. The researchers achieved almost perfect conceptual congruency regarding emerging themes and codes and some modifications were made to increase semantic congruency. We entered all coded parts of the transcripts into a qualitative data management program, QSR Nudist, printed code reports, and presented them to the research advisory committee in Bella Bella/Waglisla. The principal investigator and project coordinator conflated 53 codes into 23. The research team worked with the research advisory committee on interpretation and presentation of the findings within a culturally appropriate framework (CIHR, 2007).

3.5. Data analysis: survey data

The first round of survey data analysis, using the Statistical Package for the Social Sciences, consisted of generating frequency tables for all questions and running correlations for all fields. We highlighted statistically significant correlations and ran further statistical tests on these interesting questions. We cut and pasted tables into a word document and presented them to the research advisory committee in Bella Bella/Waglisla for comment and preliminary interpretation. During the second round of data analysis, we created frequency tables for all interesting fields as identified by the advisory committee and categorized them based on which birth category women fit into (birth away before and including 2000; birth away after 2000; or birth in Bella Bella/Waglisla). We then wrote findings from interviews and surveys into narrative form and presented them to the advisory committee for validation. Upon completion of the final community report, the Heiltsuk Band Council issued a resolution ratifying the project recommendations.

4. Results

4.1. Overview

Between 1996 and 2004, there were 144 births among the women of Bella Bella/Waglisla. Of the 55 women who completed the survey, 19 indicated that they had lived in Bella Bella/Waglisla all their life, while 32 had lived in the community for over 13 years. The average age of women at time of survey completion was 32 years old. Thirty-five survey participants gave birth away from the community and 20 gave birth in the community. For those who gave birth away, the majority birthed at BC Women's Hospital ($n=15$), a tertiary care facility in Vancouver, British Columbia, or other hospitals in Metro Vancouver. All but one survey participant received prenatal care, which consisted of physician care, routine diagnostics, and specialist appointments where necessary. Of the 12 women we interviewed, 9 gave birth in Bella Bella/Waglisla, and 3 gave birth in a referral community. All of the interviewees who remained in the community gave birth before 2000, when local services, including caesarean section back-up, were available.

This paper represents findings from surveys and interviews with women who gave birth in Bella Bella/Waglisla at least once. Some women had also experienced childbirth in a referral community and were able to compare the experiences of birth

away versus birth at home. Themes that arose from the interviews included the importance of community support, the overriding belief that women should be able to give birth in Bella Bella/Waglisla, and the difference in experiences of birth before and after local services were closed. All interviewees described important ties to their family, community, and place that formed not only their home but also their identity, and which were made stronger through experiences of local birth. Each of these themes is discussed in detail below.

4.2. Importance of community support

Most survey participants noted family members were present during labour and delivery, ranging from “10–20”, to “lots—too many to count”, and “half the village.” While only four (20%) survey participants who gave birth in Bella Bella/Waglisla noted that only their physician was present at the time of delivery, 16 (80%) noted their physician, family members, and/or friends were present. When asked why women should give birth in the community, all survey participants and interviewees focused on the availability of family support and the difficulties of being away from family. Women interviewed saw this extended network of support as part of a larger Heiltsuk commitment to relationships, caught perhaps most clearly by the phrase of one woman, “If you are here ... you are not alone” [006:445]. Stories of community members providing material and emotional support exemplified this sense of being part of a larger association. As one interviewee said,

And I couldn't believe the support – you get a lot of support here ... If something happens, something goes wrong in one family, the whole community pitches in and helps out to support them, whether it's financial or, you know, if it's death, there's going to be food sent over. [006:86–94]

The most consistent – and dramatically expressed – descriptions of community support were of support during the labour and delivery itself, which, for all the interviewees and for teen moms in particular, was marked by the presence of family and community members at the hospital:

When I came out, it was wall-to-wall people. I said, ‘What's going on?’ Everybody heard that [my baby] was born. And it was wall-to-wall people. It was so nice because my father-in-law was there, and I was holding my baby. He was the first and only grandson. [005:84–90]

Most interviewees recalled how friends and relatives would care for other children. This was seen to mitigate the stress of the immediate post-partum period and even help combat “the blues”:

I think it makes a big difference to have our babies here, because you have all that family support and you really do need it because some mothers go through the post-partum blues here, and just to have all the support. [006:423–427]

For many, the celebration of local birth took the form of an ‘uplifting,’ which involved having the hereditary chief, the community's leader, present the baby to the community and bestow a name, sometimes within the context of a potlatch, a First Nations ceremonial feast. Other interviewees described fondly how Elders and grandmothers provided guidance on natural, unmedicated birth, which was seen to be enveloped within a sense of caring. For some, the importance of this support exceeded concerns about giving birth in the community without immediate access to specialist care: “I would rather take the risk of having my baby here than to have all the high-tech equipment and be in an atmosphere that wasn't familiar.” [007:130–132]

Most interviewees also described positive aspects of the care they received in their community, emanating in part from the ongoing relationships they had with the care providers. Women's confidence in the care providers' skills and abilities led to a strong sense of trust in the advice given regarding labour and delivery – including location of birth. As one interviewee noted,

[The doctor] told me, you know, about the different complications that could happen during labour and delivery and he said, ‘But you have nothing to worry about, so I think it is going to be okay to have your baby here.’ I said, ‘okay.’ I took his word on it and I was fine with it. [006:90–94]

Several women incisively juxtaposed their in-community experiences with observations of the experiences of women giving birth now in referral communities. As one commented,

I think it just all goes back to having... the family here. My niece is giving birth to another baby [out of the community]. I'm not going to be there. I've never seen any of her kids being born. All my nieces were born out of town and I've never seen any of them. I just wish they would have their babies here. [012:205–210]

4.3. The importance of birth in Bella Bella/Waglisla

All of the women we listened to – whether they gave birth at home or away – expressed the importance of birth in Bella Bella/Waglisla. Our survey data found that 70% of participants responded “Bella Bella” when asked where local women should give birth. Of those who gave birth in the community, 15 (75%) felt it was very important that they birthed at home and 2 (10%) felt it was somewhat important (1 felt it was not important). In addition, when we asked if they thought birth was important to their community, 16 (80%) of the survey participants who birthed locally felt it was very important, 1 felt it was somewhat important, and 1 felt it was not important. Of the survey participants who birthed away after the closure of services, 19 (86%) felt birth was very important to the community while 3 (14%) felt it was somewhat important. For most survey participants and interviewees, the importance of local birth was tied to a sense of connection to history and to the Central Coast region, and gave rise to their identity as mothers but also as Heiltsuk peoples. As we discussed with one woman:

Participant: I was glad that [all my children] were born here.

Interviewer: What does that mean to you?

Participant: It felt good. You know, I was born here. I was born in the old hospital. My mom had all of us in the old hospital there. ... We are all from here. [009:44–51]

The sense of a continuation of history underlay many of the women's observations of the roles their mothers, grandmothers, or aunts played historically in supporting women through the process of birth. Almost all of the interviewees referred to a family member or friend who they described as a midwife.

Cultural and emotional ties to the land were also concretely expressed through multiple women's unsolicited comments in both interviews and surveys on the importance of having Bella Bella/Waglisla on their children's birth certificates:

I would want my grandchildren to be born here, like other kids. This is where we're from! You know, looking on the birth certificates, they say ‘Vancouver, BC.’ You know, they're not from Vancouver. We're from Bella Bella! So when they are born in Vancouver, does that mean they are from Vancouver? [012:271–279]

This sense of community also motivated some women to return to Bella Bella/Waglisla from away in order to participate in the rituals of Heiltsuk birth:

Our culture has always celebrated life. Our children got their first traditional name at birth: it was their child name. At 10, they get another name. As an adult, another name. As they become older, another name. So there was tradition. We've always celebrated life. And uplifted our children. [007:255–260]

For some interviewees, the timing of birth within the life cycles of others in the community was a poignant reminder of the inter-connectedness of life and death. When a child was born in the community soon after the death of an Elder, the concurrent mourning and celebration was marked either formally (such as at a potlatch) or informally, through marking the passage of time by the growth of a child.

For some, the absence of birth within the community, like an unbalanced mobile, shifted the weight of experience to death:

I think it's a huge void for people not to be born here, because all we see is death. You've probably heard that before. We're in a small community and it's constantly death, death, death, death. When you don't have birth here, and they're born outside, you know, it's different. There has to be a balance. There's end of life and beginning of life. [007:58–65]

4.4. Comparison of services: before and after

Several women had given birth both in Bella Bella/Waglisla before services closed and in a referral centre after closure. The contrasting experiences led to observations of the differences between the two locations from both the perspective of individual experience and the larger community context. Interviewees spoke of the sense of comfort arising from familiarity of their own surroundings in contrast to the alienation felt in the new environment. As well, many interviewees noted contrasting levels of community involvement in the birth:

We've always celebrated life. But rather than the whole community waiting for the baby to be born, and family members [being] up all night and people in the hospital, you know, it's toned down to, you know, this baby has come home and we need to recognize and acknowledge this baby and celebrate the baby's life. Whereas if the baby's born here, it would be a whole different thing. [007:267–272]

This woman went on to describe the details that give rise to birth as a cultural event in the community and the concomitant sense of loss when it occurs away:

Let's say that they're coming off the plane and [the mom] is there and her mother and the grandfathers go meet them ... There's like two people meeting them, meeting the new baby. While if they delivered here, there would be like 50 people. So to me, it feels like a loss ... Eventually they will have a baby shower or a tea or whatever, but that's basically it. There's like a disconnect. It's like, 'Oh ... they had a baby,' and you know, 'How's the baby doing,' versus 'how are you recovering? You were screaming away in there – I didn't know you could swear like that.' There's a disconnect. [007:290–302]

Almost all interviewees expressed a preference for birthing at home for convenience ("I just find it easier to have babies in your hometown rather than having to fly out and then fly back" [011:75–77]) and the support they received. The women who chose to leave the community when local services were available

– and those who would have left anyways after they closed – expressed an appreciation for being close to specialist care should any complications arise. This group of women did note, however, a lack of continuity of care with their care provider leading to, in some instances, the sense of having received impersonal care.

The loss of antenatal services in a community often leads to diminished services in the prenatal and post-partum period as care providers become less current with this aspect of practice. The loss of attendant services after the closure of the maternity service in Bella Bella/Waglisla was noted by several of the interviewees. As one commented:

When I was pregnant with [my first child] ... once a month the health centre would drop off all these different kinds of fruit, potatoes, vegetables, milk ... That was something I really appreciated. But they didn't do that [for my second pregnancy]. That stopped. [004:96–103]

5. Discussion

The findings from this study illuminate the social significance of local birth for Heiltsuk women. The importance of family and community support for parturient women in the perinatal period reflects qualities of culture and well-being which must be understood differently for Aboriginal women and non-Aboriginal women, and, for Aboriginal women, understood in relation to the importance of their geographic home. In her article, "Therapeutic landscapes and First Nations peoples: an exploration of culture, health and place," Wilson (2003) notes:

The identity of indigenous peoples, whose concept of self is rooted in the context of community and place, differs strikingly from the identity of many Euro-Canadians whose concept of self is frequently encapsulated in independence of the individual." (p. 9)

The idea of providing a *context* for the experience of birth that extends beyond medical needs (e.g., the hospital as a context of birth) has not been given consideration within current health planning. The context expressed by the women in this study was one of family, friends and community but extended to the recent historical context of birth in Bella Bella/Waglisla, evidenced through the many references made to either giving birth in Bella Bella/Waglisla – or others who had – and the symbolic importance of the place name recorded on the birth certificate. For women who birthed locally, these qualities led to a sense of belonging-through-birth. Snyder et al. (2003) refer to the loss of possession, kinship or belonging as "cultural loss" (p. 107).

Although we easily understand the therapeutic value of places (i.e., hospitals) and systems (transportation and referral systems) in contributing to health, it may be instructive also to consider the value of therapeutic *networks*. Smyth (2005) and Laws and Radford (1998) describe these as networks through which people receive support and care, though they are separate from traditional biomedicine approaches, involving families, friends, therapists, and kinship groups. This encourages us to think of health as an integration of the physical, psychosocial, and spiritual realms and thus of the importance of the context of health care provision.

The social relationships that women in this study identified as being important to birth occur primarily within the geography of Bella Bella/Waglisla (although some extended outside of the community), which suggests an inter-relationship between social relationships and place. Snyder et al. (2003) describe this inter-relationship by noting that for indigenous peoples, "relationship to land or resources involves an intimate bond or sense of place,

that take on the characteristics of kinship ties and belongingness, which are inalienable" (p. 108). Wilson (2003) takes this idea further to suggest that beyond merely *shaping* identity, the land is *part of* Aboriginal identity and shapes all aspects of their lives, a notion that Oneha (2001) suggests is consistent with all indigenous peoples on the planet. This gives rise to the sense of spirituality associated with the land by Aboriginal peoples (Royal Commission on Aboriginal Peoples, 1996), which in turn leads to the natural interweaving of culture and geography. When culture and geography are separated, however, Snyder et al. (2003) note that cultural knowledge and practices may lose meaning and change the nature of social relationships, which may have disastrous consequences:

Because so much of what constitutes a culture is woven into spatial patterns and localized meanings, to move a culture would be tantamount to destroying it. Much of what is valuable to the culture is embedded in the place." (p. 109)

Despite the growing literature on the importance of community – both geographic and social – to both Aboriginal culture and health, this understanding has not been reflected in health services delivery policy. This is due to several reasons including fiscal constraints and the dichotomization of clinical and social concerns, with clinical management (including ensuring access to care) taking precedence. This is evidenced by the devolution of patient travel subsidies and lack of escort support from First Nations and Inuit Health (Health Canada) for women who must leave their communities to give birth. However, as the growing body of literature suggests, the social morbidities associated with this policy are significant and may have an impact on the short- or long-term health of rural parturient women and their families.

In some instances it may not be possible or feasible to support local birth due to low volume, lack of recruitment and retention of care providers willing to include maternity care within their scope of practice, or the desire of women to be closer to specialist care should it be necessary. In these instances the role of geography and culture need not be overlooked but instead used to inform appropriate practices to support women throughout their child-bearing experience.

6. Limitations

This study focuses on the birth experiences of women who belong to a specific geographic and First Nations community. Consequently, care must be exercised in adapting findings to other rural and Aboriginal environments. As in all qualitative research, selected participants are able to articulate more compellingly than others. Care was taken to adequately represent narratives contributing to each theme among all participants.

7. Conclusion

This qualitative exploratory study articulates the experiences of women giving birth in the rural First Nations community of Bella Bella/Waglisla. Findings reveal the importance of community support, the overriding belief that women should be able to give birth in Bella Bella/Waglisla, and the difference in experiences of birth before and after local services were closed. Central to participants' birth experiences were the ties to their family, community, and place. This web of kinship ties, which form their identity, were made stronger through experiences of local birth.

This project was guided by the principles of participatory research, an approach that ensures community participation in research design, methods, data collection, and analysis, as well as

shared power and a culturally responsive framework (CIHR, 2007; Kaufert et al, 1999; Strickland, 1999). The recommendations that emerged from this study, which were formally ratified by the Heiltsuk Band Council, emphasize the importance of community involvement in the decision-making around allocation of resources for maternity care and the importance of place and community in giving birth (Kornelsen et al., forthcoming).

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A Report on Best Practices for Returning Birth to Rural and Remote Aboriginal Communities

This document was reviewed by the Aboriginal Women's Health Committee and approved by the Executive and Council of the Society of Obstetricians and Gynaecologists of Canada.

PRINCIPAL AUTHOR

Carol Couchie, RM

CONTRIBUTING AUTHOR

Sheila Sanderson, PhD

Abstract

Background: During the last four decades, policies and practices based on modern obstetrical techniques and knowledge have replaced traditional practices in many rural and remote Aboriginal communities. As most of these communities do not have obstetrical facilities or staff, women often have to leave their communities to give birth.

Objective: To review policies currently in place in Aboriginal communities that recommend evacuation of all pregnant women at 36 to 37 weeks' gestation to deliver in a Level 2 hospital.

Options: Allowing Aboriginal women, their families, and their communities to decide whether it is safe and practical for women to deliver close to home.

Outcomes: Increased opportunities for Aboriginal women in remote and rural communities to deliver within their own communities or closer to home in a familiar environment.

Evidence: PubMed was searched for articles on subjects related to birth in Aboriginal communities, birth in rural and remote communities, and midwifery in Aboriginal and remote communities. The web sites and libraries of the National Aboriginal Health Organization, The First Nations and Inuit Health Branch, and Health Canada were also searched for relevant documents.

In addition, the authors visited three communities that have trained local midwives and that support deliveries within the community to observe and participate in their programs.

Benefits: It is hoped that improved communication between health institutions and remote and rural communities and changes in policies and procedures concerning the care of pregnant women in these communities will contribute to reductions in perinatal morbidity and mortality.

Sponsors: First Nations and Inuit Health Branch (FNIHB), Health Canada.

Key Words: Pregnancy, birth, obstetrical care, midwives, Aboriginal, First Nations, Inuit, Métis, community

Recommendations

1. Physicians, nurses, hospital administrators, and funding agencies (both government and non-government) should ensure that they are well informed about the health needs of First Nations, Inuit, and Métis people and the broader determinants of health.
2. Aboriginal communities and health institutions must work together to change existing maternity programs.
3. Plans for maternal and child health care in Aboriginal communities should include a "healing map" that outlines the determinants of health.
4. Midwifery care and midwifery training should be an integral part of changes in maternity care for rural and remote Aboriginal communities.
5. Protocols for emergency and non-emergency clinical care in Aboriginal communities should be developed in conjunction with midwifery programs in those communities.
6. Midwives working in rural and remote communities should be seen as primary caregivers for all pregnant women in the community.

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INTRODUCTION

The recommendations in this paper are intended to support, to the extent it is practical and safe, the return of birth to all remote and rural Aboriginal communities. However, as the National Aboriginal Health Organization notes, "there is less information available on First Nations and still less on Métis birthing practices than those of Inuit."¹ Partly because of this, and partly because Inuit communities are almost by definition rural and remote, most of the observations and examples in this paper draw on Inuit experience.

It is clear, too, that practices and traditions vary widely, even among communities in a given area. The focus of this paper is not the specific historical conditions of any group or culture but the need to assist communities to retain or restore what is important from their own birth traditions without losing the benefits of modern obstetrical practice.

Until the middle of the 20th century, Aboriginal women in rural and remote areas gave birth in their communities, usually assisted by family members, traditional midwives, or

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both.¹ Studies of traditional birthing practices and midwifery have differed in their findings, but it is clear that despite considerable variations in approach, for most Aboriginal cultures, birth was important to the whole community, and strong traditions governed its conduct.²

In the case of Inuit women, the community was not a fixed settlement but one of several camps that families moved among as seasons changed. When Inuit were moved into permanent settlements, women gave birth at newly established nursing stations, usually assisted by non-Inuit nurses or midwives.³

Changes in training and recruitment meant that by the 1970s, nursing station staff were often reluctant to perform deliveries in remote communities, and women were routinely sent to regional centres (Iqaluit, Yellowknife, and Churchill) or to larger hospitals in the south, typically at 36 weeks' gestation.^{3,4} Although this practice has undoubtedly reduced morbidity and mortality associated with high-risk pregnancies, it has also created hardship for many women, and there is growing evidence that it may contribute to postpartum depression and increased maternal and newborn complications.⁵ Kornelsen et al. note that women need "continuity of caregiver, involvement in decision making, and presence of partners, family, and social support."⁶

EFFECT ON ABORIGINAL WOMEN IN REMOTE COMMUNITIES

These effects are usually even greater for Aboriginal women and for their communities. Douglas et al. report comments from women whose first children were born before evacuation was routine: "they told [other researchers] that only their first children were real Inuit, not the later ones."³

Women who live in remote communities often spend three or more weeks hundreds of kilometres away from home in an unfamiliar place. Language may be a barrier, and cultural norms and expectations may be different. Women may be unable to eat at a time when nutrition is important. Inuit women have traditionally been encouraged to eat more "country foods" (caribou, seal, char, etc.) while pregnant, and they may find southern food unappealing.⁷ If they have lengthy labours, they may find themselves alone on occasion, which one Inuit midwife described as "incomprehensible in our culture."⁸

It is often difficult for physicians and medical staff who live and work in the south to understand why a community would choose to offer delivery without the immediate availability of modern obstetric services. The reasons are complex, but the following quotation from Nellie Tooliguk, one of the senior Inuit midwives working at a maternity centre in Nunavik, offers a vivid analogy.

Just imagine this: You are having a baby. A group of people with PhDs have decided that Denmark's perinatal statistics are better than Canada's. They decide it will improve the medical outcome for you and your baby if you are flown to Denmark three weeks before your expected delivery date. You will remain there, without your family, until your baby is born. You arrive alone in this place where you have never been. You can't adjust to their strange food, so you eat very little for your last weeks of pregnancy. Everything is in a different language. Sometimes an interpreter is available. Your family calls after two weeks to say that your children have been taken to another relative's. The house you know is already over-crowded. The children cry on the phone to you, and you know you can't pay for this phone bill when you return home.

If you refuse this new plan, which has no evaluation of impact, you are considered selfish, undereducated and willing to put your family's health at risk! When you ask if this money could be used to simply improve the health care at home you are told studies need to be done first to see if it is possible. This is just a small piece of what injustice we have been put through by health care policies and policy makers.⁹

Like other women, First Nations, Inuit, and Métis women want control over their birth experiences: they want to choose where they give birth and who provides care for them in the childbearing year, and they want birth to be as safe as possible for themselves and their babies. When policies and practices are formulated, consideration must be given not only to the safety of delivery, but also to family and cultural needs at the time of delivery.^{2,4}

Recommendation

1. Physicians, nurses, hospital administrators, and funding agencies (both government and non-government) should ensure that they are well informed about the health needs of First Nations, Inuit, and Métis people and the broader determinants of health.

MOVING BIRTH CLOSER TO THE COMMUNITY

Clearly women at high risk of complications benefit from evacuation, but for women at lower risk, alternatives to southern hospitals are emerging.

In Puvirnitug, a Nunavik community about 1100 miles north of Montreal, the Inuulitsivik Health Centre maternity ward, known locally simply as "the maternity," has served the communities of the Hudson Bay coast (a total population of about 5500) since 1986.^{1-4,10} In addition to physicians and nurses, the Inuulitsivik maternity has registered

midwives, community midwives, and maternity workers on staff. In 2001–2002, there were 94 births at the centre. Maternity services for the communities of the Ungava coast are provided at the Tulattavik Health Centre in Kuujuaq. Although it does not currently provide a program comparable to the Inuulitsivik maternity's, the centre has a permanent staff of general practitioners, nurses, and other health professionals.

A smaller maternity centre has been operating in Inukjuak since 1998.¹⁰ Care is provided by midwives, with students from the community working under the supervision of a senior midwife. A retrospective review of the centre showed that this team had attended a total of 132 births during the five-year period of the study. The percentage of women giving birth in the community increased, particularly after a policy that did not allow women to have their first baby in Inukjuak was changed in 1998.¹¹

In Nunavut, the birthing centre in Rankin Inlet began as a pilot project in 1993 and is now a regional centre for low-risk births. The centre has Inuit maternity care workers, but as Nunavut has no midwifery legislation—and therefore no midwifery training program—midwives are still recruited (often with difficulty) outside the territory.^{1,3,4}

Women from remote communities may still have to travel to these centres, but the care they receive and the people who provide it are closer to their experience and expectations. Inuit midwives are part of the team, culture and language are understood and respected, and family members may be able to accompany the pregnant woman to the centre.⁴

The development or enhancement of community birthing programs and facilities requires communication and trust between pregnant women and their families, community Elders, political leaders, and medical professionals. Studies of all aspects of prenatal care and delivery are also needed to ensure that rates of maternal and neonatal morbidity and mortality are comparable with (or better than) those associated with evacuation to southern hospitals. There is little recent information in the literature and therefore no good basis of comparison for perinatal outcomes at the existing birth centres.^{3,10,12,13}

Recommendation

2. Aboriginal communities and health institutions must work together to change existing maternity programs.

UNDERSTANDING THE DETERMINANTS OF HEALTH

The healing map, outlined in “Community Healing and Aboriginal Social Security Reform,”¹⁴ shows the determinants of health essential to social security reform. The healing map examines questions such as “Who is responsible for community health and health education?” as well as

risks and benefits of proposed reforms. Physicians, nurses, midwives, and other care providers, as well as pregnant women and their families, need to be aware of the potential adverse outcomes for each woman giving birth in the community and for those providing her care.

Recommendation

3. Plans for maternal and child health care in Aboriginal communities should include a “healing map” that outlines the determinants of health.

MIDWIFERY AND COMMUNITY-BASED CARE

First Nations, Inuit, and Métis populations want to select from their own communities women to be trained to deliver midwifery services within those communities. If this is to succeed, health care providers must encourage the development of community-based midwifery programs. Ideally, such programs will allow community-chosen student midwives to be taught and mentored by a supervising midwife. Students would be involved in the care of all pregnant women at their local health centre or hospital. Students would also provide care, sexually transmitted infection screening, and health education to all girls and women of childbearing age.

Protocols for clinical care must be developed in conjunction with those providing midwifery care and with midwifery training programs. Perinatal review committees should meet regularly to plan for care. For example, every Thursday afternoon, staff in Puvirnituq, Inukjuak, and Salluit review the charts of women in each community who are over 34 weeks' gestation, risk is assessed, and a care plan is made for each woman. The plan may be for the woman to give birth in her own remote community, which has no transfusion capacity; to give birth at the Inuulitsivik Health Centre maternity, which has transfusion capacity; or to be sent to a tertiary care centre in Montreal.

Rather than the usual risk scoring methods, the Inuulitsivik maternity used a community-based model in which evaluating risk was the responsibility of a committee with equally weighted representation from midwives, medical staff and the community. The decision to evacuate was the sole responsibility of this committee, not the physicians alone.³

Recommendations

4. Midwifery care and midwifery training should be an integral part of changes in maternity care.
5. Protocols for clinical care should be developed in conjunction with midwifery programs.

6. Midwives working in rural and remote communities should be seen as primary caregivers for all pregnant women in the community.

CONCLUSION

Evidence suggests that expanding health centres and providing training for Aboriginal midwives within the communities will help to improve prenatal and birth experiences for Aboriginal women.

The models of care offered by the Inuulitsivik Health Centre maternity ward in Puvirnituk, the Inukjuaq maternity centre, and the Rankin Inlet birthing centre demonstrate that low-risk births can be safely managed in local or regional centres.

Standard means of assessing risk may need to be modified for women in remote and rural communities and to take into consideration the levels of care that can be provided by regional centres.

Aboriginal women in remote and rural communities should not have to choose between their culture and their safety.

ILLUSTRATIVE CASES

The authors visited three Inuit communities in Nunavik that are now able to support deliveries. Protocols and standards have been established to determine the practicality of keeping a pregnant woman in her community for the birth.¹⁴ The following composites are representative of cases dealt with at these centres. The characteristics of the patients described in these cases are similar to those of the patients in whose care the authors assisted during their stay.

Case One

An Inuit woman, Elizabeth, and her partner arrived at the Inuulitsivik Health Centre maternity in Puvirnituk on April 1, 2006. Elizabeth was expected to deliver her second child that evening. She and her partner had travelled from Inukjuak for the birth because Elizabeth had a hemoglobin level of < 100 g/L. Blood products are not available in Inukjuak, so during Elizabeth's prenatal care it was determined that she should deliver in the Puvirnituk maternity, which has transfusion capacity.

Elizabeth and her partner were together for the duration of her labour, and she was able to communicate with the midwives in Inuktitut.

A postnatal worker was assigned to stay with Elizabeth and her baby after the midwives went home. Postnatal workers are trained at the maternity centre in maternal and infant postnatal care and breastfeeding support, and they can take vital signs. Some postnatal workers go on to take community midwifery training.

The community was not her own, but the language and culture were. The birth was straightforward, with no complications, and the infant came into a world where his parents were together and where they felt comfortable and safe. Elizabeth had relatives living in Puvirnituk, and they were able to visit to welcome the infant and congratulate the proud parents.

Case Two

Sarah, a 16-year-old primiparous Inuit woman, arrived at the Inukjuaq maternity centre in early labour. A senior community midwife (not a registered midwife) was prepared to attend and manage the birth, and a registered midwife was asked to assist.

When Sarah was first assessed at approximately 4:00 a.m., the vertex was at station -2 to -3 and not well applied, her contractions were irregular and mild to moderate in strength, the membranes were intact and bulging, and the cervix was about 5 to 6 cm dilated.

Sarah's labour was slow to progress. Her contractions continued to be irregular and mild to moderate. By 11:00 a.m., there was no significant change, and the vertex was still too high to perform an artificial rupture of membranes. It was decided to augment the labour with herbal remedies long used by midwives as a gentle way to help stimulate contractions and sometimes even to induce labour. Although these herbs do not always work, they are used as a last resort if labour is not progressing, because it would not be safe to augment labour with oxytocin in such a remote setting.

Sarah was tired, but she was with her mother, her grandmother, her boyfriend, and the Inuit midwives she knew and trusted. She and the baby were still doing well: fetal heart rate was reassuring, and there were no signs of dehydration or fever. The herbs appeared to work, and Sarah's labour progressed.

At about 2:00 p.m., Sarah was checked by both the community midwife and the registered midwife. Although the dilatation had not increased much, there had been enough descent of the vertex for safe artificial rupture of the membranes, which resulted in better application of the vertex to the cervix. The labour also became more effective, with regular strong contractions.

By 5:00 p.m., Sarah had the urge to push. The urge quickly became very strong and the head was already visible. Sarah, tired of labour and pain, ignored the midwives' instructions (offered in both Inuktitut and English) to slow down and not push between contractions. The baby, born at 5:15 p.m., did not breathe spontaneously and needed a couple of puffs of positive pressure ventilation (PPV). He was watched closely, and he was given some free-flow oxygen over the next hour to make sure his breathing rate (which

had been high) came down to normal. A glucose check and a complete blood count were ordered. By one hour postpartum, the infant was breathing normally and was nursing.

Once both mother and baby were stable, special outdoor lights were turned on to signify to the community that a new baby had been born. Within a short period of time, many family members and friends had found their way to the maternity centre to meet the newest member of their community, bringing food and good wishes. Sarah and her son were surrounded by those who knew and loved them, by their language, and by their traditions and culture. The birth was celebrated into the evening, and the story of the new life was even told on the local radio so that those who could not come and meet the infant in person would be able to share in the story. Sarah's mother and grandmother expressed profound gratitude that Sarah had been able to give birth at the centre; both of them had been evacuated for their deliveries.

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Canadian First Nations Women's Beliefs About Pregnancy and Prenatal Care

Elizabeth H. Sokoloski

Les faits indiquent le lien entre des soins prénatals appropriés et de meilleurs résultats quant aux naissances. La recherche cependant montre que les femmes autochtones ne participent pas de façon régulière aux soins prénatals. Dans la présente étude, sept informatrices, représentant trois tribus autochtones, ont été longuement interviewées concernant leurs convictions sur la grossesse et leur participation à des soins prénatals. Les femmes autochtones conçoivent la grossesse selon un contexte spirituel et croient qu'il s'agit d'un processus sain et naturel qui ne requiert aucune intervention. Dans la mesure où elles estiment que la responsabilité leur incombe de «s'occuper d'elles-mêmes» pendant leur grossesse, elles font leur les pratiques culturelles censées favoriser une bonne grossesse. Les femmes autochtones semblent souvent insatisfaites des prestataires de soins de santé dans les cliniques d'accouchements. Souvent, on ne satisfait pas à leurs attentes et leurs convictions par rapport à la grossesse sont en conflit avec celles des prestataires de soins de santé. On pourrait briser les barrières qui empêchent le recours aux soins prénatals en améliorant la communication et en offrant des soins holistiques axés sur la culture spécifique.

Evidence links adequate prenatal care to improved birth outcomes. Research, however, indicates that First Nations women do not attend regularly for prenatal care. In the current study, seven informants, representing three First Nations tribes, were extensively interviewed to examine their beliefs about pregnancy and participation in prenatal care. First Nations women conceptualized pregnancy in a spiritual context and believed it to be a healthy, natural process requiring no intervention. Since they believed they were responsible for "taking care of themselves" during pregnancy, cultural practices that were thought to promote a healthy pregnancy were espoused. First Nations women were reportedly often dissatisfied with health-care providers in prenatal clinics. Their expectations of freely offered explanations and a friendly non-authoritarian approach were often not realized and their beliefs about pregnancy were in conflict with those of health-care providers. Barriers to prenatal care might be reduced by improving communication and providing holistic culture-specific care.

Considerable evidence links adequate prenatal care to improved birth outcome in Caucasian and various ethnic groups (Graham-Cumming, 1967; Morris, Berenson, Lawson, & Wiemann, 1993). Although it is not the only factor contributing to a healthy pregnancy outcome, it enhances the possibility for appropriate health-related interventions as required.

Research indicates that First Nations women do not regularly attend prenatal care (Baskett, 1977; Graham-Cumming, 1967), despite the fact that they tend to be a high-risk group for several health-related reasons. Baskett (1977) found that 14.3% of First Nations women received minimal prenatal care (fewer than four visits) and 9.2% received none; Graham-Cumming found that 30% made good use of prenatal services, 30% made fair use, while 40% made little or no use of these services. The First Nations population

Elizabeth H. Sokoloski, R.N., B.N., M.N., is a lecturer in the Faculty of Nursing, University of Manitoba—St. Boniface General Hospital Site, in Winnipeg, Manitoba.

tends to have a high incidence of adolescent pregnancy, complications of pregnancy, grand multiparity, low and high birthweight babies, and greater infant mortality following preterm birth (Baskett, 1977; Community Task Force on Maternal and Child Health, 1981). Additional risk factors include inadequate nutrition during pregnancy (Bureau of Nutritional Sciences, 1975), high blood pressure, gestational diabetes, and antepartum bleeding (Wotton & Macdonald, 1981).

Background

Only six studies have explored First Nations women's beliefs and practices related to pregnancy. Hildebrand (1970) and Clarke (1990) focused on the Chippewa of the Great Lakes and the Salish of British Columbia, respectively, whereas other researchers studied American First Nation groups: Navajo (Loughlin 1965), Iroquois (Evaneshko, 1978), and Northwest Coastal (Bushnell, 1981; Horn, 1978) groups.

Reportedly, Canadian First Nations women believe that breaching traditional teachings surrounding pregnancy can result in harmful consequences (Clarke, 1990). Violating food taboos is believed to result in a difficult labour (Clarke, 1990; Hildebrand, 1970) and abnormalities in the baby (Clarke, 1990). Inactivity is believed to cause the placenta to adhere to the uterus (Hildebrand, 1970) or the baby to attach to the womb, resulting in a difficult labour (Clarke, 1990). Sensory experiences of the mother are believed to be passed on to the fetus. Women believe that by "listening" to their bodies they can learn what is beneficial or harmful for themselves and their babies (Clarke, 1990).

Among American First Nations women, pregnancy is believed to be a normal, natural process requiring no intervention (Bushnell, 1981; Horn, 1978; Loughlin, 1965). Little preparation is made for the coming baby (Bushnell, 1981; Loughlin, 1965) because it is believed that illness, injury, or even death of the unborn child could result (Loughlin, 1965). Women believe they give care to their babies through their own good health and nutrition (Bushnell, 1981), and are encouraged to maintain a normal work schedule (Evaneshko, 1978) without any extra support (Bushnell, 1981).

Canadian and American First Nations women identified barriers to prenatal care attendance, including dislike of vaginal examinations (Hildebrand, 1970), lack of continuity of care (Hildebrand, 1970; Horn, 1978), communication difficulties (Hildebrand, 1970), transportation problems (Hildebrand, 1970; Horn, 1978), and attitudes of prejudice on the part of the health-care workers (Horn, 1978). Women questioned the value and need for prenatal care (Bushnell, 1981; Horn, 1978; Loughlin, 1965) and the appropri-

ateness of prenatal classes as a source of information because the family (especially grandparents) has primary responsibility for teaching (Clarke, 1990). In summary, they embrace a natural approach to pregnancy and rely on culturally prescribed practices to maintain a healthy pregnancy.

Factors Associated With Prenatal Care Attendance

Numerous studies have investigated factors associated with prenatal care attendance, although none were based on First Nations women. Socio-demographic variables that have been found to improve attendance were: older age of the mother (Lia-Hoagberg et al., 1990; McDonald & Coburn, 1988), higher education of the mother (Lia-Hoagberg et al., 1990; Parken, 1978), lower parity (Kaliszer & Kidd, 1981; Kieffer, Alexander, & Mor, 1992), married marital status (Collver, Have, & Speare, 1967; McDonald & Coburn, 1988) and employment of husbands (Kaliszer & Kidd, 1981; McKinlay, 1973). Psychosocial factors found to enhance prenatal care attendance include available support, such as verbal encouragement and provision of transportation to appointments (Lia-Hoagberg et al., 1990; Poland, Ager, & Olson, 1987), planned pregnancy (Lia-Hoagberg et al., 1990; McKinlay & McKinlay, 1972), and previous pregnancy complications (McKinlay & McKinlay, 1979; Parsons & Perkins, 1982).

In contrast, several factors have been identified that appear to deter prenatal care attendance: impersonal treatment, long waits to see the doctor, rushed visits (Curry, 1989), fear of medical procedures (Lia-Hoagberg et al., 1990), lack of continuity of nursing care (Poland, 1976), lack of child care, and transportation problems (Curry, 1989; Lia-Hoagberg et al., 1990). Negative feelings toward pregnancy (Watkins, 1968) and fear of pressure from a doctor to have an abortion (Simms, 1984) also have been found to delay prenatal care attendance.

Research Questions

Few studies have investigated the cultural, psychological, and decision-making processes of women seeking prenatal care; notably these were not studies of First Nations women. If prenatal care attendance by First Nations women is to be improved, more research is needed. Therefore, the purpose of the current qualitative study was to explore the health beliefs of Canadian First Nations women regarding pregnancy and prenatal care. The research questions were:

What are the health beliefs of First Nations women about pregnancy?

What are First Nations women's beliefs about prenatal care?

What factors influence First Nations women's participation in prenatal care?

Method

Informants

Seven English speaking key informants residing in a Canadian urban centre, participated in the study. An *N* of seven was considered an appropriate number based on previous studies where six to 12 informants were used to gather qualitative cultural data (Evaneshko & Kay, 1982; Horn, 1978). Informants were selected on the basis of three criteria suggested by Spradley (1979): they were familiar with, and currently involved with the First Nations culture; and they had adequate time. In addition informants were 18 years of age or older, had one or more children, had previously attended prenatal care, and were leaders in First Nations women's health. Informants represented three First Nations tribes located in Canada: Cree ($n=3$), Saulteaux ($n=2$), and Ojibway ($n=2$). One of the seven informants completed only part of the study because she moved to another province; the information was nevertheless included in the analyses. All informants had lived on a First Nations reserve for 8 to 15 years.

After approval was obtained from an Ethical Review Committee, potential informants were telephoned or personally approached and invited to participate in the study. Names of potential informants were obtained from acquaintances of the researcher and from informants who participated in the study. Ten potential informants who met the study criteria were identified and contacted, but three refused to participate.

Data Collection

During the initial interview the study was explained more fully and consent was obtained. Interviews were conducted by the researcher at the informant's convenience in the informant's or researcher's home or the informant's work place. Four to five in-depth, tape-recorded interviews of one to three hours each were conducted with each of the six informants, and one and one quarter hours with one informant, for a total of 45 hours.

An interview guide was developed by the researcher and reviewed by a First Nations nurse with a baccalaureate degree in nursing and two non-First Nations nurses with masters of nursing degrees. The interview guide consisted of general topics such as beliefs about spacing of children, prenatal practices, pregnancy, and prenatal care. Examples of specific questions asked during the interviews were: "What do First Nations women generally think about having children?" and "What do First Nations women think are things that are good for them and their babies during pregnancy?" Initial interviews were based on the interview guide, but as concepts and themes for further exploration emerged, these became the focus of subsequent interviews. For example,

when some informants began discussing support for single mothers, this topic was explored.

The tape-recorded interviews were transcribed verbatim and content analysis was used to code the data and identify themes and categories (Holsti, 1969). In the development of categories, frequency counts were used. Thus, if four or more informants concurred on a belief, this was subsumed as a category under a particular theme.

Findings

Seven major themes were identified from the interviews. These related to beliefs about pregnancy, children, spacing of children, helpful prenatal practices, harmful prenatal practices, prenatal care, and interactions with health-care providers.

Beliefs About Pregnancy

Traditional beliefs were those that informants identified as being part of their culture. Informants consistently stated that pregnancy is traditionally believed to be a blessing from the creator. "And if you were pregnant...that was a blessing for you....You were being blessed and you were chosen to carry this new baby." Because pregnant women are believed to be carrying extra life for the creator and because of changes and risks associated with childbearing, pregnant women are respected and hold special status in First Nations society.

First Nations women also believe pregnancy to be a natural process, maintained by nature and requiring no interference:

It's seen as a very natural process. It's nature....the nurturing is done by Mother Nature. And of course the baby is taken care of by nature in a similar way. And you don't want to interfere too much with the growth.

Informants cited indicators of pregnancy such as a missed period, morning sickness, and weight gain. Some women "just know" that they are pregnant before any signs appear due to a "feeling" they have. It also is believed that pregnant women have a certain look in their eyes. "My mother was saying that there is that certain spark or twinkle in the eyes. That is because of this new life that is beginning inside you."

Informants unanimously stated that pregnancy is not believed to be a sickness. "Grandma will teach that it's [pregnancy is] not a sickness. It's a natural process." Most also thought that First Nations women believed they were not susceptible to sickness during pregnancy; half reflected the view that

sickness during pregnancy was not serious, while the rest thought that sickness during pregnancy could be somewhat or very serious. "No, it [pregnancy] is considered such a normal process that you would not anticipate problems or difficulties unless there is some previous experiences."

The conceptualization of pregnancy as a normal, natural process was also evident from First Nations women's beliefs about who should attend them during childbearing. It was believed that attendants during pregnancy and childbirth should be older, experienced women, not doctors, although physicians are considered appropriate consultants for medical problems. Men are believed to be harmed by participating in pregnancy-related affairs.

I was told it's a woman's role and it's not for a man to be there when a child is being born because that can affect the man as well.... The reason it could be harmful to the man is because of the power behind it.

Beliefs About Children

Children are considered to be a gift from the creator and each one is welcomed and treasured. Although it is believed that marriage should precede childbearing, it is thought that mothers should keep out-of-wedlock babies. Unwed mothers and their children tend to be accepted and supported.

Another belief is that the role of parents is only temporary. Parents have a responsibility to care for a child for the creator until the child becomes independent. First Nations people believe the responsibility for children should be shared by the entire community. The application of this concept is evident in the case of the childless couple. It is common for a family member or friend to offer their own child for adoption by a childless couple.

Beliefs About Spacing Children

Traditional First Nations women's beliefs about spacing children are linked to their view of pregnancy as a natural process and a blessing from the creator: people "should not specify the number of children to have," but rather children should be accepted naturally as they come.

Childbearing is closely aligned with womanhood. "You are a woman and a woman is made to have children, to have babies, and if you don't have babies, then you are looked at as being not really a woman." As a consequence a tubal ligation and hysterectomy are unacceptable to traditional First Nations women. Since life is believed to begin at conception, therapeutic abortion is also not accepted. ("It's almost like saying you got rid of that life you were blessed with.") Guilt and an inability to bear future children are thought to be consequences of having an abortion.

However, informants concurred that beliefs about spacing children have changed and some women now choose various available methods to limit family size. It is believed to be a woman's decision to have children or to take measures to prevent pregnancy.

Among urban-dwelling women, a range of two to four children is currently considered ideal with a period of one to five years between pregnancies. Breast-feeding is believed to be an effective method of birth control. Herbal preparations, which are considered natural, are used by some First Nations women to prevent pregnancy.

Helpful Prenatal Practices

First Nations women believe that various practices implemented by the expectant woman will promote a healthy pregnancy. Women are responsible for "taking care of themselves" so that the outcome of pregnancy will be a healthy baby. This was illustrated by an informant when she described the advice of an elder to a pregnant woman: "...take care of yourself as the way that the creator would want you in order for your child to be healthy....You don't drink, you don't smoke, you eat properly and that type of thing." Women believe that miscarriages and preterm births result when they do not take care of themselves during pregnancy.

A well-balanced diet and moderate portions are believed to help maintain a healthy pregnancy. Foods such as wild meat or fish, white carrots, potatoes, rice, and berries are thought to be particularly beneficial. Exercise in moderation is believed to be a healthy practice during pregnancy. Walking is thought to be particularly suitable because groups of First Nations people walked from camp to camp. Adequate rest, sleep, and quiet times are also thought to be important.

It is believed that the mother's emotions can be transmitted to her baby during pregnancy. As a consequence, expectant women are encouraged to have positive, pleasant thoughts during pregnancy and to communicate with the baby.

Harmful Prenatal Practices

First Nations women believe that during pregnancy strenuous activity, consumption of chemical substances such as alcohol and drugs, and smoking can endanger the health of a mother or baby.

Informants unanimously stated that strenuous maternal activity is thought to result in miscarriages or preterm births. Controlled breathing and physical exercises (such as those taught in prenatal classes) are believed to affect the baby adversely; no further explanation of consequences was offered.

Consumption of alcohol during pregnancy is believed to cause miscarriage. Smoking is also considered harmful, although no explanation of the harmful effects had been given by those who taught the women. Traditional First Nations women believe that taking medications during pregnancy is unnatural.

Technological interventions during pregnancy are believed to be detrimental and some women are fearful of them. Ultrasound, for example, is thought to affect the baby's development, delay delivery, and interfere with the communication between mother and baby. Artificial induction of labour, fetal monitoring, pelvic examinations, and the use of obstetrical forceps are also considered harmful interferences.

Beliefs About Prenatal Care

Some First Nations women believe that prenatal care is beneficial, but many perceive no benefits. They think that the frequency of visits during normal pregnancies could be reduced, but increased if complications arise; women should develop a pattern of attendance based on their own perceived needs.

Informants specified that the primary factor enabling prenatal care attendance was the belief that problems would be identified and treated so the outcome would be a healthy baby. Problems encountered in a previous pregnancy would be a factor strongly motivating women to attend prenatal care.

The primary factors limiting prenatal care attendance were a lack of babysitting services and the absence of past or current problems during pregnancy. Informants consistently identified the prospect of pelvic examinations as being a deterrent, especially if performed by a young male doctor; an older female doctor was preferred. An additional limiting factor was the belief that staff would pressure women into having an abortion. One informant recalled: "I thought maybe the doctor might want to talk me out of my pregnancy.... So I stayed away from the doctor for as long as I could."

Interactions With Health-Care Providers

First Nations women believe that communication with staff during prenatal care visits is less than ideal, yet they desire positive interactions. They find such appointments to be rushed, cold, and impersonal, with long waiting periods to see the doctor. Satisfying visits occur when staff offer explanations freely and a friendly non-authoritarian approach is taken. The following narrative by an informant illustrates a personalized caring approach:

The nurse would come in there and tap somebody on the shoulder ...and say, "How are you?" You know that touch on the shoulder is a connection to say you are important too. And she would tell them

who she is and shake hands with them. So she'd introduce herself to them.... And then she would...sit there and talk to them.... It's almost like she centred her whole attention on you. It really made you feel comfortable. All of a sudden she made you feel you are so important.

According to the informants, First Nations women are characteristically shy and reluctant to ask questions during prenatal visits. They believe it is inappropriate for others to ask them too many direct questions or to discuss personal matters such as their menstrual periods.

You don't talk about your periods, your menstrual cycle.... If you ask a woman when was her last menstrual period, they will just ignore you. They will not look at you, they will not respond, they will just clam up.... They would become embarrassed and they would become uncomfortable.

First Nations women tend to refrain from giving feedback to staff and generally do not express satisfaction with care. Dissatisfaction with care is customarily expressed to a third person, who in turn discusses the situation with the health-care worker involved.

Some First Nations women tend to identify the timing of events by occurrences in nature, rather than stating a precise date (e.g., they may identify the date of their last menstrual period as being when the leaves started to come). As described in the following excerpt, nonverbal communication is believed to be more critical than verbal communication.

Indian people communicate very much through body language and they also look at how the next person behaves through their body language. We refer more to their actions.... It has so much weight. More so than any words that you can say, is the way that your actions are.

Discussion

The current study had two major limitations. Non-English-speaking First Nations women, whose beliefs may be different from those who are English-speaking, were excluded. Additionally, since three different First Nations tribes were represented by seven informants, there were too few representatives of each tribe to examine inter-group differences.

Results indicate that discrepancies exist between the beliefs of First Nations women and those of health-care providers. The former explain pregnancy in a spiritual context. This is a basic concept underlying many of the explanations they give for behaviours and practices related to pregnancy and

for their attitudes towards children. Pregnancy is viewed as a natural, normal process requiring no intervention. Similarly, Bushnell (1981), Horn (1978), and Loughlin (1965) found that First Nations women question the need for prenatal care. Clarke (1990) also found that First Nations women believe in "no change required" during pregnancy. In contrast, health-care providers in Canadian society (especially male medical personnel) often view pregnancy as a medical event. In a study of four national cultures Jordan (1980) found that American health-care providers view pregnancy as a medical event and take a technological approach in managing pregnancy and birth. As revealed in the current study, some First Nations women do not believe they are susceptible to serious illness during pregnancy, whereas health-care providers focus much of their care on monitoring for complications of pregnancy. These cultural differences may be obstacles to effective inter-ethnic relations (Boyle & Andrews, 1989), and signs of conflict and stress may occur if health personnel impose their ideas and practices upon clients (Leininger, 1991).

The current study reveals that spiritual, social, and psychological factors motivate First Nations women to bear children, and that womanhood is closely linked to childbearing. Horn (1983) also found that American First Nations teenagers believed the feminine role to be most clearly identified through pregnancy and childbirth.

The barriers to prenatal care attendance cited in the current study were babysitting problems, the belief that attendance is required only in the event of present or past problems with pregnancy, and dislike of pelvic examinations. First Nations women in Hildebrand's (1970) research also delayed initiating prenatal care because of dislike of vaginal examinations.

The current findings indicate that healthy prenatal practices such as a well-balanced diet, walking, avoidance of stress, and adequate rest and sleep are advocated. Bushnell (1981) and Evaneshko (1978) also found that First Nations women are encouraged to walk during pregnancy and to avoid emotional stress. So why do First Nations women have birth outcomes that tend to be unhealthy? This is a complex issue. Two possible factors may be the loss of traditional lifestyles because of social change, and poverty with its attendant stress. Furthermore, cultural beliefs may be espoused without being acted on. For example, women may believe that foods from the land provide a healthy diet during pregnancy but have no access to such foods. Perhaps health-care providers need to place more emphasis on promoting healthy traditional practices and reducing poverty in order to enhance pregnancy outcomes.

Because the current study was exploratory in nature, it would be premature to draw from it any implications for nursing. However, informants did offer recommendations for improving prenatal care attendance: interactions

in prenatal clinics should be enhanced by providing non-authoritarian, individualized care in a quiet, unhurried fashion. Consideration should also be given to providing nurse-midwifery services, First-Nations health-care workers, and continuity of health-care workers.

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Traditional First Nations Birthing Practices: Interviews With Elders in Northwestern Ontario

Terry O'Driscoll, MD, CCFP,¹ Lauren Payne, MPH,² Len Kelly, MD, MClIn Sci, CCFP,¹
Helen Cromarty, RN, HBScN,³ Natalie St Pierre-Hansen,¹ Carol Terry⁴

¹Division of Clinical Sciences, Northern Ontario School of Medicine, Sioux Lookout ON

²Faculty of Health Sciences, Simon Fraser University, Burnaby BC

Abstract

Objectives: Traditionally, First Nations maternity care was provided by community-based midwives trained through apprenticeship. Obstetrical practices and beliefs were integrated to provide holistic care. The Sioux Lookout Meno Ya Win Health Centre has a mandate to be a centre of excellence for Aboriginal health care. We undertook a literature review and performed a qualitative research study to understand some of the traditional practices in maternity care.

Methods: We conducted qualitative semi-structured interviews in English and Oji-Cree with 12 elders who had knowledge and experience of historical birthing practices in their home communities. Research team members included nursing and medical personnel and Anishinabe First Nation members. Interviews were analyzed and themes developed and verified by member checking and triangulation.

Results: The hands-on training for a community-based midwife often began in her teenage years with observation of childbirth practices. Practices were handed down by oral tradition and included prescriptions for healthy diet and moderate exercise during pregnancy; intrapartum care with preparation of clean cloths, moss, and scissors; the involvement of certain supportive family and community members; careful attention to the sacred handling of the placenta and umbilical cord; and careful wrapping of the newborn in fur. Complications, sometimes fatal, included retained placentas and stillbirths.

Conclusion: The provision of modern maternity care to Aboriginal patients should include acknowledgement of, and respect for, traditional birthing practices. Facilities providing care for these patients should consult with the relevant Aboriginal communities to understand their needs and initiate appropriate programming.

Key Words: First Nations, Aboriginal, traditional, obstetrical care, culture

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Résumé

Objectifs : Traditionnellement, chez les Premières Nations, les soins de maternité étaient offerts par des sages-femmes issues de la communauté formées par stage d'apprentissage. Les pratiques obstétricales et les croyances étaient intégrées à l'offre de soins holistiques. Le *Sioux Lookout Meno Ya Win Health Centre* a le mandat d'être un centre d'excellence pour ce qui est des soins de santé des Autochtones. Nous avons mené une analyse documentaire et une étude qualitative en vue de comprendre certaines des pratiques traditionnelles dans le domaine des soins de maternité.

Méthodes : Nous avons mené des entrevues qualitatives semi-structurées en anglais et en Oji-Cree auprès de 12 sages qui disposaient de connaissances et d'une expérience quant aux pratiques d'accouchement historiques au sein de leurs communautés respectives. Parmi les membres de l'équipe de recherche, on trouvait du personnel infirmier et médical, ainsi que des membres de la Première Nation Anishinabe. Les entrevues ont été analysées et des thèmes ont été développés et vérifiés par contrôle et triangulation auprès des membres.

Résultats : La formation pratique d'une sage-femme issue de la communauté commençait souvent à l'adolescence par l'observation des pratiques d'accouchement. Ces pratiques étaient transmises par tradition orale et comprenaient des prescriptions pour ce qui est de l'adoption d'un régime alimentaire sain et de la pratique d'exercices modérés pendant la grossesse; des soins intrapartum (préparation de linges propres, de mousse et de ciseaux); de la participation de certains membres de la famille et de la communauté à titre de soutiens; de l'attention rigoureuse devant être portée à la manipulation sacrée du placenta et du cordon ombilical; et de l'utilisation de fourrures pour envelopper le nouveau-né. Parmi les complications, parfois mortelles, on trouvait la rétention du placenta et la mortinaissance.

Conclusion : L'offre de soins de maternité modernes aux patientes autochtones devrait comprendre la reconnaissance et le respect des pratiques d'accouchement traditionnelles. Les établissements offrant des soins à ces patientes devraient consulter les communautés autochtones en question afin de comprendre leurs besoins et de mettre en œuvre une programmation appropriée.

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INTRODUCTION

First Nations communities in Northwestern Ontario provided their own intrapartum care until the late 1970s, when medical evacuation from remote communities became commonplace. Little is known of their traditional maternity care. We set out to document available information by interviewing First Nations elders who had been involved in maternity care. We were particularly interested to learn how these practices might inform the development of hospital-based cross-cultural maternity care.

Aboriginal women in Northern and remote areas commonly travel out of their home communities at 36 to 38 weeks' gestation to give birth in larger urban or regional centres.¹⁻³ There is a lack of capacity for obstetrical care in these women's home communities. Their primary care is provided by nurses at outpost stations with visits by physicians every few weeks. This is viewed by many as a dangerous clinical environment in which to give birth because of the lack of local obstetrical resources.^{4,5} Despite their success in reducing morbidity and mortality on an epidemiological level,^{6,7} programs for evacuating women for delivery have contributed to negative psychosocial consequences, including loneliness, worry, anxiety, depression, loss of appetite, and increased smoking behaviour.⁸ The Society of Obstetricians and Gynaecologists of Canada recently recommended that Aboriginal communities and health institutions should work together to change maternity programs to include culturally appropriate hospital care and to develop care resources closer to home.⁹

The Sioux Lookout Meno Ya Win Health Centre in Northwestern Ontario has a catchment population of 28 000, of which 82% are Anishinabe First Nations.¹⁰ Like many rural maternity centres, this facility attempts to provide care "close to home."¹¹ A further mandate of the Centre is the development of culturally appropriate care across the complete spectrum of hospital services, including maternal child care.¹² The Centre's obstetrical population is widely distributed geographically and has relatively high-risk pregnancies, with double the provincial rate of gestational diabetes and Ontario's highest rates of adolescent pregnancy and smoking.¹¹

METHODS

Literature Search

A search of Medline, HealthSTAR, Embase, SWAB, AMED, PsycINFO, and CINAHL from 1960 to 2009 was undertaken using the MeSH terms "health services," "indigenous," "Indians, North American," "Canada;

pregnancy," "prenatal care," "maternal welfare," "infant, newborn," "maternal health services," "medicine, traditional," "complementary therapies," and "spiritual therapies." Thirty articles were retrieved, and we included 29 relevant to our interest in actual birthing practices and associated beliefs.

Interviews

We conducted interviews in four remote communities in Northwestern Ontario, two of which are accessible only by fixed wing aircraft. The communities have populations of 600 to 1200, and all are over 400 km from a tertiary care centre. Interviews took place in either a nursing station or a community centre. Twelve participants were chosen by key informants and snowballing techniques. All were women aged between 50 and 80 years.

Semi-structured interview questions were developed in consultation with our First Nations advisor. Permission was obtained from each participant as well as the community health directors and First Nations chiefs. The interviews were conducted in English, sometimes through an Oji-Cree interpreter, and were audiotaped and transcribed.

The interviews were analyzed by five investigators, including two First Nations members of the research team, using qualitative techniques of immersion and crystallization. Triangulation of content and theme analysis were achieved through discussions of the findings with key informant First Nations non-participants and clinicians providing obstetrical care in the region and by referring to previous studies in the area. Trustworthiness was ensured by having three investigators perform theme analysis and member checking independently.

Ethics approval for this study was provided by the Meno Ya Win Research Review Committee.

RESULTS

Literature Search

The literature regarding Aboriginal traditions and childbirth often discusses the loss of both the traditional knowledge and the community involvement of traditional local midwives. Some authors advocate the "rebirth of traditional midwifery" across Canada as a potential means to bring birth closer to Northern communities.^{9,13-18}

Some remote community-based programs have been successful when the right resources, triaging, and local expertise were available. In Nunavik, the Inuulitsivik midwifery service is a successful midwifery-based model for

returning birth to the remote Hudson coast communities. Assessment and treatment involve physicians, midwives, and community personnel.¹³

An earlier study in our region described Nishnawbe Aski Nation traditional midwifery practices based on interviews with 19 traditional midwives.¹⁴ They described seven roles of the traditional midwife: teacher, healer, caregiver, nurturer, dietician, deliverer, and “do-dis-seem” (the midwife becomes a spiritual partner of the child through a cutting of the umbilical cord).

The term “midwife,” however, is subject to many interpretations that vary across cultures. In the Mohawk community, the term for midwife translates to “she is pulling the baby out of the earth,” among the Nuu-chah-nulth of British Columbia it means “she who can do everything,” among the Ojibwe it translates to “the one who cuts the cord,” and in Cree communities midwives are “the ones who deliver.”^{16,19}

Informants from a 1995 study with Cree, Saulteaux, and Ojibwe First Nations peoples expressed feelings consistent with the historical practice of having older, experienced women as attendants during birth, although physicians could appropriately be involved for management of medical complications.²⁰

Pregnancy among indigenous communities of North America is largely governed by a varying set of practices that women have historically followed; some of these practices may be helpful and some may be harmful. Beneficial practices, as normally outlined by community elders, more generally relate to remaining active, eating naturally, and maintaining a positive emotional demeanour.^{7,13,14,20,21}

The process of childbirth itself is also shaped by a number of practices and taboos that vary across North American indigenous cultures. Common to many populations, including the Mi'kmaq of Nova Scotia, Inuit populations, and other Canadian Northern Aboriginal communities, is the belief that a mother should make very little noise during labour because her noise may discourage the baby from coming out or indicate a lack of courage or concentration.^{7,21-26} Knots were not allowed during pregnancy in some Native American and Inuit populations, especially during childbirth, when all knots including hair ties and shoe laces were to be untied to decrease the possibility of nuchal cords at delivery.^{13,21,24}

Breastfeeding was viewed as the normal practice for many North American indigenous populations and lasted for at least two years.^{21,27} Besides mother's milk, the first food

given to infants among the Alberta Woodland Cree was a soup or broth made from meat or fish and introduced between two months and one year of age.²⁸

The practice of keeping the umbilical cord in a small bag as a sacred object was common in many communities.^{23,27} Among the Chippewa, this container would be attached to the cradleboard for the child to play with and was later dropped on a hunting trip to help the child become a good hunter.²⁷

The care of a mother after childbirth was seen as important to ensure the wellbeing of the child and the family in general. Care of the mother often took the form of isolation after birth and provision of natural remedies.²⁴

Interviews

Participants described a way of life in which pregnancy care was an integrated part of community life. Women delivered wherever they were when they went into labour, usually in a teepee or cabin. Community members with experience in delivery, most often women, were called upon to act as midwives.

Typically, midwives in a remote First Nations community were taught by older women. They learned by watching and helping, beginning in their teenage years. The gathering for a birth began by the midwife calling elders and some of the younger female community members to accompany her to the labour. Midwifery experience was passed from generation to generation through younger women watching and learning from their elders. The community-based midwife needed to have a calm character and was expected to come to a woman in labour with the necessary supplies: scissors, clean cloths, soap, moss, and thread for tying off the cord. She would be “prepared, willing and courageous.”

Midwives were often involved in prenatal care. They would see the pregnant woman every month for the first five months of pregnancy and subsequently every two weeks. Once the midwife determined that the fetal head felt engaged, it was assumed that the delivery was 7 to 10 days away. Pregnant women were encouraged to eat and sleep well and to get regular exercise but to refrain from overly strenuous work. An active lifestyle was believed to help with delivery and maternal and neonatal health. The recommended diet limited fatty foods to prevent too much weight gain.

Traditionally a midwife and one or two helpers attended a labouring woman and prepared a bed of boughs or moss as a temporary delivery bed. The mother would deliver where she was living: in a bush camp, a teepee, or a house. The midwife

Three Anishnabe infants in their tikinagans (traditional cradle boards)



would have the labouring woman wash herself but continue to wear a dress. Warm water was heated on a stove and everyone involved washed their hands. Moss bundles were arranged on the floor and the scissors were heat sterilized.

Women often delivered quietly and rarely in lithotomy position. Usually she was “sitting on a moss mattress ... or lying sideways.” Having the mother remain modestly covered and quiet was thought to encourage the baby not to be afraid to come out.

At birth, the newborn was dried off, wrapped in rabbit fur, and wiped clean around its mouth. The placenta was often referred to by participants as “sacred.” It was wrapped in birch bark or cloth, carefully handled, and subsequently taken out into the forest and buried or hung in a tree.

Retained placenta was often described as a life-threatening complication that was sometimes beyond the scope of the local attendant. One participant, describing a woman with a retained placenta, said “they couldn’t take it out, she was bleeding too much.” Two women attended by study participants died in

childbirth because of “trouble with the placenta.” Stillbirths were also attended, but participants found these to be very stressful: “I couldn’t deliver a baby after that.”

All participants remarked on the need for saving the umbilical cord stump when it fell off. The cord was considered very important, and when it detached it was placed in a moose hide and often attached to the baby bag so that the baby would not cry for its loss.

Breastfeeding immediately after delivery was the norm both for practical and emotional reasons; one participant noted “that is the only way you can attach to your baby, to really love your baby.” If breastfeeding was not possible, fish broth was fed to the infant from a pouch made from a jackfish stomach.

The use of a traditional cradle board, a “tikinagan” (Figure) was standard both for safety reasons and because it was thought to strengthen infant legs. Moss was used during delivery as a disposable material, but also inside the tikinagan as a natural diaper. A certain type of soft moss was picked during the summer and kept for winter use.

When asked about hospital-based care, the elders regretted the loss of traditional teaching and practices. Some felt a return to community-based deliveries was desirable, while others acknowledged the safety net that standard medical care provides for complicated pregnancies or large babies. They also felt that there were roles for the involvement of elders in hospital-based maternity care: to attend deliveries, to encourage breastfeeding and a healthy lifestyle, and to speak of the traditional teachings.

DISCUSSION

The participants in this study described maternal-child care that was community-based and informed by a set of beliefs and practices. Knowledge of these practices was handed down by oral tradition and trans-generational apprenticeships.

The general beliefs in health, active lifestyle, and diet echoed other published studies.^{13,14,20,21} Breastfeeding was identified as vital, and in the region of the study it was supplemented with fish broth when needed. Quiet demeanour during labour was also valued in other First Nations, as both a sign of stoicism and a strategy to “not scare the baby.” A theme common to our study and others was the importance of saving and honouring the umbilical cord remnant and keeping it close to the child as it grew up.^{23,28} Unique to our study was the emphasis on the sacred treatment of the placenta.

Interestingly, the use of the tikinagan (cradle board) for infant safety was often mentioned as promoting leg development, despite its association in medical circles with a predisposition to hip dysplasia.²⁹

Participants regretted trends away from traditional teachings and practices, as well as negative changes in health status and self-care. When asked about the role of hospital care, there were suggestions for the institutional incorporation of some of the traditional influences.

The research questions elicited rich descriptions and consistency between participants. Reliability of the findings was achieved with triangulation and member checking, but transferability of the findings may be limited due to the sampling methods used. Our findings may also be limited by the variation in terms used by different interpreters.

Returning childbirth to all small, remote communities without in-community midwives or physicians may never be feasible. Efforts to bridge the gap created by hospital care might require a concerted effort to integrate elders' teachings, First Nations community members, and doulas

into current hospital-based maternity care. Suggestions for change included involving elders and community members more actively in maternity care and teaching in order to support women away from their home communities. The ability to support simple traditions such as keeping the placenta and umbilical stump may require a change in practices for hospital caregivers.

The Sioux Lookout Meno Ya Win Health Centre has established and instituted a cultural orientation program for all hospital personnel. It has a robust Oji-Cree interpreter service and a developing traditional foods and medicine program.

CONCLUSION

Traditional indigenous birthing practices were once robust and highly integrated into community life. Some knowledge of traditional practices has already been lost as maternity care has become distanced from the community. We are aware of the need to learn from and honour the past while providing modern obstetrical care to our First Nations patients. This will require tertiary care and regional hospitals currently providing obstetrical care to First Nations women to consult with these communities to understand their needs and initiate appropriate programming.

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Delivering away from home: the perinatal experiences of First Nations women in northwestern Ontario

Terry O'Driscoll, MD

Len Kelly, MD

Division of Clinical Sciences,
Northern Ontario School of
Medicine, Sioux Lookout,
Ont.

Lauren Payne, MPH

Faculty of Health Sciences,
Simon Fraser University,
Burnaby, BC

Natalie St. Pierre-
Hansen, BA

Division of Clinical Sciences,
Northern Ontario School of
Medicine, Sioux Lookout,
Ont.

Helen Cromarty, RN

Sioux Lookout Meno Ya
Win Health Centre,
Sioux Lookout, Ont.

Bryanne Minty, BSc

Faculty of Medicine,
University of Manitoba,
Winnipeg, Man.

Barb Linkewich, RN

Sioux Lookout Meno Ya
Win Health Centre,
Sioux Lookout, Ont.

Correspondence to:

Dr. Len Kelly; lkelly
@univmail.cis.mcmaster.ca

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Introduction: Our objective was to understand the perinatal knowledge and experiences of First Nations women from northwestern Ontario who travel away from their remote communities to give birth.

Methods: A systematic review of MEDLINE, HealthSTAR, HAPI, Embase, AMED, PsycINFO and CINAHL was undertaken using Medical Subject Headings and keywords focusing on Canadian Aboriginal (First Nations, Metis and Inuit) prenatal education and care, and maternal health literacy. This qualitative study using semistructured interviews was conducted in a rural hospital and prenatal clinic that serves First Nations women. Thirteen women from remote communities who had travelled to Sioux Lookout, Ont., to give birth participated in the study.

Results: We identified 5 other qualitative studies that explored the birthing experiences of Aboriginal women. The studies documented a negative experience for women who travelled to access intrapartum maternity care. While in Sioux Lookout to give birth, our participants also experienced loneliness and missed their families. They were open to the idea of a culturally appropriate doula program and visits in hospital by First Nations elders, but they were less interested in access to tele-visitation with family members back in their communities. We found that our participants received most of their prenatal information from family members.

Conclusion: First Nations women who travel away from home to give birth often travel great cultural and geographic distances. Hospital-based maternity care programs for these women need to achieve a balance of clinical and cultural safety. Programs should be developed to lessen some of the negative consequences these women experience.

Introduction : Nous voulions chercher à comprendre les connaissances et les expériences périnatales des femmes des Premières nations du Nord-Ouest de l'Ontario qui vont accoucher loin de leur communauté éloignée.

Méthodes : Nous avons effectué une synthèse systématique à partir de MEDLINE, HealthSTAR, HAPI, Embase, AMED, PsycINFO et CINAHL en utilisant les sujets MeSH (*medical subject headings*) et des mots clés portant sur l'éducation prénatale des Canadiennes autochtones (Premières nations, Métisses et Inuites) et la littératie en soins et en santé de la mère. Cette étude qualitative basée sur des entrevues semi-structurées a été effectuée dans un hôpital rural avec clinique prénatale qui dessert les femmes des Premières nations. Treize femmes de communautés éloignées qui s'étaient rendues accoucher à Sioux Lookout (Ont.) ont participé à l'étude.

Résultats : Nous avons trouvé 5 autres études qualitatives explorant les expériences périnatales des femmes autochtones. Les études ont décrit une expérience négative pour les femmes qui se sont déplacées afin d'avoir accès à des soins de maternité intrapartum. Pendant qu'elles étaient à Sioux Lookout pour accoucher, nos participantes ont aussi ressenti de la solitude et leur famille leur manquait. Elles étaient ouvertes à l'idée d'un programme culturellement adapté de doula et de visites à l'hôpital par des aînées des Premières nations, mais les télévisites avec des membres de leur famille dans

leur communauté les intéressaient moins. Nous avons constaté que nos participantes ont reçu la majeure partie de leur information prénatale de membres de leur famille.

Conclusion : Les femmes des Premières nations qui vont accoucher loin de chez elles parcourent souvent de grandes distances culturelles et géographiques. Les programmes de soins de maternité dispensés à ces femmes en milieu hospitalier doivent établir un équilibre entre la sécurité clinique et la sécurité culturelle. Il faut élaborer des programmes pour atténuer certaines des expériences négatives que vivent ces femmes.

INTRODUCTION

Hospital-based maternity care has become the norm in Canada. Because maternity services require many resources, many small rural hospitals can no longer provide maternity care. These closures affect rural women and, in particular, Aboriginal women, who tend to live in remote areas.

Travel to a distant centre, referred to in the literature as "medical evacuation," is controversial for many reasons. For many Aboriginal women, the loss of the community experience of birth is seen as a cultural loss, and forced evacuation is associated with colonial practices.

The return of the birthing experience to remote Inuit communities has been very successful since 1986,¹ and excellent outcomes have been demonstrated in the 3 existing birthing centres without the capability for cesarean delivery.² The return of local birthing goes hand in hand with the development of an Aboriginal, community-based midwifery program and appropriate risk assessment and triaging. Inuit women have long been known to have low rates of shoulder dystocia and a rate of cesarean deliveries between 2% and 4%.^{2,3}

The experience of First Nations women is not as well explored as that of the Inuit.⁴ In northwestern Ontario, we see a rate of cesarean deliveries of 24% (lower than the provincial rate of 28%), the highest rate of smoking in the province and high rates of type 2 diabetes, gestational diabetes and large-for-gestational-age babies in our First Nations population.⁵

The Society of Obstetricians and Gynaecologists of Canada supports the return of the birthing experience to all remote and rural Aboriginal communities "to the extent it is practical and safe."⁶ The Sioux Lookout Meno Ya Win Health Centre offers a regional maternity program and strives to be a centre of excellence of Aboriginal health care.^{5,7} In conducting this study, we sought to understand the experiences and needs of First Nations women who have travelled for maternity services. A goal of the Sioux Lookout Meno Ya Win Health Centre is to

mitigate some of the hardships experienced by these women where possible and provide a culturally safe environment for maternity services.

METHODS

Data sources

We conducted a review of the literature using the following databases: MEDLINE (1966–2010), HealthSTAR (1966–2010), HAPI (1985–2010), Embase (1996–2010), AMED (1985–2010), PsycINFO (1987–2010) and CINAHL (1985–2010). We also searched the *Journal of Aboriginal Health* and the *Journal of Obstetrics and Gynecology*. We used the following Medical Subject Headings: "Indians, North American," "Prenatal care (education/organization and administration/utilization)," "cultural competence," "Inuits" and "Canada." We used the following keywords to better structure the search: "prenatal," "prenatal education," "First Nations," "Aboriginal," "antenatal education" and "maternal health literacy." We searched the *Journal of Aboriginal Health* and the *Journal of Obstetrics and Gynecology* independently, because they are not included in the aforementioned databases.

Participants

In the summer of 2010, a convenience sample of First Nations women from remote communities who had travelled to the Sioux Lookout Meno Ya Win Health Centre to give birth (at 38 weeks) or who had just delivered at the centre were asked to participate in the study. The centre provides health care services in northwestern Ontario for a population of 30 000, over 80% of which is First Nations. The centre's maternity program has around 320 deliveries annually. Travel is federally funded for family-member escorts to accompany the pregnant woman to Sioux Lookout, Ont., only if there are medical complications or if the expectant mother is under 18 years of age.

Data gathering

Semistructured questions were designed by First Nations and non-First Nations researchers. The audiotaped interviews were undertaken in English, with assistance from Oji-Cree interpreters if needed. The 3 interviewers were female and obtained written consent for the interviews, which took place either on the maternity floor or in the prenatal clinic. Near the end of the interviews, we included several specific questions concerning the development of the maternity and prenatal program at the Sioux Lookout Meno Ya Win Health Centre.

Data analysis

Three researchers coded the interviews and analyzed them for common themes using immersion and crystallization techniques.

Ethics approval

The centre's advisor on First Nations health care participated in the study's design and approved the article's final draft and submission for publication. This study received ethics approval from the centre's research review committee.

RESULTS

Literature review

We retrieved 22 articles and reports that discussed prenatal or maternal care among rural or remote indigenous populations, most of which focused on Canadian Aboriginal populations in the far north. Included were 5 qualitative research studies exploring the birthing experiences of Aboriginal women.

A 1993 study in Moose Factory, Ont., explored "dissatisfaction with medical evacuation for child-birth" as portrayed by avoidance to attend prenatal clinics, refusal to leave the community or an unwilling acceptance of a medial evacuation.⁸ The authors found that one of the greatest challenges for pregnant woman was leaving behind other young children. Participants experienced loneliness and boredom in hospital and suggested improvement, which included funding for transportation for the partners of all women who travelled to give birth and apartment-type accommodations. After a discussion of the risk of delivering in their community, most participants expressed a preference for hospital-based deliveries.

In 2000, Chamberlain and Barclay interviewed 20 postpartum Inuit mothers about the psychosocial costs of delivering away from their community.⁹ These participants were also preoccupied with the family they left behind. Participants documented the costs associated with a distant delivery, which included long-distance phone calls, babysitters and airfare for their partners' travel. They also noted difficulty reintegrating mother and newborn into the community after their (often) 3-week absence.

In a series of West Coast studies from 2005 to 2010 (including a participatory mixed-method study conducted with members of the West Coast Aboriginal community of Heiltsuk), Kornelson and colleagues examined the effects of closures of rural maternity services on rural and First Nations women.¹⁰⁻¹² Although some participants had positive experiences of medical care and accommodations, they also noted social disruption and loneliness. They described how stressful it was to leave their other children behind and the financial costs incurred. The authors spoke of the "cultural and geographic context of the birth experience": participants noted the importance of support from extended family and community and their historic and emotional ties to the land where they live. Participants pointed out the need for adequate social supports for those who travelled for deliveries.

The Sioux Lookout Meno Ya Win Health Centre seeks to bring culturally competent care closer to home through its regional location, traditional programming and 24-hour interpreting services.⁷ The studies described above generally document the experiences of parturient women who travelled to distant centres as negative. Our qualitative study sought to understand whether the development of culturally competent programming could mitigate any of these effects.

Delivering away from home

Participant characteristics

About half of the 13 women who participated in our study were primigravida. The participants' ages ranged from 17 to 34 years.

Experience in Sioux Lookout

Not surprisingly, participants were lonely and missed the families they had left behind: "It's kind of lonely when you have nobody around ... nobody to talk to because I hardly know people around here."

"I always need a person to support me during the pregnancy, and leaving my partner behind ... when I leave him behind, it feels different." "The hardest part is not having my (3-year-old) baby here."

Several participants directly mentioned the absence of funding for family escorts in the region: "Another thing that sucks when you come out here is that they don't allow escorts." "My boyfriend took it really hard, he really wanted to be here ... if you're over 18, you don't get an escort, you just come out here by yourself."

Many participants expressed having fear of pain during labour: "You know you are getting close to the date, and you're feeling more nervous or more scared." "I heard 'it hurts ... you're going to be in pain.' ... I was scared and actually hoping for a c-section." "My cousins and friends told me when the baby is coming out, that's when the pain feels worse, so when it happened to me I just decided to keep on pushing."

They usually recounted a positive experience at the hospital: "I just feel more secure ... I feel safe."

Prenatal knowledge

Most participants learned about how to care for themselves during pregnancy from their immediate and extended family, rather than from nurses or physicians. They learned that a healthy diet, exercise and avoiding alcohol and drugs were important: "I had to cut out drinking, that was one of my big accomplishments." "There's a really big pill problem [oxycodone] ... with pregnant ladies, most of them can't stop ... so I didn't quit for me, I quit for my baby." "They always tell me to eat right and don't go crazy on junk food." "My mom suggested being active during pregnancy ... we usually walk most places, so I get quite a bit of exercise like that."

Breastfeeding was commonly encouraged by family and friends: "My boyfriend's mom wouldn't let me buy formula, because she said that babies don't get sick as much and it would help my body get back to normal." "My mom told me if you breastfeed the baby will grow faster."

Traditional teachings were not something many participants acknowledged receiving. It was attested to by only one participant. However, several participants did know of the traditional importance of keeping the detached stump of the umbilical cord: "The elders take a piece, so the child doesn't have that feeling that something is missing." "Once it comes off the baby you wrap it in leather and keep it with the baby."

Almost all of the participants planned on using the traditional cradleboard, the *tiKinagan*: babies are swaddled to the board in a cocooning fashion. "It's better for the baby because the baby feels secure and sleeps longer." "Like when they are inside you, once they come out they still want to be secure." "It helped my boy a lot with him calming down."

Doulas, elder visits and tele-visitation

We asked directed questions about several areas in which the hospital was exploring program development.

Most participants answered positively about the possibility of having First Nations doulas help them through their labour: "That would be good with your first baby as you don't know what you're doing."

They were also generally in favour of having the option of having First Nations elders visit them while they were in Sioux Lookout and in hospital: "I think the elders are important in the community ... it is important that they are able to teach their kids." "The old ways are kind of interesting; it's supposed to be our heritage." "You could balance the old with the new."

A proposal for establishing tele-visitation with family members back home met with divided responses. Those not in favour expressed a general discomfort with the idea mainly because of shyness: "I tried that with my last child. It was embarrassing seeing someone on TV and then they're looking at me ... my kids were all too shy."

DISCUSSION

The other studies we reviewed found parturient women who travelled for delivery struggled with that model of care. Our patients expressed similar feelings. Although women in our study were generally positive about their medical care, they commonly expressed loneliness being away from their family and community members. This finding is in keeping with the social and emotional disruption documented by Kornelson and colleagues in British Columbia.¹⁰⁻¹² The absence of a funded escort program for mothers over the age of 18 was consistently identified as a difficulty. The Society of Obstetricians and Gynaecologists recommends integrating Aboriginal values into the development of programs.⁶

Participants did not report any difficulty in reintegrating into their communities on their return, as Chamberlain and Barclay found in their far north study.⁹ The participants in our study generally noted

positive community support for their pregnancies and motherhood.

Lines of questioning about ideas for improvement were not productive. It is unclear whether this was because there was no glaring change identified or the participants felt uncomfortable expressing ideas for improvement.

Because the Sioux Lookout Meno Ya Win Health Centre looks at all fruitful integration of traditional ways into patient care, we asked participants about having a doula program developed. This generally met with positive responses, as did having an elder drop by occasionally. These are program areas now being explored by the centre.

Questions about providing a tele-visitation program for expectant mothers to contact family members back home revealed a negative attitude toward tele-visitation. Shyness was stated as the main concern. This was surprising to some of the researchers, who generally had more experience and comfort with virtual communication in their own professional and personal lives. This attitude is, however, in keeping with regional cultural norms as best we could discern. This finding may change in coming years when virtual communication becomes more common in our region, especially in remote communities.

Limitations

One of the limitations of this study was the difficulty we often encountered in getting participants to fully engage in the interview process. Despite the offer of interpreters, the young women we spoke to were reticent in sharing their feelings. The 3 interviewers were themselves young women, one of whom brought along her own newborn son. None of the interviewers were First Nations, and that may have contributed to awkward communications at times.

Because we used a convenience sampling of 13 women, our sample may not be representative of the population as a whole. As with all qualitative studies, our ability to identify all of the issues participants felt, but did not want to disclose, was a limiting factor. We did reach saturation of information and themes with our present sample, even though it was small. Our findings are not necessarily applicable to other First Nations regions in Canada. Further study to understand attitudes toward tele-visitation may be prudent.

CONCLUSION

Delivering away from home for women from remote First Nations communities places emotional hardship on the mother and her family. Personnel at the medical facilities caring for these patients should understand the perinatal knowledge and emotional needs of these patients and develop culturally appropriate responses. Some of the negative aspects of this experience may be lessened by successful program innovations, which is the intention at our centre. At the policy level, there is a need to understand the implications of the absence of funding for partners or escorts to be present for birthing.

Competing interests: None declared.

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Midwifery Care

Kreiner M. Delivering Diversity: Newly Regulated Midwifery Returns to Manitoba, Canada, One Community at a Time. *Journal of Midwifery & Women's Health* 2009;54:e1-e10.

Kreiner documents strategies for implementing regulated midwifery and addressing diversity issues. She emphasizes the need for community building approaches and consultations in order to achieve sustainable and culturally appropriate solutions.

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This document outlines key issues around Aboriginal women's reproductive health, midwifery and birthing centres. Several successful programs are discussed.

Recommendations for improving reproductive health outcomes and supporting Aboriginal midwifery practices are listed.

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Delivering Diversity: Newly Regulated Midwifery Returns to Manitoba, Canada, One Community at A Time

Meta Kreiner, MSc

Through its publicly funded health care system, Canada is committed to offering accessible, quality maternity health services to all its citizens, yet this remains a challenge in its First Nations, rural and immigrant communities. With the implementation of midwifery as a self-regulating health profession in Manitoba, Canada, in 2000, initiatives were incorporated into the structure of the profession to try to address this issue. This qualitative investigation documents and explores these initiatives through a case study combining semistructured interviews and documentary sources. The innovations discussed include the development of an Aboriginal midwifery degree program, the supports put in place to assist rural midwifery practices, and the efforts to increase ethnic diversity and cultural competence within the midwifery profession. What unites these efforts is a community building approach which attempts to strengthen communities through local midwifery services and midwives drawn from community members. *J Midwifery Womens Health* 2009;54:e1-e10 © 2009 by the American College of Nurse-Midwives.

keywords: midwifery, history, Canada, health services accessibility, indigenous health services, rural health services

INTRODUCTION

As midwifery became legalized across Canada in the 1990s, many advocates recommended that the regulation and public funding of midwifery be based on the midwife's ability to help address current national challenges within the public maternity care system.¹⁻⁴ One primary national challenge was the identified need to end the practice of evacuating all pregnant women out of First Nations communities for childbirth, and the desire of many community members to include the revitalization of Aboriginal midwifery traditions with the return of childbirth to these communities. The term Aboriginal includes all Indian (First Nations), Métis, and Inuit peoples, and all self-identifying individuals regardless of their legal status. First Nations community is the preferred term for Indian reserves. Aboriginal midwifery refers to midwifery practice which blends traditional Aboriginal teachings and ceremonies with modern midwifery care. It means that Aboriginal midwives attempt to offer culturally relevant, community-based care to Aboriginal women. The specific practices and approaches used are as diverse as the number of Aboriginal nations in Canada.⁵⁻⁸

Another central concern was the decline in the number of rural communities offering maternity care services at the same time that there was increasing recognition both of the costs to rural women of traveling long distances for childbirth and the importance of quality health services

for sustainable rural communities.^{9,10} Finally, advocates of regulated midwifery pointed out the appropriateness of the midwifery model of care for addressing socioeconomic risk factors in pregnancy and childbirth, and that access to publicly funded midwifery care could potentially improve the birth experiences and birth outcomes of women from socioeconomically disadvantaged populations.¹⁻⁴ In the context of this article, "regulated" refers to legalization through the passage of midwifery legislation and the other government or government-sanctioned policies that control and define the profession such as those of a midwifery college, a provincial funding body, or a university teaching midwifery.

Although nurse midwives have a long history of serving socioeconomically disadvantaged populations internationally, the movement to regulate midwifery in Canada primarily came out of the homebirth movement, which has largely been made up of white, urban, middle class, well educated women and their families.¹¹⁻¹⁴ After regulation, most midwives and their clients continued to come from this demographic group, and there was little impact on any of the aforementioned challenges.^{5,14} As the fifth province to regulate midwifery in Canada, the women who implemented midwifery in Manitoba saw what had occurred across the country. They recognized that Manitoba could not afford to lose this opportunity, and attempted to develop a midwifery practice that could and would focus on the maternity care needs of Aboriginal, rural, and socioeconomically disadvantaged women.¹⁵

The objective of this article is to document and review the strategies which were incorporated into the implementation of regulated midwifery in Manitoba to try to address these diversity issues. The article is based on data

Address correspondence to Meta Kreiner, MSc. E-mail: mjkreiner@gmail.com

from a thesis research project conducted by the author which was the first to extensively study midwifery implementation in Manitoba. The strategies are discussed separately in the areas of: 1) revitalizing Aboriginal midwifery, 2) serving rural communities, and 3) serving a socioeconomically diverse client population. This is done to highlight the unique initiatives developed specifically for these communities for practitioners serving similar populations. What unites these efforts is a community building approach that attempts to strengthen communities through local midwifery services and midwives drawn from community members. The article concludes with a discussion about how these strategies came together to explicate the underlying community building processes which aided their development.

This article adds to the growing international literature documenting the importance of using community building approaches when addressing the maternity care needs of disadvantaged populations. When successful, these programs attempt to offer maternity care which is culturally sensitive, locally relevant, and accessible, whether by enhancing the existing care practices and motivations of traditional birth attendants, pregnant women, families, and communities to increase access to basic life-saving measures,^{16,17} or developing the cultural competence of professional services through cultural responsiveness—incorporating the client's values beliefs, lifeways, and practices into mutually acceptable care.¹⁸ It may also take the form of incorporating community members into medical practices who can play a bridging role, offering language translation and cultural/religious services to clients.¹⁹

Another developing trend is an effort to draw health professionals directly from the populations being served. It has long been recognized that the physical, emotional, and cultural well being of socioeconomically disadvantaged clients are positively affected when they are cared for by health professionals drawn from their own communities, yet the number of minority practitioners remains low around the globe.^{20–22} In Australia, successful local programs for recruiting and supporting indigenous and rural medical, nursing, and midwifery students will now be leading a national effort to achieve a greater number of indigenous people in the medical workforce. The schools that have already established such programs illustrate the community building approach necessary for success, which includes working with local communities to enhance educational readiness from alternative university entry schemes to working with middle and high schools. Partnerships with local rural and indigenous community groups are also built to assist in developing the social, cultural, and financial support needed to help students complete their programs. These programs then

graduate physicians, nurses, and midwives who can work in the areas of indigenous health in both urban and rural locations. These efforts are expected to not only better meet the health needs of indigenous clients, but also increase the educational opportunities, economic base, and self-sufficiency of indigenous communities.^{20,21}

Increasing the diversity of health professionals also benefits the health professions themselves. Health practitioners from diverse backgrounds can bring certain strengths and sensitivities garnered from the barriers they have had to overcome and the ability to draw on other midwifery and healing traditions to offer individualized ethnic-specific care.²² As this article will demonstrate, midwifery in Manitoba is at the forefront of this international movement to increase the diversity of practicing health professionals.

METHODS

Ethical approval for the study was sought and received from the University of Manitoba Health Research Ethics Board, and informed consent was obtained from all participants before the onset of their involvement. A qualitative, embedded case study design was employed in this study. The purpose of qualitative research is to generate knowledge of social events and processes by exploring and documenting these processes, and by understanding what they mean to the people involved.²³ A case study is an investigation of a specific event or intervention within its real-life context. The researcher collects detailed, in-depth information using multiple sources of data.²⁴ Because of its less structured nature, case studies can combine the more factual aspects of documentary data with open-ended interview data used to access the thoughts and motivations of participants that informed their actions.²⁵ An embedded case study identifies subunits within the larger case that provide different perspectives on the event. The products of case studies are often a detailed description of the case (the event or intervention) and the real-life context in which it occurred.²⁴

In this study, the broader case is the implementation of regulated midwifery in Manitoba. The specific interventions which are the focus of this article are the strategies employed by Manitoba midwives to improve maternity care for Aboriginal, rural, and socioeconomically disadvantaged women. The subunits identified were five stakeholder groups: 1) midwives; 2) women as maternity care consumers; 3) other health care professionals; 4) government administrators; and 5) midwifery implementation and regulatory bodies.^{13–15,26}

The primary data for this study came from documentary and interview sources. Primary documents from midwifery implementation in Manitoba collected include: policy reports; submissions to policy-making committees; newsletters from consumer, midwifery, and medical organizations; government press releases; legislative proceedings; newspaper articles; minutes of the Manitoba Midwifery Imple-

Meta Kreiner, MSc, earned her degree from the University of Manitoba, Winnipeg, Manitoba, and works as a freelance health researcher.

mentation Council meetings; and the College of Midwives of Manitoba reports and practice standards.

Documentary data were combined with data from in-depth interviews with 26 participants who were involved with midwifery implementation. Participants were selected through stratified purposeful sampling. Purposeful sampling means that participants were selected based on the information richness they can offer the project (i.e., the length or depth of their experience with the central phenomenon under study) or the particular role that they played. Stratified purposeful sampling involves identifying groups and subgroups among the individuals involved in the case, and contacting possible participants to represent these categories. Stratified purposeful sampling was used because it allows the researcher to look for themes that emerge even in the presence of many differences between participants.²³ Individuals who met the sampling criteria were identified from the primary documents and contacted about participating in the study through an introductory letter (Table 1 provides a summary of participants interviewed).

Open-ended interviews were conducted using the interview guide approach, which allows the discussion topics to be identified in advance. The interview guide approach makes data collection generally systematic for each respondent, while still allowing the interviews to retain a fairly conversational style.²⁷ Twenty-three of the interviews occurred in person, and three were done over the phone because of geographic distance. Written notes were typed and interview recordings were transcribed verbatim. All of the participants were sent their interview transcripts and/or notes to review and edit to improve accuracy and confidentiality.

The data for this project were analyzed using content analysis. Analysis began with a review of the Canadian midwifery literature and information on Manitoba ma-

ternity services. Content analysis of primary case study data involves aggregating the data into codes or categories, clustering these codes into broader themes, and then describing these themes in the research product.²⁷ All primary data for this project were copied into an electronic format so that coding and categorizing could be computerized. Primary documents were coded first to create a chronology of events unaffected by recall bias. This was then compared with data derived from interviews, which offered insight into the motivations behind actions, reflections on the results of the strategies used, and plans for future revisions of those strategies. The codes were continuously modified to integrate new data, and there was an iterative triangulation of the data from the literature, primary documents, and interviews. The process of triangulation involves corroborating evidence from different sources to shed light on an emerging theme.²⁷ The codes were then clustered to form themes, and these themes then became the organizational framework for the results.

BACKGROUND

Manitoba is a Midwestern Canadian province with a population of just more than 1 million people.²⁸ Health services are publicly funded provincially and administered by 11 Regional Health Authorities.²⁹ Almost 800,000 residents live in the capital city, Winnipeg, while the rest are scattered in small towns and First Nations communities.²⁸ Around 150,000 residents report an Aboriginal identity, while just slightly less (135,000) are immigrants to Canada.^{30,31} The largest non-European immigrant populations are from the Philippines, China, and India.³² About 18% of households in the province are considered low-income households.³⁴ On average, around 13,500 births occur annually in Manitoba.³³

Table 1. Summary of Participants' Stakeholder Group and Subgroup Affiliations, N = 26.

Stakeholder Group	No. of Participants ^a	Subgroups Represented Within Each Stakeholder Group
Registered Midwives	8	Nurse Midwives Association of Manitoba; Traditional Midwives Collective; Manitoba Association of Midwives; midwives practicing in rural/northern Regional Health Authorities; midwives practicing in the Winnipeg Regional Health Authority
Women as Maternity Care Consumers	6	Women who participated in midwifery implementation on behalf of consumers from rural, northern, immigrant and Aboriginal communities, and midwifery consumer groups
Health Care Professionals	6	College of Physicians and Surgeons of Manitoba; College of Registered Nurses of Manitoba; practicing nurses involved with midwifery implementation; practicing obstetricians/gynecologists and general practitioners involved with midwifery implementation; staff of community clinics with midwifery practices
Government Administrators	5	Manitoba Health; administrators from Winnipeg, rural, and northern Regional Health Authorities
Midwifery Implementation and Professional Bodies	15	Working Group on Midwifery; Midwifery Implementation Council; College of Midwives of Manitoba

^aNumbers add to more than 26 because most participants in the "midwifery and implementation professional bodies" stakeholder group" were also a member of one of the other four stakeholder groups. Some participants also represented more than one subgroup within their stakeholder group.

Table 2. Chronology of Midwifery Regulation in Manitoba

Date	Event
1988	The first Manitoba government report recommends the regulation of midwifery services
1994	The Manitoba Health Minister announces midwifery will be regulated as an autonomous profession, and will become an insured service; the Manitoba government establishes the Midwifery Implementation Council to implement regulated midwifery services in the province
1997	<i>The Midwifery Act</i> is passed unanimously by the Manitoba Legislative Assembly; the Aboriginal Standing Committee immediately begins meeting, and renames itself <i>Kagike Danikobidan</i>
1998	The assessment and upgrading for midwives starts in Winnipeg; it runs until 2001
2000	<i>The Midwifery Act</i> is proclaimed and midwifery becomes a self-regulated profession in Manitoba; the <i>Midwifery Regulation</i> comes into force; the first 11 midwives register with College of Midwives of Manitoba—by the end of the year, there are 18 midwives registered; the priority populations policy immediately comes into effect; provincially-funded midwifery practices are started in northern, rural, and inner city communities
2003	The Prior Learning and Experience Assessment (PLEA) process is run for the first time to assess and register new midwives
2004	The Aboriginal Midwifery Education Program (AMEP) is approved for further development
2006	The Aboriginal Midwifery Education Program, named <i>Kanáci Otinawawasowin</i> , begins accepting students; there are more than 30 midwives registered and practicing in Manitoba

About one quarter of those births are to Aboriginal women, who often face barriers to care secondary to geographic location, cultural differences, and disproportionate rates of poverty.¹⁵ Since the 1980s, almost all pregnant women living in First Nations communities have been evacuated as many as 6 weeks before their due dates to wait in often unfamiliar towns and cities for birth. These evacuations create many hardships for the women, who must wait alone and then give birth without the support of family in an unknown city. They usually wait in hostels with ill individuals transferred for an array of medical procedures, and will then be cared for by providers largely unfamiliar with their culture and living circumstances. Many worry about their older children, who are often left in unstable childcare arrangements. However, returning childbirth to these communities is about more than just reforming the maternity care that women receive. Through the revitalization of Aboriginal midwifery and the return of childbirth to First Nations communities, it is hoped that it will also be possible to begin reforging the generational links which have been severed by the past removal of Aboriginal children into residential schools and foster care, the suppression of language and culture, and the removal of women for childbirth.^{6,7,11}

This movement towards centralizing childbirth has also been put in place for residents in rural parts of the province. Between 1996 and 1997 (the year midwifery legislation was passed in Manitoba), 56% of all births among rural residents took place in only two locations. This centralization is largely related to a shortage of rural general practitioners offering maternity services.³⁴ Traveling long distances for prenatal care, in early labor, and with a newborn after birth can be very stressful—especially during Manitoba's long winters. It means time away from family and friends during a critical period and added costs for travel and partner accommodations.¹⁰ Returning childbirth to rural communities was a primary reason behind the implementation of midwifery in Manitoba.⁴

Midwifery was also implemented because the midwifery model focuses on offering extra support to clients such as adolescents, immigrant/refugee women, and low-income women who have social risk factors.⁴ Midwives provide individualized care that addresses a client's social, economic, and cultural needs and values. The profession's commitment to informed choice, woman-centered care, emotional support, and education were considered the right match to meet the needs of these populations.^{2,5} However, consultations with immigrant/refugee women about their vision of culturally appropriate maternity care have indicated that often the attribute they most look for in a practitioner is someone who speaks their first language.^{3,5,35}

Based largely on these arguments about the benefits regulated midwifery could have for Manitoba, government reports began recommending the legalization of midwifery in 1988, and the Manitoba government followed up with the establishment of the Midwifery Implementation Council in 1994.^{4,15} The purpose of the Midwifery Implementation Council was to legislate midwifery and register the first midwives. The Midwifery Act was passed in 1997, and registered midwives began practicing in 2000. Midwives are autonomous, primary health care providers who are self-regulated through the College of Midwives of Manitoba.³⁶ There are currently more than 30 midwives working in publicly funded, salaried positions in 6 of the 11 health regions in Manitoba. About half of the midwives work in the capital city, Winnipeg, in four community clinics. Midwives in the rural and northern Regional Health Authorities practice in community clinics and stand-alone practices.³⁷ From 2001 to 2006, midwives attended about 5% of all births in Manitoba (Table 2).³⁸

RESULTS

Three strategies were implemented in Manitoba to help create a diverse midwifery profession with the flexibility

and necessary supports to offer customized services to women from a range of backgrounds: 1) revitalizing Aboriginal midwifery, 2) serving rural communities, and 3) serving a socioeconomically diverse client population.

Strategies to revitalize Aboriginal midwifery included creating a standing committee on Aboriginal issues at the College of Midwives of Manitoba and developing an Aboriginal midwifery degree program. Supports to assist the development of rural practices included expanding the scope of practice of regulated midwives, targeting funding for rural regions, assisting midwives with integration into local health services, and new recruitment strategies. Finally, efforts to increase the ethnic diversity and cultural competence within midwifery were facilitated through changes to the registration requirements and the attempt to improve access to midwifery care by prioritizing certain populations and urban neighborhoods.

The Revitalization of Aboriginal Midwifery

A community building approach was taken in the formation of the midwifery professional structure, and women from across the province were consulted extensively. Particular attention was paid to meeting with Aboriginal women.³⁹ During these consultations, many Aboriginal women reiterated their concerns about the policy of evacuating all pregnant women to urban centers for childbirth. Instead, they described returning childbirth to their communities through the creation of a new midwifery profession which could combine some of the healing aspects of traditional Aboriginal midwifery taught by community elders, with the clinical skills of Western care. They spoke of the need for a community-based education program to make this a reality.⁴⁰

Following these extensive consultations with women of Aboriginal descent, there was a commitment to ensure this would produce tangible results. The *Standing Committee on Issues Related to Midwifery Care for Aboriginal Women* was made a requirement for the College of Midwives of Manitoba in *The Midwifery Act* to ensure that issues in midwifery for Aboriginal women would continue to be heard and shape the profession.⁴¹ The Aboriginal Standing Committee began meeting in 1997, and renamed itself *Kagike Danikobidan*, translated as "Always making grandparents." From the very beginning, an Aboriginal midwifery education program for northern Manitoba became a central issue for *Kagike Danikobidan*.⁴² Without such a program it quickly became clear that there would be no impact on the number of women being evacuated for childbirth. This is because initially there were only 2 to 3 midwives practicing in the north, located in two towns.⁴³ Most women living in First Nations communities receive their prenatal care in federal nursing stations and do not have access to these midwives.¹¹ Many participants spoke of their disappoint-

ment and frustration that midwifery services were not immediately offered in First Nations communities:

"One of the big issues in Manitoba that was presented from the very beginning was services for Aboriginal and Northern residents. That was one of the issues that actually moved midwifery forward. But then the attention to that didn't follow [. . .]; there is minimal midwifery presence in any of the First Nations communities. That is a very frustrating issue, because that was a huge part of the intent of the initial legislation. It was to have that service available to Aboriginal women. And all of the consultations that they did with these women and then no follow-up [. . .]"

However, the commitment to creating an Aboriginal midwifery education program remained, and in 2004, federal and provincial funding to develop an Aboriginal bachelor of midwifery program at the University College of the North in Manitoba was received (to date, all five Canadian midwifery education programs developed within regulated midwifery are direct entry baccalaureate degree programs).^{44,45} It was developed as a joint effort between *Kagike Danikobidan*, the College of Midwives of Manitoba, all levels of government, and First Nations communities. The program started in September 2006. Named *Kanáci Otinawáwasowin*, which means "sacred midwifery" in Cree, this program is designed to include Aboriginal ways of knowing and learning in all aspects of teaching and practice. It is centered in both a northern town and a First Nations community. The program also has links to the Canadian territories of Nunavut and the Northwest Territories, and is part of their efforts to return childbirth to their Inuit communities which presently evacuate the majority of pregnant women for childbirth.⁴⁵⁻⁴⁷ Although the first graduates are still a few years away, the existence of this program has already increased access to midwifery services in the north because more midwives were hired to both teach and practice in the northern Regional Health Authorities. The number of midwives practicing has doubled, and the first midwifery practice in a First Nations community was opened.³⁷

The *Kanáci Otinawáwasowin* program is also the first Aboriginal midwifery education program in Canada to prepare graduates who can register with their provincial regulatory body and practice off-reserve.^{6,47} The fact that graduates of this program will be able to register with the College of Midwives of Manitoba is significant, because it adds to the legitimacy of Aboriginal midwifery as a viable health profession. More importantly, it also expands who will be able to access Aboriginal midwifery care to include individuals of Aboriginal descent who could benefit from it, but who do not live in First Nations communities. This unique program offers hope that a sustainable and culturally appropriate solution may fi-

nally be moving into place in Manitoba to return child-birth to all Aboriginal communities.

Midwifery in Rural Communities

At the same time that there was an effort to make the midwifery profession responsive to the needs of Aboriginal communities, there was also a focus on strengthening rural communities. Compared to other Canadian provinces, many changes were made to the midwifery standards of practice to facilitate midwives practicing in rural communities. These included expanding the scope of practice to include a greater range of well-woman care services, more extensive emergency skills, greater prescriptive privileges, and allowing midwives to practice at greater distances from tertiary hospitals. The profession was also set up to facilitate midwives working in collegial teams with other health care professionals in consideration of small communities which could only support one midwife.^{8,43,48}

Once the first midwives were registered in the province, Manitoba Health targeted a portion of the midwifery funding available for rural Regional Health Authorities, and soon three of the seven rural health regions in Manitoba had thriving midwifery practices.⁴³ As Regional Health Authority employees, participants noted that these practices were not left on their own to develop, but had the assistance of Regional Health Authority administrators to assist with advertising, community outreach, and integration into what were sometimes less than welcoming medical communities. As regional employees, the midwives also have geographic catchment areas which allows them to continue doing home visits while recognizing the greater travel time involved in rural practice.^{9,43}

However, because the midwives cannot take clients from the four rural health regions that do not have midwifery services, this leaves many rural women without any access to midwifery care:

"What I don't understand is how a service can be described as a publicly funded service, but currently, if you're in half of the Regional Health Authority in Manitoba, you will not have access to a midwife. It is a contradiction."

According to participants, existing rural midwifery positions sit unfilled, and midwifery appears to be facing the same rural provider shortages as medicine when conventional recruitment strategies are used. Again, the College of Midwives of Manitoba is taking a community building approach to address this problem through the Midwifery Education Programs Approval process. Midwifery Education Programs Approval allows the College to approve self-study or distance education programs combined with community-based preceptorships for eligibility to register.⁴⁷ Participants noted that this means

students from rural areas will not have to leave their communities for midwifery education and then (hopefully) return. However, Midwifery Education Programs Approval is still in the early stages of implementation, and it is not yet clear what form the education programs approved through it will take, nor how many rural students will be able to enroll in and successfully complete these programs.

Serving a Diverse Client Population

When the Midwifery Implementation Council was developing the regulatory framework for the midwifery profession, they also knew one of the priorities for the service was going to be caring for clients who are inadequately served by the existing maternity care system because of their socioeconomic status, age, language, or cultural differences.⁴ It was felt that a diverse midwifery profession which valued cultural competence and cultural proficiency and which was easily accessible to women would be best prepared to meet this goal.^{19,39}

Creating a Diverse Midwifery Profession

To incorporate midwives from a wide range of educational and cultural backgrounds, the initial assessment and registration used a competency-based process which could accept candidates whether their education and experience had been in direct entry midwifery, nurse midwifery, or another related health discipline. It did not require local or recent practice experience for women who had only practiced in other countries before immigrating to Canada. The Midwifery Implementation Council had a communications testing and language upgrading program developed solely for midwifery, the *English for Midwives* program.³⁹

Partly because of these initiatives, 11 of the first 26 practicing midwives were immigrants to Canada.¹⁴ Further, the Prior Learning and Experience Assessment (PLEA) was started in 2003 as a continuous means of assessing the knowledge and skills of foreign educated midwives who wish to register in Manitoba.⁴⁹ Many participants stated that this has meant that more immigrant women are able to get midwifery care in their first language and discussed the benefits of a more diverse group of midwives:

"I personally feel that diversity in the midwives' backgrounds is really a strength in our group. I think that because they come from different backgrounds, different countries, different perspectives and training, that they all have something very unique to offer [. . .] and if we have a client who is looking for a particular style we can try and match them up."

However, despite the intentions of these efforts, only 2 of the first 11 immigrant midwives had trained in a

non-European country. Thus, the changes to the initial assessment and registration appears to have successfully increased access to the profession for European-trained midwives, but was less successful with candidates from Asia, Africa, or South America. Many of the unsuccessful non-European immigrant candidates had not practiced for many years (most European-trained midwives were practicing within nursing before regulation). They knew that they needed some sort of refresher course in midwifery, but no organized system of doing this was available.^{39,42} Many participants discussed the benefits of developing a more extensive midwifery upgrading and refresher program for women who had trained in significantly different models of midwifery in other countries and who had not practiced for some time.³⁹ At the time that this article was written, the creation of such a program is anticipated through the Midwifery Education Programs Approval process, but planning and development have not yet begun.³⁸

Improving Access to Midwifery Services

To improve access to midwifery services, each midwifery practice was required to work toward having 50% of their clients from identified priority populations. These populations include single women, adolescent women, newcomers to Canada, Aboriginal women, socially isolated women, low-income women, and other at-risk women. This policy was put in place to promote outreach efforts and referrals.⁵⁰ This policy also led the Winnipeg Regional Health Authority to locate the midwives' practices in community clinics in lower income neighborhoods which are commonly used by pregnant women from the identified priority groups.³⁴ The midwifery practices in Manitoba have had no difficulties meeting the requirements of this policy,³⁸ and most participants felt that the midwifery model of care was working to give women extra support.

The priority populations policy also influences any further expansion of the service, and participants talked about wanting to implement new ways of offering care:

"We don't have enough midwives from various cultural groups. You really need a couple and they need to be working together to be able to actually offer service, say in a woman's language. I think too, now that there has been some experience, there needs to be a look at what are some of the other things we can do, a look at different models of delivering care. Like at [Clinic 1] midwives have started coming to Teen Clinic and see teens who drop in who are pregnant. We've been looking at things like group appointments, some of the other more creative models of care. Because for women, if you are socially isolated, to have prenatal group appointments is a really good way to build support groups, for instance."

In this vein, there has been recent community advocacy for a midwifery birth center in Winnipeg which would offer group prenatal appointments, prenatal and postpartum education, and health interpreter/doula services (doulas who also offer language and cultural interpretation).³⁸

DISCUSSION

In many ways, the first few years of midwifery in Manitoba have the appearance of a demonstration project: lofty goals were espoused about attempting to resolve formidable maternity care challenges, and a number of innovative policies and supports were put in place, yet the small number of registered midwives practicing meant they could only serve a fraction of the clients necessary to address these issues in a substantive way. However, having these goals clearly stated did motivate the profession to exhibit their ability to address the problems identified. While the issues discussed in this article may seem somewhat disparate, they are linked by the community building approach which was taken to address them.

This community building approach involved first, recognizing the central role quality maternity services can play in the sustainability and cohesion of nonurban and minority communities. Towards this end, midwifery services were targeted for First Nations, rural and inner city communities in the province. Second, community consultations were used to assist with the development of culturally appropriate and accessible midwifery services. Following these consultations, a standing committee on Aboriginal issues at the College of Midwives of Manitoba was created to incorporate Aboriginal perspectives in the development of the profession. The scope of practice and model of care were also modified to facilitate rural practice. Third, there was an attempt to draw midwives from the communities being served so that women could receive care from midwives who had a closer understanding of their lived experiences, and these midwives could assist the profession to remain responsive to the changing needs of these communities. Consequently, one of the first baccalaureate degrees in midwifery in the world which incorporates traditional Aboriginal midwifery skills was developed and initiated in the province. The College of Midwives of Manitoba has also developed assessment processes that facilitate the registration of midwives trained outside Canada, especially midwives who can offer care in more than one language. Finally, still in implementation is a program which will also allow rural students to remain in their communities while training to be a midwife, the first of its kind in Canada.

Thus, the small group of midwives practicing in Manitoba has upheld and built on the long history within midwifery of trying to strengthen the unique communi-

ties that birthing women come from. At the same time, they have recognized all women as a single community worthy of quality care irrespective of their cultural, socioeconomic, or geographic identities.

CONCLUSION

Other settings may find the work which occurred in Manitoba applicable in two ways. First, the specific strategies developed in Manitoba may be of interest to other maternity service providers serving similar populations. The initiatives that are already having a recognizable impact, such as the College of Midwives of Manitoba Aboriginal standing committee, the priority populations policy, the supports given to rural practices, and the integration into midwifery of culture interpretation and bilingual services may be of special interest. Second, other localities may be able to recreate the community building approach which was used to develop other new and innovative strategies adapted to their own unique circumstances. Such initiatives could improve the quality of services offered to women, increase the sustainability and strength of their communities, and enhance the ethnic diversity and cultural competence of the midwifery profession.

Finally, the midwifery profession in Manitoba has also developed new strategies for increasing the diversity among practicing health professionals. Kennedy et al.²² write that women from visible minority groups may be less likely to choose the midwifery profession because midwifery's peripheral position within maternity care in the United States amplifies their minority status within the health care realm. In Manitoba, the women regulating the profession used the freedom which comes with a less institutionalized profession to construct a culturally safe place, and built relationships with a number of socioeconomically disadvantaged communities in the province. With open dialogue, they were able to tailor the midwifery educational programs being developed to better support midwifery candidates from these communities. Such efforts reflect a conception of diversity which tries to move beyond numbers and quotas towards creating a sense of community ownership of the profession.

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**Aboriginal Women
And
Reproductive Health,
Midwifery, and
Birthing Centres**

An Issue Paper

Prepared for the
National Aboriginal Women's Summit
June 20-22, 2007
in Corner Brook, NL

Aboriginal Women and Reproductive Health, Midwifery, and Birthing Centres

Aboriginal ancestral laws and spiritual beliefs recognize that health is the result of a holistic approach and interconnectedness. Health for Aboriginal women means wellness and a balance of physical, mental, emotional and spiritual factors with her personal situation, nature and the environment, as well as her family, community and other relationships and societal settings and interactions. When illness appears, traditional healing treats the mind, body, and spirit, which is a much more inclusive and holistic approach than typical western medicine, which mostly seeks to relieve symptoms as opposed to finding and remedying causes of ill health.¹

The recognition of how various life issues cross over with health issues is an important one which our Grandmothers, Mothers and Aunties have known for generations. As other Canadians begin to also address this basic truth in relation to contemporary circumstances,² Aboriginal women can seek more effective combinations of traditional practices and healing approaches and 21st century western-based primary health care, in order to take care of our reproductive health. This includes the important components of having our own midwives and birthing centres available to us during pregnancy and delivery of our babies.

In this paper, we highlight a number of issues related to reproductive health, midwifery, and birthing centres, plus several examples of Aboriginal-women-specific policies and programs that we consider successful. We conclude following these three subtitles, with related recommendations.

Reproductive Health

Aboriginal women have traditionally had the highest respect within their communities for their gift by the Creator as life givers.³ In keeping with this gift, most of us marked, for example, the beginning of menstruation as a significant life event, with ceremony and teachings. This celebrated the physical transition to womanhood; it was also seen as the start of a spiritual life journey that honoured maintaining the health and well being of each woman and her family. This practice continues today in many communities.

Continuing reproductive health throughout a woman's life is an especially serious issue for Aboriginal women because of our higher birth rate (1.5 times higher) than non-Aboriginal Canadian women.⁴ We presently also experience higher rates (2 to 2.5

¹ See our concurrent National Aboriginal Women's Summit issue paper, *Aboriginal Women and Traditional Healing* for more information.

² Health Canada has identified 12 determinants of health: income and social status, employment, education, social environments, physical environments, healthy child development, personal health practices and coping skills, health services, social support networks, biology and genetic endowment, gender and culture. Health Canada, "Women's Health Strategy," 2004, online: www.hc-sc.gc.ca/ahc-asc/pubs/strateg-women-femmes/strateg_e.html (Accessed June 16, 2007).

³ Indian and Northern Affairs Canada, "Aboriginal Women: Meeting the Challenges," 2004, online: www.ainc-inac.gc.ca/ch/wmn/index_e.html (Accessed June 16, 2007).

⁴ Statistics Canada, "Canada's Aboriginal Population in 2017," *The Daily*, June 28, 2005 online: www.statcan.ca/Daily/English/050628/d050628d.htm (Accessed June 16, 2007).

times higher) of prenatal, stillbirth and newborn death than that of the Canadian average.⁵

Our traditional understandings of pregnancy and childbirth as normal life events contrast with the more prevalent western medical view of pregnancy throughout the 20th century, as akin to an illness requiring treatment. However, together with the legacy of colonialism which marginalized Aboriginal women and created social and economic conditions leading to our severe disadvantage on many fronts, a gap has grown between individual and community preventive and healthy practices, and obtaining western medical care when appropriate, especially in culturally relevant ways.

For example, physical examinations require regular access to health care providers. Unfortunately, a major barrier to reproductive as well as health care generally for Aboriginal women, is the lack of access to health care providers and, specifically, to Aboriginal health care providers.⁶ The isolation of some reserves and communities is often a factor in this situation. Also, it is well-known that Canada is facing a crisis in the number of all health care providers such as doctors, nurses and midwives.

Health care providers play a vital role in promoting important screening tests. An example is for detecting gestational diabetes during pregnancy – the development of diabetes specifically during pregnancy – which increases health risks to mothers and has long-term risks and potential harmful life health consequences for babies whose mothers have this condition, especially if this condition has not been diagnosed and treated properly.⁷

Aboriginal women need Aboriginal health care providers for many reasons, but perhaps the most important is that this gives us an opportunity to share and transfer knowledge on an Indigenous-to-Indigenous basis. As well, “insider care” by our own people does not have to adjust to cultural differences, sensitivities and communication patterns of patients.

In Canada, most universities have a specific admissions process for Aboriginal students, including into the health sciences. This does not mean presently though that Aboriginal women and men are enrolling in large numbers. In 2002-2003, there were 56

⁵ Beverley Chalmers and Shi Wu Wen, “Perinatal Care in Canada,” *BMC Women's Health*, 2004, online: www.biomedcentral.com/content/pdf/1472-6874-4-S1-S28.pdf (Accessed June 16, 2007).

⁶ Eileen Antone and Junko Imai, *Defining Aboriginal Health Literacy in a Canadian Context: Bringing Aboriginal Knowledge into Practice*, Canadian Association for the Study of Adult Education National Conference, Toronto, May 2006, online: www.oise.utoronto.ca/CASAE/cnf2006/2006onlineProceedings/CAS2006Eileen%20Antone.pdf (Accessed May 22, 2007). [hereafter “Antone and Imai”]

⁷ This is documented in sources such as: Roland F Dyck, Leonard Tan, and Vern H Hoepfner, “Short Report: Body Mass Index, Gestational Diabetes and Diabetes Mellitus in Three Northern Saskatchewan Aboriginal Communities,” *Chronic Diseases in Canada* Vol. 16, No. 1, 1995, online: Public Health Agency of Canada, http://www.phac-aspc.gc.ca/publicat/cdic-mcc/16-1/b_e.html (Accessed June 15, 2007); Eilish Cleary, Sora Ludwig, Nichole Riese, and Lorna Grant, “Educational Strategies to Improve Screening for Gestational Diabetes Mellitus in Aboriginal Women in a Remote Northern Community,” *Canadian Journal of Diabetes* 2006;30(3):264-268, online: Canadian Diabetes Association, <http://www.diabetes.ca/files/CJDSep06GDM%20in%20Aboriginal%20Women.pdf>.

Aboriginal students enrolled in medical programs across Canada.⁸ Hiring and keeping Aboriginal nurses was talked about at a national conference in 2003, including that it was noted that there are virtually no Inuit nurses.⁹

While the Aboriginal Health Human Resources Initiative started in 2005 and funded by Health Canada is now providing encouragement and some financial support to Aboriginal women and men who wish to become health professionals,¹⁰ even with this assistance, it will still be many years before there are significant numbers of graduates in practice and available to our communities. The NWAC takes the position that all health care, educational and other social sectors as well as communities need to pay attention to encouraging Aboriginal women to, for example, choose midwifery training and/or to specialize in gynaecology and obstetrics within their medical nurse, nurse-practitioner or doctor training.

Another issue in reproductive and general health that Aboriginal women say is a problem, is that existing health care providers frequently do not ensure the fully informed consent of Aboriginal women – providing full information in plain language about the potential and suggested or recommended treatments or medications for her and their possible risks and side effects, and allowing her to consider and make a truly individual decision on her care.

Midwifery

Midwifery was always been an essential aspect of Aboriginal tradition. Since time immemorial, midwives had not only ensured the physical survival of successive generations, but also helped develop significant social relationships in the vital life cycle event of birth.¹¹ Midwives knew how to ease the pain and intensity of labour, save the lives of women and babies, and ensure that the sacred knowledge of birth is maintained. Traditionally, birth was viewed not only as Creation's addition to the family and community, but as a reinforcement of relationship to the land, as a strengthening of cultural relationships, and as a way to teach and transfer knowledge to the younger people involved in helping out at birthings.

Midwives regard pregnancy, labour, birth and the post-birth period as a normal healthy process. Support and respect so that women can deliver safely with empowerment and dignity in a culturally relevant way are goals in Aboriginal midwifery, which in turn recognize and value the importance of a woman to herself, her family and the larger community.

⁸ Susan Horsfall, Adam Spencer, Sarah Williams et al., "Survey on Aboriginal issues within Canadian medical programmes," *Medical Education*, 39(11) (November 2005): 1103.

⁹ Canadian Association of Schools of Nursing, *National Workshop on Strategies to Recruit and Retain Aboriginal Nursing Students in the Nursing Profession*, Ottawa, Sept. 2003, online: www.casn.ca/media.php?mid=226 (Accessed June 16, 2007).

¹⁰ For more information on the AHHRI, see Health Canada's *Aboriginal Health Human Resources Fact Sheet* (February 2007), online: www.hc-sc.gc.ca/ahc-asc/media/nr-cp/2007/2007_12bk1_e.html.

¹¹ Lesley Paulette, "Midwifery in the North", research study prepared for the Royal Commission on Aboriginal Peoples, cited in Canada, *Report of the Royal Commission on Aboriginal Peoples*, vol. 4, ch. 2 [Women's Perspectives] (Ottawa: 1996), online: Indian and Northern Affairs Canada, www.ainc-inac.gc.ca/ch/rcap/sg/sj9_e.html#8.1%20Birth%20and%20Midwifery.

One of the significant barriers to Aboriginal reproductive health and specifically to women's health related to pregnancy, delivery, and the post-birth period is the critical lack of Aboriginal health care providers noted earlier in this paper, including midwives.¹² This has been the result, in large part, of the interruption of traditional Aboriginal midwifery during much of the 20th century in particular, by laws which made midwifery illegal and even punishable by imprisonment.¹³

Another legacy of colonialism and a dominating society imposing its ways on Aboriginal peoples that contributed to the erosion of Aboriginal midwifery was the widespread acceptance and establishment of the male-dominated non-Aboriginal belief that a doctor-supervised hospital birth was superior to, and required instead of, a birthing at home on the land. This often meant – and presently continues to mean for women in small and remote communities in particular – removing pregnant women from their own communities for birth.

The effects of shifting birthing to hospitals combined with outlawing the practice of midwifery not only eroded traditional midwifery knowledge, it took away the power of women and their families to be active participants in the labour, delivery and post-birth periods of child-bearing. Fortunately, midwifery has been regaining its rightful place. In 1994, after decades of lobbying and protests, Ontario became the first province in Canada to regulate and fund midwifery. Since then, other provinces and territories have provided legislation and funding for midwifery.¹⁴

Evidence-based practices¹⁵ and ongoing research into the safety of all birth settings are goals equally shared by the NWAC and non-Aboriginal medical establishment organizations such as the Society of Obstetricians and Gynaecologists of Canada (SOGC), whose members are committed to provide excellent care for women and their babies.¹⁶ In fact, in March this year, the SOGC published "A Report on Best Practices for Returning Birth to Rural and Remote Aboriginal Communities" which endorses and calls for Aboriginal midwifery as well as the promotion of partnerships between communities and health care providers.¹⁷ As part of this approach, the NWAC supports and encourages Aboriginal women to enter midwifery training with a view to serving Aboriginal women, families and communities.

¹² Antone and Imai.

¹³ Holliday Tyson, "The Re-emergence of Canadian Midwifery: A New Profession Dedicated to Normal Birth," online: Birth International www.acegraphics.com.au/articles/holliday01.html (Accessed May 17, 2007).

¹⁴ See Appendix A: Status of Midwifery in provinces and territories.

¹⁵ For example, a 2005 study published by the reputable *British Medical Journal* found that planned home births for low-risk women in North America using certified professional midwives were associated with lower rates of medical intervention and similar intrapartum and neonatal mortality to that of low-risk hospital births in the United States. Kenneth C Johnson, "Outcomes of planned home births with certified professional midwives: large prospective study in North America," *British Medical Journal*, 330, (June 2005), online: www.bmj.com/cgi/content/full/330/7505/1416?ehom. (Accessed May 17, 2007.)

¹⁶ Society of Obstetricians and Gynaecologists of Canada, "Policy Statement: Midwifery," 2003, online: www.sogc.org/guidelines/public/126e-ps-march2003.pdf (Accessed May 17, 2007).

¹⁷ Society of Obstetricians and Gynaecologists of Canada, "A Report on Best Practices for Returning Birth to Rural and Remote Aboriginal Communities," 2007, online: www.sogc.org/jogc/abstracts/200703%5Fsogcreport%5F1.pdf (Accessed May 18, 2007).

Birth Centres

Ask any woman about her labour and delivery experiences and she will likely tell a story with vivid details about her feelings (physically, emotionally and spiritually), the nurse(s), doctor and/or midwife, words that were spoken or not spoken, who else was present, possibly the colour of the room and even describe the smells. The value and importance of the birth experience can stay with a woman her whole life. Unfortunately, sometimes the stories of what should be these most cherished events are not as positive as they should be.

As we have already noted in the two earlier sections of this paper, birth is a vital life event for women, their families and communities. It was also traditionally a time for sharing and reinforcing sacred knowledge of birth, and for strengthening social relationships and ties to the land. When the process of birth was removed from its community foundation, a fundamental life event was also removed.

Taking healthy, low-risk women out of their communities to deliver in the sterile setting of a hospital sacrifices the cultural, social and spiritual importance of birth and relationships among all the women involved – mothers and midwives – and their communities. Within hospitals, care providers are unlikely to have the Aboriginal-specific, culturally-relevant birth knowledge passed on from generation to generation to ensure Aboriginal women give birth in an empowering and dignified manner.

A birth centre is a means of returning birth close to or actually back into the community. It also can serve to economize on scarce resources (operation of the facilities, availability of midwives, traditional birth attendants, health care workers) within geographically large areas while still providing “continuity of place”¹⁸ and a birthing environment which many women might likely favour over a hospital setting.

There are multiple models of birth centres, ranging from complete life-care centres to a physical building provided solely for the labour, birth and immediate post-birth period. A number of provinces now have established birthing centres,¹⁹ some of which are Aboriginal or include Aboriginal midwives in their practice (see examples below).

Successful and Best Practice Examples

Seventh Generation Midwives Toronto (SGMT)

In Toronto, the Seventh Generation Midwives Toronto (SGMT) midwifery practice provides care to Aboriginal women and others in the downtown area. A team of registered midwives, some of whom are also traditional Aboriginal midwives, offers a choice of birthplace: at home, or in the hospital.

¹⁸ Many Aboriginal women have spoken to the importance of “continuity of place” as a necessary component of good maternity care. “Continuity of place” refers mainly to not having to leave your community.

¹⁹ The need for more birthing centres, particularly in the western Canada has been noted by Aboriginal women. For example, presently, there are none in Saskatchewan or British Columbia.

As well, the SGMT practice is dedicated to the support and mentoring of Aboriginal community members who wish to enter health care professions. The SGMT vision statement illustrates their members' dedication to women and birth:

SGMT believes in the sacredness of all life, and respects the beauty and power of nature and creation. We believe that birth is a profound and awesome event in a woman's life.²⁰

kanáci otinawáwasowin Baccalaureate Program (KOBP)

Aboriginal midwifery education is currently being offered at the University College of the North located in The Pas, Manitoba. The kanáci otinawáwasowin Baccalaureate Program (KOBP) is a four-year degree program in midwifery which incorporates a mentoring model of instruction rooted in Aboriginal values and traditions. It focuses on Aboriginal perspectives and trains midwives in the competencies required for registration with the College of Midwives of Manitoba.²¹ Course instructors include registered and non-registered Aboriginal midwives, and other Aboriginal academics are vital to the continued curriculum development in this program.

Tsi Non:we lonnakeratstha Ona:grahsta'

The Six Nations Birthing Centre in southern Ontario, Tsi Non:we lonnakeratstha Ona:grahsta' is a community-directed birth centre that also provides comprehensive life care. All the centre's midwives are members of the Six Nations community and offer a choice of birth place to the mother: at home or at the birth centre.

The midwives at this birth centre provide a variety of services including complete prenatal, labour and birth care, traditional family teachings, well-baby advice, infertility information and support, pregnancy and pap tests, traditional medicine, educational and emotional support, annual birth celebrations and breastfeeding support. The centre itself also provides many programs, which include prenatal classes, "Moms and Tots" groups, female traditional self-care, male traditional self-care, traditional medicine workshops and traditional parenting workshops.

The centre also has an Aboriginal Midwifery Training Program, which had its first graduating class in 2003.²²

Tsi Non:we lonnakeratstha Ona:grahsta' is an excellent example of a best practice. This centre not only has continuity of place but offers more than labour and birth care. It builds and strengthens the community, trains midwives, encourages traditional

²⁰ Seventh Generation Midwives Toronto, "About Us," 2006, online: www.sgmt.ca/SGMTabout.html (Accessed May 18, 2007.)

²¹ University College of the North, "2007-2008 Annual Calendar," online: www.keewatincc.mb.ca/Academic%20Calendar%202007-2008.pdf (Accessed May 18, 2007.)

²² Six Nations Maternal and Child Centre, "Tsi Non:we lonnakeratstha (the place they will be born) Ona:grahsta' (a Birthing Place)," online: National Aboriginal Health Organization www.naho.ca/french/pdf/ABirthingPlace-SixNations.pdf (Accessed May 17, 2007).

knowledge keepers and elders, and incorporates knowledge from all community members.

What is Needed to Support and Promote Aboriginal Women's Reproductive Health, Midwifery, and Birthing Centres?

Aboriginal women have identified recommendations for increasing our reproductive health, fostering the re-growth of Aboriginal midwifery practice in the modern regulatory setting, and for birth centres. Our recommendations include:

1. Recognize the role and value of traditional Aboriginal reproductive, pregnancy and birthing knowledge;
2. Acknowledge the loss of continuity of family and community care and involvement for women who must leave their communities during late pregnancy to give birth;
3. Understand the importance of Aboriginal women's roles in teaching young women about the physical aspects of womanhood and holding related ceremonies;
4. Provide support and recognition to Aboriginal midwives, including their training and registration under provincial health professional laws and regulations;
5. Conduct research that is specific to traditional First Nations, Inuit, and Métis midwives and restoring their roles in individual, family and community health;
6. Research how traditional approaches to reproductive health can be more effectively combined with other health services;
7. Focus research enquiry on and identify how Aboriginal women may better access culturally relevant pregnancy and birthing support and experiences;
8. Research and publicize programs related to the spectrum of lifetime reproductive health that work, whether these are traditional or a combination of traditional and western medical approaches;
9. Continue to provide encouragement, and increase financial support and opportunities for Aboriginal women to enter midwifery training;
10. Encourage meaningful dialogue between Aboriginal midwives and non-Aboriginal midwives for mutual benefits to their care and services for all women, and to promote more culturally sensitive care for Aboriginal women when they are only able to access non-Aboriginal settings for birth, such as hospitals;
11. Emphasize the importance of cultural sensitivity in all health services;
12. Commit to making immediate, substantial improvements to the social, economic and political conditions within which Aboriginal women and their families live; and,

13. Commit to engaging Aboriginal women in the development and delivery of women-specific health and reproductive health action plans; including that all such plans and resulting policies and programs will include a culturally relevant gender-based analysis.

Appendix A: Status of Midwifery in Canada†

Province/Territory	Midwifery Legislation	Funded Midwifery Care	Formal Education Program?	Are there Aboriginal Midwives?
Alberta	Yes	No	No	Yes
British Columbia	Yes	Yes	Yes	Yes
Manitoba	Yes	Yes	Yes	Yes
New Brunswick ²³	No	No	No	Unknown
Newfoundland and Labrador	No	Yes, if midwife is also an RN	No	Unknown
Nova Scotia	No	No	No	Unknown
Ontario	Yes	Yes	Yes	Yes
Prince Edward Island	No	No	No	Unknown
Quebec	Yes	Yes	Yes	Yes
Saskatchewan	Yes	No	No	Unknown
Northwest Territories	Yes	Yes	No	Unknown
Nunavut	No	Yes	Pilot project beginning 2005	Yes
Yukon	No	No	No	Unknown

† Please note that the information in this appendix should not be quoted without reference to the applicable laws and regulations, and specific provincial/territorial circumstances. Due to time constraints preparing this paper, it was not possible to verify the accuracy of all information before submission of this paper.

²³ According to a news release on May 16, 2007 “[The] government will take the necessary steps to make midwives an integral part of New Brunswick’s publicly funded health care team...”
 “Province to legislate practice of midwifery,” Communications New Brunswick online:
www.gnb.ca/cnb/news/he/2007e0612he.htm (Accessed June 16, 2007.)



Reclaiming Birth, Health, and Community: Midwifery in the Inuit Villages of Nunavik, Canada

Vicki Van Wagner, RM, Brenda Epoo, Julie Nastapoka, and Evelyn Harney, BA, SM

This article describes the Inuulitsivik midwifery service and education program, an internationally recognized approach to returning childbirth to the remote Hudson coast communities of Nunavik, the Inuit region of Quebec, Canada. The service is seen as a model of community-based education of Aboriginal midwives, integrating both traditional and modern approaches to care and education. Developed in response to criticisms of the policy of evacuating women from the region in order to give birth in hospitals in southern Canada, the midwifery service is integrally linked to community development, cultural revival, and healing from the impacts of colonization. The midwifery-led collaborative model of care involves effective teamwork between midwives, physicians, and nurses working in the remote villages and at the regional and tertiary referral centers. Evaluative research has shown improved outcomes for this approach to returning birth to remote communities, and this article reports on recent data. Despite regional recognition and wide acknowledgement of their success in developing and sustaining a model for remote maternity care and aboriginal education for the past 20 years, the Nunavik midwives have not achieved formal recognition of their graduates under the Quebec Midwifery Act. *J Midwifery Womens Health* 2007;52:384–391 © 2007 by the American College of Nurse-Midwives.

keywords: community health services, indigenous health services, maternal health services, newborn, perinatal care, postnatal care, pregnancy, prenatal care, reproductive health services, women's health services

To bring birth back to the communities is to bring back life . . .

—Puvirnitug Elder, 1988¹

INTRODUCTION

This article describes the Inuulitsivik midwifery service and education program, an internationally recognized model of care, which has returned childbirth to the remote communities of Nunavik, Quebec, Canada. Nunavik is one of the Inuit regions of the Canadian Arctic (Figure 1), just south of the new Canadian Territory of Nunavut. It is a vast region of more than 500,000 square kilometers of tundra. Traditional Inuit and modern ways of life mix, and many families continue to practice subsistence hunting and fishing. Inuutitut is the region's primary language, although English and French are also spoken. Nunavik has a very young population; 50% of the inhabitants are under the age of 20. The population is growing, and has a birth rate that is twice the Canadian average. First-time mothers are young, with 25% of births occurring in women under 20. Most women have three or more children.²

The Inuulitsivik Health Centre serves seven communities on the Hudson Bay and Hudson Strait coasts (Figure 2), with a population of about 5500. Inuulitsivik encompasses a local health center in each community,

often called “the nursing station”; a small, 25-bed general hospital in Puvirnitug; and a mental health center in Inukjuak. All of the communities are remote fly-in villages, with transfer for tertiary care more than 1000 kilometers to the south, in Montreal.³

BACKGROUND

Inuit have something to learn from the southern health system. And Inuit culture has much to offer and much more to reclaim.

—Annie Palliser Tulugak, Past Director of Inuulitsivik⁴

Although midwifery was an integral part of traditional Inuit culture, the official “standard” of maternity care that developed in the mid 1970s for many northern Canadian communities was the evacuation of all pregnant women to hospitals to give birth, often in distant southern Canada. Women were flown south at 36 weeks' gestation or earlier, spending weeks and sometimes months away from home.⁵ As stated in a report to the Quebec Ministry of Health, “This intimate, integral part of our life was taken from us and replaced by a medical model that separated our families, stole the power of the birthing experience from our women, and weakened the health, strength, and spirit of our communities.”¹

In 1986, the first birth center or “maternity” was opened in Puvirnitug to serve the women of the Hudson coast, as a direct result of community organization by Inuit women and activism for Inuit cultural revival and

Address correspondence to Vicki Van Wagner, RM, Associate Professor, Ryerson University Midwifery Education Program, 350 Victoria St., Toronto, Ontario M5B 2L4. E-mail: vvanwagn@ryerson.ca



Figure 1. Map of the Nunavik region. Reprinted with permission from Makivik Corporation.

self-government. The initiative was supported by the community board that governed Inuulitsivik. The board's commitment to the education of Inuit health workers and an approach to health care rooted in community development formed the philosophy of the birth center. The community had a strong desire to reclaim the birth experience by using midwifery skills and traditional knowledge about birth, integrated with modern approaches to care.

Vicki Van Wagner, RM, is a midwife in Toronto and Nunavik, Canada, and is an Associate Professor at the Ryerson Midwifery Education Program.

Brenda Epoo is a community midwife in Inukjuak, Canada, and past coordinator of Perinatal Services for Inuulitsivik Health Centre.

Julie Nastapoka was among the women who fought for the establishment of the Inuulitsivik birth centers and one of the first midwives to practice in Inukjuak, Canada.

Evelyn Harney has a BA in Health Studies from McMaster University and is a student midwife at Ryerson University in Toronto.

FORMATION OF THE BIRTH CENTER

The formation of the birth center involved consultations with elders, traditional midwives, childbearing women, and young women. Midwifery students were selected by the community, and *Quallunaaq* (non-Inuit) midwives were hired to support the development of an Inuit midwifery service.^{1,4} The success of the Puvirnituk Maternity inspired other communities to work to bring birth back to their villages. There are currently about 200 births per year taking place at birth centers in the three largest communities: in Puvirnituk (population approximately 1400); Inukjuak (1400), which opened in 1998; and since 2004, in Salluit (1100). The maternities are located in the local health centers.

Discussion about the consequences of returning child-birth to the villages took place at community meetings with women's groups, leaders, and elders. This process included dialogue with local health care providers about



Figure 2. Map of villages in the Nunavik region. Reprinted with permission from Makivik Corporation.

the capacity and limitations of care in these remote settings, the potential for adverse outcomes related to distance from tertiary care, and discussions of the communities' perspectives about the potential benefits of returning birth to the north.

I can understand that some of you may think that birth in remote areas is dangerous. And we have made it clear what it means for our women to birth in our communities. And you must know that a life without meaning is much more dangerous.
—Jusapie Padlayat, a Salluit elder⁶

MIDWIFERY-LED INTERDISCIPLINARY MODEL

In the Inuulitsivik model, midwives are lead caregivers for maternity, well women, and newborn care for the population, regardless of risk status. Midwives and students work together to provide care and to facilitate the “on the job” education students receive. Midwives and student midwives are employees of the health center and are the on-call primary care providers for maternity care.

The midwives work as part of a team with nurses, physicians, and social workers in the health centers. Nurses provide on-call, first line primary care for non-

maternity care emergencies in all of the villages. Family physicians based in the largest Hudson Bay communities (Puvirnituk, Inukjuak, Salluit, and Kuujjuaraapik) are available for consults on-site, and they also make regular visits by plane to the other villages.

For women living in Inukjuak, Puvirnituk, and Salluit, prenatal care, “low risk” births, and postpartum care occur with midwives in the birth centers. Because these are the larger villages, 75% of the Hudson coast population has access to intrapartum care in their home community. Women from the four smaller villages (population, 300–700) where there are no birth centers, receive prenatal care from nurses in the nursing stations in consultation with the midwives, and travel to one of the birth centers at 37 to 38 weeks' gestation for delivery. Although this means that 25% of women still have to “leave home” for birth, they receive care in their own region, language, and culture from Inuit midwives. Women who travel for birth often stay with relatives in the larger villages and give birth surrounded by relatives or friends. Air Inuit, the only regional airline, offers reduced airfare for partners to travel with women for childbirth. This is markedly different than the loneliness and disruption of evacuation to southern hospitals.

The hospital staff in Puvirnituk is governed by an interdisciplinary council, which sets policy and protocols. Key to the collaborative approach to care is the Perinatal Committee, an interdisciplinary team led by midwives, which reviews each woman's case at 32 to 34 weeks' gestation. This review considers both medical and social factors, and creates a care plan, including place of birth.

Births are usually attended by two midwives. A physician is on-call 24 hours a day in Puvirnituk, and nurses are on-site in the hospital to assist if needed. A second physician is on-call by phone for the other villages during the evenings and weekends, and a nurse can be called to come into the health center when a birth is taking place. The physician on-call is responsible for arranging medical evacuation after consultation with the midwives. Specialist consultation is by phone, electronic communication, or transport. Transport time to Montreal ranges from 4 to 8 hours, weather permitting.

RISK SCREENING

Perinatal care and risk screening are guided by an extensive and evolving set of guidelines for practice. Risk screening is a fundamental principle of safe care in this remote setting. The whole concept of risk in birth, however, is conceptualized in a much broader context than protocols or risk scoring systems. Risk screening is seen as a social, cultural, and community process rather than simply a biomedical one.

In Inuit culture, health is regarded as more than the absence of disease, and includes health of the individual's physical, mental, emotional, and spiritual aspects, in addition to health in the family and the community as a whole.

Evacuation is seen by the health care team to carry its own kind of risks, assessed on the basis of both social and medical status. Even routine evacuation is a risky process, in that it can recreate the trauma and social dislocation of the old residential school policy, which is a trauma felt at both individual and community levels. Evacuation is associated with the loss of autonomy, a poor diet, substance use, family stress, and child neglect. Inuit report that care in the south is often marked by a lack of understandable information; a lack of sensitive, culturally appropriate care; and high rates of intervention.⁷⁻⁹ In Nunavik, taking birth out of the community is understood as an act of disrespect, neglect, and a colonialist approach to health care and to indigenous communities.^{1,4}

If a woman's case involves risk factors that indicate more ready access to services such as laboratory or emergency transport, births are planned for Puvirnituk. Examples include: hypertension that is unresponsive to therapy; history of postpartum hemorrhage or retained placenta; postdates > 42 weeks; first trimester complications; and preterm labor before 36 weeks. If tertiary

care is necessary, births are planned for Montreal. Women with twins, breech presentation, those who want to have a vaginal birth after cesarean, severe hypertension, preexisting/other medical conditions, and preterm labor before 35 weeks' gestation are transferred to Montreal when possible. In Puvirnituk, there is access to lab services, blood transfusion, induction, augmentation, and admission of newborns for care, monitoring, and treatment. There is usually access to ultrasound and intermittent access to providers skilled in uterine evacuation. Planned transfer is by scheduled flight on the regional airline.

In an emergency air transfer, Puvirnituk is the first step in the evacuation process from the other villages to tertiary care in Montreal, as there is a landing strip for an emergency medical services jet that comes from Montreal. Emergency transfer from the smaller villages to Puvirnituk is via smaller planes contracted through the regional airline. This process may take as many as 6 to 8 hours, weather permitting.

RESULTS OF EVALUATION STUDIES

Uniform data have been collected at each birth since the beginning of the midwifery service. These data have the strengths and limitations inherent to audits of clinical records. A summary of the external evaluations and a report on more recent data gathered internally follows. Some evaluations used historical comparisons looking at data from 1983 before the Puvirnituk Maternity opened; evaluations were then performed during the following years: 1987 to 1988,^{10,11} 1990 to 1991,¹² and 1995 to 1996.¹³

When the Puvirnituk Maternity opened, it served the Hudson coast, and women on the neighboring Ungava coast continued to be cared for by physicians at Tuulatavik Hospital in Kuujuaq. Studies using regional cohorts have reported the obstetric outcomes of this "natural experiment," by comparing groups of women who were very similar demographically, but who were cared for by different services.¹¹⁻¹³ The research shows improved outcomes and lower rates of intervention, both historically and in comparisons between regions (Table 1).¹ A report of the outcomes for the first 5 years of the Inukjuak Maternity is consistent with the previous research.¹⁴

Outcome Statistics for the Birth Centers

Ongoing internal evaluation of outcomes report more than 2200 births in Puvirnituk, 200 births in Inukjuak, and 40 births in Salluit, with approximately 3000 women cared for in total since the Puvirnituk birth centre opened in 1986. Between 1986 and March of 2005, 80% of women from the Hudson coast communities gave birth in Nunavik.

An internal audit of medical evacuations between 2002 and 2005 showed that of the 374 births planned for

Table 1. Rate of Interventions by Region both Before (1983) and After (1987) the Establishment of the Inuulitsivik Midwifery Service on the Hudson Coast

Intervention	Hudson Coast (%)				Ungava Coast (%)				Quebec (%)			
	1983	1987-88	1990-91	1995-96	1983	1987-88	1990-91	1995-96	1983	1987-88	1990-91	1995-96
Cesarean section	4.1	2.6	—	3.1	—	6.2	8.0	—	—	28.3	—	26.8
Induction	10.0	10.4	5.5	4.8	—	8.4	13.4	—	—	—	—	23.6
Episiotomy	25.2	7.2	4.9	3.5	49.0	28.8	28.8	—	—	—	65.4	36.5
Transfer south	91.0	17.2	8.3	9.4	15.0	25	31.9	28	—	—	—	NA
Transfer of adolescents	—	—	—	7	—	—	—	32	—	—	—	NA

NA = not applicable.

Adapted with permission from Crosbie C, Stonier J.¹

the Inuulitsivik birth centers, 92% took place in Nunavik, 9.3% involved maternal transfer (antepartum, intrapartum, or postpartum), and 1% involved neonatal transfer. Of the maternal transfers, 7.8% were transferred to Montreal, and 1.6% transfers were to Puvirnituk.

The most common reason for transfer was preterm labor (14/42; 33%). However, 64% (n = 9) of the women who were transferred for preterm labor without ruptured membranes delivered at term, often after returning to the north. The health center is currently exploring the use of fetal fibronectin as a test that might aid management and decrease unnecessary transfers of women at preterm gestations. The other reasons for transfer were hypertension (n=5, 11%), neonatal problems (n=4, 9.5%), and evaluation after an unplanned home birth in a village with no midwifery care (n=3, 3.7%). The reasons for the remaining 16 medical evacuations were: preterm prelabor rupture of membranes (n = 2); twins (n = 2); placental abruption (n = 2); labor dystocia (n = 2); and 1 case each of placenta previa, third degree perineal tear, breech presentation, prelabor rupture of membranes at term, postpartum hemorrhage, maternal choice, incomplete miscarriage, and intrauterine growth restriction. Further research is needed to identify the most common indications for and outcomes of births planned in Montreal.

There have been 2253 births planned for or occurring in Nunavik between 1986 and 2004. In total, there were 21 perinatal deaths, including 12 antepartum or intrapartum deaths, and nine neonatal deaths, which resulted in a perinatal mortality rate of nine per 1000 (0.9%). Of the antenatal and intrapartum deaths, seven were intrauterine fetal demise; two were placental abruptions; one was cord prolapse/compound presentation; one baby had multiple congenital anomalies; and one cause of death was unexplained. Seven neonatal deaths were caused by extreme prematurity, and two were term infants with intrauterine growth restriction (n = 1) or congenital anomalies (n = 1).

Although direct comparisons are not valid, these perinatal outcomes are consistent with previous research in the Western Arctic¹⁵ and Canada as a whole, which has a perinatal mortality rate of 8 to 10 per 1000

(0.8%–1%).¹⁶ In addition, the outcomes from Nunavik are lower than the combined rates of fetal and neonatal mortality in comparable populations of the Northwest Territories (19/1000; 1.9%) and Nunavut Territory (11/1000; 1.1%), as reported in the 2003 Canadian Perinatal Health Report.¹⁶

It is important to note that despite risk screening, this is not a uniformly low risk population, and transfer out is not always possible. The midwives care for many women with significant health risks, and much of the population faces considerable socioeconomic challenges. Genetic screening and termination of pregnancy are almost universally declined in this population, which has an impact on reporting and comparing perinatal mortality. Access to ultrasound is also limited. In this community, perinatal mortality and loss are understood as an aspect of the life cycle, and in the context of the limits of remote health care for many other aspects of life. This means that some of the underlying assumptions and cultural norms dominant in urban perinatal care in southern Canada, such as the quest for perfect outcomes, immediate access to interventions, and a culture of blame and liability, are very different in this region.

EDUCATING MIDWIVES AT INUULITSIVIK

The Inuulitsivik Midwifery Education Program provides academic and clinical education for Inuit women in their own communities. The program uses a modular competency-based curriculum consistent with the clinical content of midwifery education programs in southern Canada, which has been adapted for northern realities, and an expanded scope of practice. Inuit pedagogy, such as observation, “being shown rather than told,” storytelling, and other oral methods of teaching are the foundation of learning. Role modeling, simulations, and regular case review are integrated into this apprenticeship style of learning. Evaluation occurs through ongoing monitoring and inventory of the acquisition of clinical skills and both written and oral exams. In this way, the traditional methods of knowledge transfer are preserved, while Inuit and non-Inuit midwifery knowledge and approaches blend.

Student midwives are selected from the community, and have often worked as postpartum or community health workers (known as *anniasutiapiit*) before becoming midwifery students. The gradual acquisition of knowledge is part of the observational and hands-on learning process, which in many aboriginal cultures, moves from seeing to assisting to doing. The meaningful involvement of local women in several levels of care also assists the sustainability of midwifery care in the north. Student midwives have an important role as cultural and language interpreters when working with *Quallunaaq* midwifery teachers.

In keeping with a philosophy of integrating both traditional and modern approaches to health care, Inuulitsivik hired midwives from the south and involved the elders to teach the young women who were the first group of midwifery students. Many of the graduates are now experienced teachers themselves, but the program continues to involve both Inuit and non-Inuit midwifery teachers, as well as other health professionals in the education process. In keeping with the link between reclaiming both midwifery and Inuit culture and self-determination, the emphasis was on finding teachers from southern Canada and internationally, who, according to Inuit midwife and leader Mina Tulugak, recognized that "their role is to teach but not to lead."¹⁷ Inuit midwifery teachers pass on the traditional knowledge of how to promote a healthy pregnancy, how to benefit from a healthy diet of "country foods," and Inuit approaches to labor, birth and baby care. They also teach the "high tech" skills needed in a remote setting to handle emergencies. In practice, students and midwives will respect traditional practices (e.g., avoiding knots in clothing during pregnancy or folding a finger to help control postpartum hemorrhage) while also using pharmaceuticals. The midwives and students recently organized a regional gathering of elders to pass on and document knowledge about traditional life, midwifery, and childbirth to the midwives and community.

Academic learning covers the core competencies for midwifery in Quebec, utilizing clinical situations, very much like the case-based or problem-based learning methods used in southern midwifery and medical schools. This approach is complemented with prepared learning modules, simulated clinical situations, and case review. The curriculum has a particular emphasis on the midwives' community health role, especially in the areas of sexual health and sexually transmitted infections, well woman, and well baby care, because the northern midwives' role in these areas is more extensive than comparable midwifery roles in most of southern Canada. Inuulitsivik has created a Nunavik Emergency Skills course, which is an adaptation and expansion of the Canadian Association of Midwives Midwifery Emergency Skills¹⁸ course, and is consistent with content from interdisciplinary maternity care skills courses¹⁹⁻²¹ adapted to remote practice. It focuses on when to transfer and man-

agement before transfer, and includes skills such as use of vacuum, manual removal of the placenta, intubation, and umbilical vein catheterization of the newborn.

To meet the Inuulitsivik requirements for graduation, student midwives complete a minimum of 1240 supervised clinical hours, and provide continuity of care to at least 60 women, including leading the care team during labor and birth. At the time of graduation, most student midwives will have participated in the care of about 200 women at some point during pregnancy, birth, or postpartum.¹

RECOGNIZING NUNAVIK MIDWIVES

Inuulitsivik midwifery predates the legal recognition of midwifery in Quebec by more than a decade. In 1991, before undertaking midwifery legislation, the government of Quebec authorized the evaluation of midwifery care through a pilot project establishing eight birth centers. Although well established, Puvirnituk agreed to participate in the evaluation process. Quebec passed the Midwives Act²⁶ to recognize midwifery in June, 1999. This act recognized and registered the currently practicing Nunavik midwives, but did not provide for continuing recognition of graduates. The Midwives Act recognizes only the university program at the University of Quebec at Trois Rivieres. There is agreement in the Nunavik communities that a model of education and care which is successful and culturally relevant cannot be replaced with one that has not proven successful in the north. Sending students to southern Canada for midwifery education could jeopardize the sustainability of maternity care in the north.⁷ Research points to the importance of education in the Canadian north and the recruitment and retention of health care workers from and in northern communities.²²⁻²⁵ To date, there have been nine graduate midwives in Nunavik; however, only five have been recognized under Quebec law, and there are currently seven student midwives in training. The Midwives Act included a clause that was intended to allow arrangements for Aboriginal communities to be negotiated,²⁶ and although discussions have taken place, the issue of how to recognize Nunavik midwives remains unresolved. Despite this, midwives in Nunavik continue to practice and teach new students, reminding Quebec of their presence before the enacted legislation, their excellent outcomes, and their recognition globally and within the communities they serve. There is ongoing work to resolve this situation at the regional, provincial, and federal level.

It is ironic that this struggle for recognition has been so difficult. Inuulitsivik midwifery has been used as an example across Canada, the entire circumpolar region, and globally. Inuulitsivik midwifery is used as a model in the recommendations made by the Canadian Royal Commission on Aboriginal Peoples²⁷ and by the Society of Obstetricians and Gynecologists of Canada.²⁸ The World Health Organization, in a letter to the government of Quebec, called Inuulitsivik midwifery "a very important innovative

project . . . If there ever was an example of health promotion . . . this is it."²⁹ At the International Confederation of Midwives 27th Triennial Congress in Brisbane, Australia, Inuulitsivik midwifery was featured as the opening keynote presentation. Delegates from the World Health Organization, the World Bank, and the International Federation of Obstetricians and Gynecologists who spoke later in the conference recognized Nunavik midwifery as an exemplary model, which could help meet Millennium Development Goals for Safe Motherhood.

BRINGING BIRTH BACK: SOCIAL AND CULTURAL CONTEXTS

With all the changes and women going south, the common knowledge—the things everyone knew about childbirth and health—began to disappear . . . People became very dependent on health care services . . . We knew birth had to come back to the north. Our aim was to revitalize that common knowledge and community involvement around the birth process—to put the responsibility back in the hands of the Inuit.

—Akinisie Qumaluk, Inuulitsivik midwife⁴

The establishment of the birth centers has been fundamental for community healing, and marks a turning point for many families who suffered from family violence in Nunavik. Male elders told the men that if they witnessed their partner giving birth, they would see that she has been through enough and respect and care for her.³⁰

Birth in the community is seen as part of healing, restoring skills and pride, and of capacity building in the community. Participating in birth builds family and community relationships and intergenerational support and learning, through promoting respect for traditional knowledge, and through teaching transcultural skills both within the local community and with nonlocal health care providers. The Inuit midwives are vital in promoting healthy behavior and in health education, and can be effective in this role in ways that non-Inuit health care workers could not hope to be.

After each birth, the midwives take a footprint of the newborn baby to put up in the hallway that connects the birth center to the rest of the health center. (See Back Page).

CONCLUSION

The implications of the Nunavik experience for midwifery practice and education are profound and often run counter to dominant beliefs and practices in the health care system. Inuulitsivik midwifery shows that birth in remote communities far from tertiary care can not only be safe, but also improve outcomes when compared with a policy of evacuation. It models sustainable and culturally-based local education in remote communities. Midwifery can contribute to maintaining meaning in cultures that are attempting to recover from the impacts of

colonization and rapid change. The lesson that midwives have an important role to play in promoting health and well-being and in cultural revival in Canadian aboriginal communities has the potential to inform other settings. Strong community support and collaboration between midwives from very different backgrounds has been critical to the success of Inuulitsivik midwifery.

The midwives have become a voice for our families and our ways of life.

—Nellie Tukalak, Inuulitsivik midwife¹

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Midwives practice in a wide variety of settings and the work done by midwives internationally is diverse, yet there is a common denominator: midwives *reach out* to women wherever they live. This was the theme that the International Confederation of Midwives (ICM) chose for the 2007 celebration of the International Day of the Midwife on May 5th, 2007. *'Reaching out'* is an important part of a midwife's job, not just to provide care for women who live a long way from a health facility, but to overcome other barriers to access. These barriers may be rooted in cultural or linguistic differences, or may be related to the timing, style or affordability of services. It is 'woman-centered' care that brings healthy outcomes for mother and baby and that means positive action from midwives to ensure that what they offer is what women want.

Kathy Herschderfer
Secretary General, International Confederations of Midwives

Narcotic Exposure in Pregnancy

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The occasional management of narcotic exposure in neonates

Len Kelly, MD
Division of Clinical Sciences,
Northern Ontario School
of Medicine, Sioux Lookout,
Ont.

Bryanne Minty, BSc
Faculty of Medicine,
University of Manitoba,
Winnipeg, Man.

Sharen Madden, MD
Joe Dooley, MD
Irwin Antone, MD
Division of Clinical Sciences,
Northern Ontario School
of Medicine, Sioux Lookout,
Ont.

Correspondence to:
Dr. Len Kelly;
lkelly@mcmaster.ca

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reviewed.*

Abuse of long-acting oxycodone is becoming commonplace in northwestern Ontario.¹ Among the many social and medical problems that arise from this is an increased incidence of use during pregnancy, leading to passive exposure and withdrawal in neonates. There are few Canadian data on the incidence of maternal narcotic abuse or neonatal abstinence syndrome (NAS). Standardization of diagnosis and treatment is still developing in the literature, as are treatment protocols among institutions. This paper will summarize relevant research findings and practical treatment options for rural clinicians.

INCIDENCE

The Sioux Lookout Meno Ya Win Health Centre delivers more than 320 neonates annually in a catchment area serving a population of 30 000, which is primarily composed of First Nation people.² In 2009, Kelly and colleagues noted a 13% incidence of maternal exposure to narcotics during pregnancy.³ This is in distinction to the reported rate of 5% in one American study.⁴ Unfortunately, the incidence noted by Kelly and colleagues is similar in scale to a 1992 report of exposure to cocaine in 12.5% of neonates born in a downtown Toronto hospital.⁵

Such pockets of substance abuse are documented internationally. In Yorkshire, UK, a recent study documented a significant rate of intravenous heroin abuse. In this prevalence study, women who abused substances had a concomi-

tant rate of infection with hepatitis C of 41%.⁶

NEONATAL ABSTINENCE SYNDROME

Neonatal abstinence syndrome may result from withdrawal from opiates, cocaine, amphetamines or antidepressants. The constellation of irritability of the central nervous system and respiratory, gastrointestinal and autonomic symptoms was summarized in 1975 by Finnegan and colleagues.⁷ The authors described the common symptoms that arise between 6 and 48 hours postpartum.^{7,8} The most frequent, in descending order, are tremors, high-pitched cry, sneezing, increased muscle tone, fist-sucking and regurgitation.⁹ Seizures can occur in 2% to 11% of infants who are undergoing withdrawal from opiates.¹⁰ Although acute opioid withdrawal usually manifests within 6 to 72 hours after birth, it can appear up to 6 weeks postnatally.^{8,11,12} Subacute withdrawal symptoms may occur up to 6 months after birth.^{12,13}

In the 1970s, the United States was experiencing a wave of intravenous heroin abuse and subsequent withdrawal in neonates. These often premature and sick infants were shown to do better when addicted mothers were treated with methadone.¹⁴ Much of the literature on NAS focuses on outcomes for urban-based methadone programs, and the more recent literature identifies treatment with buprenorphine as a safe alternative.^{15,16} Pregnancies in women treated with methadone are associated

with high rates of NAS (25%–85%).^{16–18} Interestingly, the dose of methadone is not always predictive of withdrawal in the neonate.^{19,20} Infants born to women who had received either long-acting morphine or methadone seemed to have a similar duration of NAS.²⁰ In one randomized study from Europe, mothers who received long-acting morphine had better harm reduction because they used less additional street opiates than mothers who received methadone.²¹ A 2008 Cochrane database meta-analysis found no significant difference in outcomes for opiate-dependent pregnant women who were given methadone, buprenorphine or long-acting morphine.²² Because rural communities, particularly First Nation communities in remote areas, often do not have access to methadone programs, long-acting morphine may be a good alternative when required.

DIAGNOSIS

Infants who were exposed to drugs before birth may develop a wide variety of symptoms, but usually seem healthy at birth. As symptoms appear, infection and hypoglycemia need to be excluded. Maternal history and collateral history are the mainstay of initial risk assessment. Routine laboratory testing is not standard. Urine testing can identify drugs consumed in the previous week. Meconium testing can detect earlier use but does not detect use of oxycodone.²³

The Modified Finnegan Neonatal Abstinence Score Sheet is becoming the international standard for assessing degree of withdrawal and parameters for treatment.²⁴ The system is somewhat subjective, but is a useful tool for assessing the occasional neonate exposed to narcotics.

The scoring system is available online.²⁵ Scoring is done after feeding in 2- or 4-hour intervals, and treatment with pharmaceuticals is commenced in neonates with scores above 8. Other scoring systems are available, including those by Lipschitz and Ortega.^{26,27}

TREATMENT

Nonpharmaceutical treatment is sufficient for neonates who score low on a NAS scale, and includes low light and stimulation, swaddling, use of a soother and side positioning.²⁸ If the infant becomes more jittery and scores above 8 on the Finnegan scoring system, oral morphine is typically instituted.^{29,30} The use of morphine as a first-line agent is supported by numerous studies and a 2010 Cochrane database meta-analysis.^{10,31,32} Its advan-

tage is seizure suppression, beneficial gastrointestinal side effects (decreases diarrhea) and assistance with development of the sucking reflex. At higher dosing, increased monitoring may be required because of risk of respiratory depression. A typical starting oral dose is 0.5 mg/kg/d divided into doses every 4–6 hours.³³ (Some protocols use incrementally higher doses for infants with higher Finnegan scores.³⁴) If the infant vomits shortly after dosing, the dose is repeated. If vomiting occurs 10–30 minutes after administration, half the dose is repeated, and if any vomiting occurs after 30 minutes, repeat dosing is not required.³³ Once the infant is stable, weaning by 10% every 2–4 days may commence.⁷ (Various concentrations of oral morphine are used in practice, including 1 mg/mL, 0.5 mg/mL, 0.4 mg/mL and 0.2 mg/mL.)

Some institutions prefer phenobarbital as first-line therapy (or in addition to morphine) for breakthrough seizures or in cases of abuse of nonnarcotic drugs. It is used at a dose of 5 mg/kg/d divided into 2–4 doses.³⁴ Some authors suggest an initial loading dose of 10–20 mg/kg, which can be given orally or intramuscularly, and generally needs no serum levels.³³ Provincial triplicate prescribing systems for controlled substances may affect hospital-based choice of agent. Physicians may choose phenobarbital because it makes for a more “acceptable” outpatient prescription once the neonate is discharged. In such cases, phenobarbital may be used as a first-line medication. Compared with morphine, phenobarbital is not as well supported by the evidence for the treatment of exposure to opiates; however, it is a familiar drug and is often also chosen for withdrawal from narcotics or unknown drugs in neonates. We have had a positive experience using it as a first-line treatment over the past 2 years. Oral clonidine, methadone or buprenorphine are other alternatives.^{35–37}

Clinicians should be aware that naloxone is contraindicated for use at resuscitation at birth in all infants who are at risk for NAS, because it will precipitate acute withdrawal.¹¹

BREASTFEEDING

The only contraindication to breastfeeding is positive or suspected HIV status.³⁸ Intoxication at birth may be reason to pump and discard the first feed, but abuse of narcotics or positive hepatitis C status are not contraindications to breastfeeding.^{39–41} Exposed neonates have lower rates of NAS if breastfed.³⁸

AFTERCARE

Many infants exposed prenatally to narcotics may not need specialized care. A recent cohort study done in England compared neonates with NAS who underwent either treatment in a neonatal ward or routine postnatal rooming-in. The authors found the latter group had a shorter length of stay with no other differences in outcome.⁴² A 2007 Vancouver study showed that rooming-in was associated with a significant decrease in the need for treatment for NAS, and mothers in the rooming-in group were more likely to take their babies home with them.⁴³

The length of stay reported in the literature ranges from days to weeks.^{8,44,46} Not all of the neonates' pharmacologic treatment needs to be in hospital.⁴⁶ One study from the United Kingdom reported that 29% of neonatal units allowed infants to be discharged home while taking medications (including phenobarbital or morphine).⁴⁶

Infants who have been prenatally exposed to narcotics need careful consideration and safety plans for discharge. Common initial recommendations include keeping all at-risk infants in hospital for at least 48 hours to ensure no late onset of symptoms from NAS. Despite somewhat chaotic family environments, many exposed neonates may be cared for within their families and may be candidates for outpatient treatment and weaning of medication. An Australian study of outpatient follow-up of 51 neonates who received treatment for NAS demonstrated a 92% follow-up rate and shorter lengths of treatment with morphine or phenobarbital.⁴⁷

Long-term studies of cognitive outcomes have not been a concern because, unlike alcohol, narcotics are not teratogenic.⁴⁸ A multiyear follow-up of infants with NAS demonstrated no cognitive impairment at preschool or school ages.⁴⁸

CONCLUSION

Rural clinicians may encounter infants with normal birth weights and Apgar scores who subsequently develop tremor, diarrhea, furtive hand-sucking and a high-pitched cry. Such neonates need frequent monitoring and the institution of a scoring system to detect NAS, such as the Modified Finnegan Neonatal Abstinence Score Sheet. If the Finnegan score is above 8, oral morphine or phenobarbital may be required for several days or weeks. Breastfeeding is encouraged unless HIV infection is present.

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Narcotic-exposed neonates in a First Nations population in northwestern Ontario

Incidence and implications

Len Kelly MD MCISc CCFP FCFP Joe Dooley MD CCFP FCFP Helen Cromarty RN Bryanne Minty Alanna Morgan
Sharen Madden MD CCFP FCFP Wilma Hopman MA

Abstract

Objective To document the incidence of neonatal abstinence syndrome (NAS) and the rate of narcotic use during pregnancy in northwestern Ontario, where narcotic abuse is a growing social and medical problem.

Design Retrospective chart review.

Setting The Sioux Lookout Meno Ya Win Health Centre catchment area in northwestern Ontario.

Participants Mothers and neonates for the 482 live births that took place in the 18-month study period (January 2009 to June 2010).

Main outcome measures Maternal drug use and neonatal outcomes were documented.

Results The incidence of narcotic (oxycodone) abuse during pregnancy increased from a low of 8.4% at the beginning of the study period to a high of 17.2% by mid-2010. Narcotic-using mothers were more likely to also use nicotine and alcohol, to have premature deliveries, and to be episodic users. Narcotic-exposed neonates experienced NAS 29.5% of the time; daily maternal use was associated with a higher rate of NAS (66.0%). While all infants roomed in with their mothers, exposed infants were more likely to require transfer to a tertiary care nursery. Infants with severe NAS were treated with oral morphine and had significantly longer hospital stays compared with the entire cohort (4.5 vs 1.5 days, $P=.004$). Narcotic abuse during pregnancy in our region is not currently associated with increased rates of HIV or hepatitis C infection, as intravenous route of administration is less common at present than intranasal and oral ingestion.

Conclusion Narcotic abuse during pregnancy is a considerable problem in First Nations communities in northwestern Ontario. Community-based initiatives need to be developed to address this issue, and medical and nursing staff need to develop surveillance, assessment, and therapeutic responses. Passive neonatal addiction and withdrawal result from maternal narcotic use during pregnancy. Rates of opioid use among pregnant Canadian women are unknown.

EDITOR'S KEY POINTS

- Narcotic abuse is a growing social and medical problem in northwestern Ontario, particularly in First Nations communities. Narcotic use during pregnancy can lead to neonatal abstinence syndrome. The researchers undertook this study to document the incidence and outcomes of oxycodone exposure during pregnancy in their region. It is the first incidence report about narcotic use during pregnancy in Canada.
- By the end of the study period, more than 17% of pregnant women were using opioids. Most used opioids occasionally, likely because access in their remote regions was often limited or episodic. As a result, few of the neonates required pharmacologic treatment for withdrawal. However, narcotic-exposed pregnancies had significantly more premature births ($P=.001$), had longer lengths of stay in hospital ($P=.004$), and were more likely to need transfer to tertiary care facilities ($P=.005$).

This article has been peer reviewed.
Can Fam Physician 2011;57:e441-7

Exposition des nouveau-nés aux narcotiques dans une population des Premières Nations du Nord-Ouest de l'Ontario

Incidence et répercussions

Len Kelly MD MCISc CCFP FCFP Joe Dooley MD CCFP FCFP Helen Cromarty RN Bryanne Minty Alanna Morgan
Sharen Madden MD CCFP FCFP Wilma Hopman MA

Résumé

Objectif Établir l'incidence du syndrome de sevrage néonatal (SSN) et le taux de consommation de narcotiques durant la grossesse dans le Nord-Ouest de l'Ontario, où l'abus de narcotiques est un problème social et médical sans cesse croissant.

Type d'étude Revue rétrospective de dossiers.

Contexte La région desservie par le centre de santé Meno Ya Win de Sioux Lookout, dans le nord-ouest de l'Ontario.

Participants Les mères et les nouveau-nés de 482 naissance vivantes survenues au cours des 18 mois de l'étude (entre janvier 2009 et juin 2010).

Principaux paramètres à l'étude On a documenté la consommation de drogues par les mères et les issues néonatales.

Résultats L'incidence de l'abus du narcotique oxycodone durant la grossesse a augmenté d'un minimum de 8,4% au début de l'étude à un sommet de 17,2% au milieu de 2010. Les mères consommant des narcotiques étaient plus susceptibles de consommer aussi de la nicotine et de l'alcool, d'avoir des accouchements prématurés et d'être des utilisatrices épisodiques. Les nouveau-nés exposés aux narcotiques ont présenté un SSN dans 29,5% des cas; une utilisation quotidienne par la mère augmentait ce taux à 66,0%. Alors que tous les nouveau-nés partageaient la même chambre que la mère, les nourrissons exposés ont plus souvent dû être transférés à une unité de soins néonataux tertiaires. Les nouveau-nés présentant un SSN sévère ont été traités par de la morphine orale et ont dû rester à l'hôpital plus longtemps que l'ensemble de la cohorte (4,5 vs 1,5 jours, $P=,004$). Jusqu'à présent dans notre région, l'abus de narcotiques ne s'est pas accompagné d'une augmentation des taux de SIDA ou d'hépatite C, la voie d'administration intraveineuse étant pour l'instant moins fréquente que la voie intra-nasale ou orale.

Conclusion La consommation de narcotiques durant la grossesse est un problème majeur dans les communautés des Premières Nations du Nord-Ouest de l'Ontario. Il faudra, conjointement avec ces communautés, élaborer des projets pour contrer ce problème, et le personnel médical et infirmier devra apporter des réponses sous forme de surveillance, d'évaluation et de traitement. La consommation de narcotiques par la mère durant la grossesse entraîne chez le nouveau-né de l'accoutumance et un syndrome de sevrage. On ignore le taux de consommation d'opiacés chez les femmes enceintes au Canada.

POINTS DE REPÈRE DU RÉDACTEUR

• La consommation de narcotiques est un problème social et médical qui ne cesse de croître dans le Nord-Ouest de l'Ontario, particulièrement dans les communautés des Premières Nations. La consommation de narcotiques durant la grossesse peut entraîner un syndrome de sevrage chez le nouveau-né. Dans cette étude, les auteurs voulaient établir l'incidence et les conséquences de l'exposition à l'oxycodone durant la grossesse dans leur région. C'est la première étude sur l'incidence de la consommation de narcotiques durant la grossesse au Canada.

• Vers la fin de l'étude, plus de 17% des femmes enceintes consommaient des opiacés, la plupart de façon occasionnelle, probablement parce que dans ces régions éloignées, la disponibilité est souvent limitée ou épisodique. Pour cette raison, peu de nouveau-nés ont nécessité un traitement pharmacologique pour sevrage. Toutefois, les grossesses exposées aux narcotiques se sont accompagnées d'un nombre significativement plus élevé de naissances prématurées ($P=,001$) et d'un plus long séjour à l'hôpital ($P=,004$), et elles étaient plus susceptibles de nécessiter un transfert dans un service de soins tertiaires ($P=,005$).

Cet article a fait l'objet d'une révision par des pairs.
Can Fam Physician 2011;57:e441-7

Neonatal withdrawal from narcotics and other medications or drugs of abuse was first described as *neonatal abstinence syndrome* (NAS) in 1975 by Dr Loretta Finnegan. She described a generalized disorder of hyperirritability of the central nervous system, gastrointestinal and respiratory dysfunction, and vague autonomic nervous system symptoms.¹

In Australia the occurrence of NAS has increased dramatically from 0.97 per 10 000 live births to 42.4 per 10 000 live births in the past 25 years.² In northern Ontario, narcotic abuse (in particular oxycodone in long-acting OxyContin or short-acting Percocet) has become an increasing problem.³ Remote First Nations communities with high rates of unemployment, poverty, and overcrowding bear the additional social and economic burden of narcotic abuse and addiction, with profound narcotic abuse in some of these communities.⁴ A 2008 survey carried out in the northern Ontario reserve of Constance Lake revealed that 46.3% of respondents abused prescription drugs and 39.6% abused illegal or street drugs.⁴

Narcotic abuse among First Nations populations affects the entire community, as well as the physical, mental, emotional, and spiritual well-being of the individuals.⁴ Self-identified risks for drug use in these communities include peer pressure, cultural loss, grief, lack of self-esteem, trauma, housing problems, domestic violence, and mental health issues.⁴

Female drug abusers are often of reproductive age—in the United States, 90% of female drug abusers are in that age group.⁵ The birth rate in First Nations communities is double that of the rest of Canada (23.0 per 1000 women vs 11.1 per 1000 women), and women who abuse oxycodone might well do so during pregnancy.⁶

The Sioux Lookout Meno Ya Win Health Centre (SLMHC) provides health care and maternity services to a widely dispersed population of 25 000 primarily First Nations patients in northwestern Ontario.⁷ The researchers at SLMHC undertook this study to document the incidence and outcomes of oxycodone exposure during pregnancy in our region. It is the first incidence report about narcotic use during pregnancy in Canada.

METHODS

This is a retrospective descriptive study of neonatal exposure to oxycodone. Maternal and neonatal chart reviews on all 482 deliveries at the SLMHC from January 2009 to June 2010 were undertaken by physicians and researchers involved in the maternity program at the SLMHC. We examined the most recent 18 months divided into 6-month periods, as we had noted a clinical increase in maternity patients who admitted to narcotic abuse. Ethics approval was obtained from the Research Review Committee of the SLMHC. Our First

Nations Special Advisor (H.C.) was involved from planning to synthesis and approval of the final paper. Our findings were shared with our regional First Nations Health Authority before submission for publication.

Data were collected in Excel and imported into PASW Statistics, version 18.0, for statistical analysis. Descriptive analysis of the overall obstetric program was followed by bivariate analysis according to oxycodone exposure using χ^2 tests for categorical data (Pearson or Fisher exact tests, as appropriate) and independent-samples *t* tests for continuous data. Our chart review included summaries of charts from patients' home communities, twice weekly prenatal clinics held in Sioux Lookout from 38 weeks' gestation onward, and patient hospital records. We asked about daily use and occasional use (defined as from several times per week to monthly, which we described as episodic or "binge" use) of opioids. Infant Finnegan scores were recorded and categorized by whether or not they were greater than 7, as that is the protocol value above which more serious withdrawal is noted and pharmacologic treatment might be required. This scoring system is widely used but not yet validated.

A priori sample size calculations were not completed, as the parameters to estimate power and sample size did not yet exist. However, post hoc power calculations on the primary outcomes revealed that the power ranged from 64% (prematurity) to 84% (length of stay).

RESULTS

During our study period we had 482 live births; 61 of the neonates were exposed to oxycodone in utero. The incidence of oxycodone exposure during pregnancy increased significantly in the study period ($P=.050$) from an initial 8.4% in the first 6 months of 2009 to a high of 17.2% in the first 6 months of 2010 (Figure 1), with most of those who used oxycodone being occasional users (Figure 2). Narcotic-using mothers were typically smokers and used more alcohol than nonusing mothers did, and there was a trend toward increased parity. The 2 groups were otherwise similar with regard to comorbidities (Table 1).

There were 61 narcotic-exposed infants in this cohort. Exposed and nonexposed groups of newborns showed equivalent birth weight and Apgar scores. Narcotic-exposed pregnancies had significantly more premature births ($P=.001$), had longer lengths of stay in hospital ($P=.004$), and were more likely to need transfer out ($P=.005$) to tertiary care facilities (Table 2). Among these 482 deliveries there were no neonatal deaths and no HIV or hepatitis C infections. Length of stay was longer among neonates with higher Finnegan scores. Infants with scores greater than 7 had a mean length of stay of 4.5 days versus 1.5 days for the total cohort ($P=.004$).

Figure 1. Percentage of exposed neonates (n=61) over consecutive 6-month periods (January 2009 to June 2010): Pearson χ^2 for differences in proportions $P=.05$.

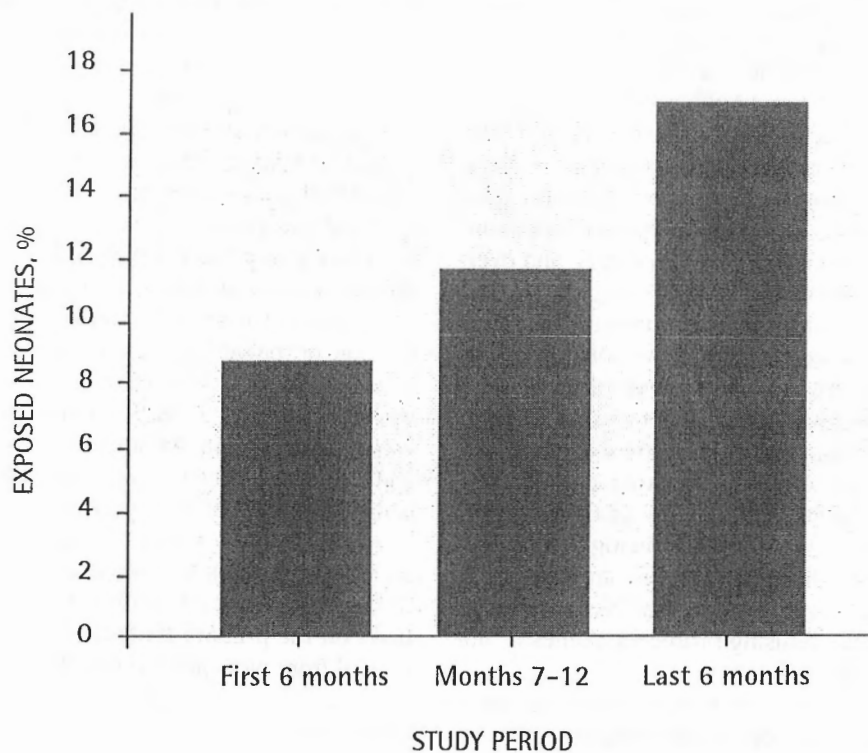
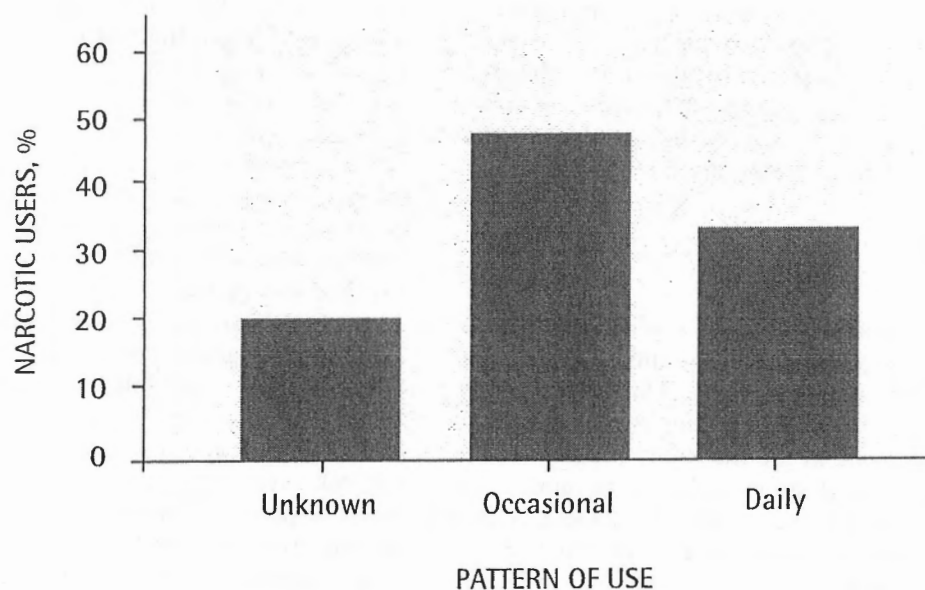


Figure 2. Patterns of narcotic use (n=61)



Twenty-one infants exhibited symptoms of NAS (4.3%) and had Finnegan scoring done; 18 of these neonates had been exposed to narcotics and 3 had been exposed to alcohol. Three required pharmacologic treatment of opioid withdrawal, 1 of whom was transferred to a tertiary care centre. Among narcotic-exposed infants the rate of NAS was 29.5%, and 11.5% were strongly affected, with at least 1 Finnegan score greater than 7. Daily maternal use of narcotics was associated with a higher rate (66.0%) of NAS-affected infants when compared with episodic users, even though occasional users were far more common (Figure 2). The exposed infants were more likely to be from remote First Nations communities and were also more likely to have been exposed to alcohol.

All our infants roomed in with their mothers, and all mothers were encouraged to breastfeed.

DISCUSSION

We have documented for the first time a very high rate of narcotic exposure during pregnancy in northwestern Ontario. Currently we are seeing a binge pattern of use, dictated perhaps by the geographic remoteness of many of our patients, where access to illicit drugs is episodic. The increasing incidence of oxycodone abuse during pregnancy is consistent with our observations and with media reports of a pervasive abuse of this specific drug in our region.

Methadone, often referenced as optimal treatment for opioid-addicted mothers, is not readily available in remote communities and might not even be the best maternal strategy for episodic users like those most commonly found in our area. The literature also supports long-acting morphine as equivalent maternal

prenatal maintenance therapy if such is required.⁸ We generally use MS Contin, a long-acting opioid that can only be ingested orally and cannot be snorted or used intravenously. Only a few of our patients received it antenatally, usually self-identified daily or intravenous opioid abusers. Breastfeeding and rooming-in are standard care at our facility for these patients.⁹⁻¹¹

Oxycodone, the common drug of abuse in our region, is generally taken as a tablet or crushed and snorted, but it can also be injected intravenously. Our area generally has low rates of HIV and hepatitis C infection, but community physicians are seeing increasing intravenous injection use of this drug of abuse. In such closed communities, this raises concerns about a changing pattern of infectious disease, including risk of HIV, hepatitis C, and methicillin-resistant *Staphylococcus aureus* infections and Gram-positive sepsis, which will further challenge maternal and child health in this region. An urban-based Australian study noted rates of hepatitis C in intravenous narcotic-abusing mothers of NAS infants to be greater than 80%.¹²

Our low rate of NAS requiring pharmacologic treatment is likely a function of the pattern and dosage of oxycodone use. Half of our patients were self-described occasional users. Infants of methadone-treated mothers described in the literature traditionally have much higher rates of NAS. The infants of our daily users did have a higher rate of NAS (66%), which is similar to these studies of methadone-treated mothers.

Our typical narcotic-exposed neonate appears well at birth. The neonates in our study had normal Apgar scores and did not have significantly lower birth weight. These findings are common to most other recent studies. The normal Apgar score is expected, as withdrawal generally occurs some time after delivery, and the change in

Table 1. Maternal characteristics: Characteristics that were statistically different between exposed and nonexposed women are boldface.

CHARACTERISTIC	ALL BIRTHS (N=482)	EXPOSED MOTHERS (N=61)	PVALUE*
Mean (SD) age, y	24.4 (6.03)	24.5 (6.2)	.326 [†]
Mean (SD) parity	1.67 (1.72)	1.82 (1.47)	.474 [†]
Mean (SD) gestational age, wk	39.1 (1.3)	38.8 (1.5)	.045 [†]
Smoking, n (%)	278 (57.7)	50 (83.3)	<.001
Alcohol use, n (%)	116 (25.3)	21 (34.4)	.050
Hypertension, n (%)	37 (7.7)	6 (10.5)	.418
Type 2 diabetes mellitus, n (%)	11 (2.3)	1 (1.7)	.735
Gestational diabetes, n (%)	26 (5.4)	2 (3.4)	.454
Hepatitis B, n (%)	2 (0.4)	0 (0)	.590
First Nations community, n (%)	379 (78.6)	58 (95.1)	.004
Cesarean section, n (%)	118 (24.5)	14 (23.0)	.935
Nonelective cesarean section, n (%)	83 (17.2)	10 (16.4)	.924
Out-of-hospital deliveries, n (%)	13 (2.7)	3 (5.0)	.244
Postpartum hemorrhage, n (%)	70 (14.5)	7 (11.5)	.462

*Significance calculated using χ^2 tests, except as marked.

[†]Significance calculated using t tests.

Table 2. Neonatal characteristics: Characteristics that were statistically different between exposed and nonexposed neonates are boldface.

CHARACTERISTIC	ALL BIRTHS (N=482)	EXPOSED NEONATES (N=61)	P VALUE*
Mean (SD) birth weight, g	3591 (519)	3516 (577)	.229
Mean (SD) 1-min Apgar score	8.48 (0.98)	8.5 (1.0)	.856
Mean (SD) 5-min Apgar score	9.00 (0.36)	8.95 (0.6)	.259
Mean (SD) head circumference, cm	34.9 (1.7)	34.9 (1.5)	.772
Mean (SD) length, cm	51.1 (3.3)	51.1 (3.2)	.768
Mean (SD) arterial pH	7.25 (0.01)	7.26 (0.8)	.539
Mean (SD) venous pH	7.30 (0.08)	7.31 (0.07)	.132
Preterm (<37 wk), n (%)	11 (2.3)	5 (8.2)	.001 [†]
NAS, n (%)	21 (4.3)	18 (29.5)	<.001 [†]
Finnegan score > 7, n (%)	9 (1.9)	7 (11.5)	<.001 [†]
Males, n (%)	261 (54.1)	40 (65.6)	.055 [†]
Transfer to tertiary care, n (%)	7 (1.5)	4 (6.8)	.005[†]

NAS—neonatal abstinence syndrome, pH—acidity.

*Significance calculated using *t* tests, except as marked.

[†]Significance calculated using χ^2 tests.

the infant's clinical presentation is one of the hallmarks of NAS. Birth weight was low in studies of heroin users in the 1970s and 1980s, but such low birth weight has not been seen in more recent studies, likely owing to improved provision of obstetric care to addicted patients.

We did find an increased risk of prematurity in the narcotic-exposed group (8.2%, *P* = .001). Other NAS studies have showed similarly higher rates of prematurity.¹³

Follow-up care for mother and child at our centre is arranged through community-based medical, nursing, and counseling services and referral to regional programs, including the Children's Aid Society when appropriate.

Physicians in our practices have ceased prescribing oxycodone-containing medications (ie, Percocet and OxyContin), and these medications have also been removed from the hospital formulary.

Limitations

Our study is limited by the retrospective methodology of chart review. Also, the topic is a difficult one to explore and we believe that many patients would choose not to disclose substance abuse during pregnancy. This would explain the 3 infants with symptoms of NAS whose mothers did not self-report oxycodone use. The Finnegan scoring system was just introduced at the beginning of the study period. This semi-objective instrument is open to great interobserver variability. Nursing orientation is also an ongoing process, particularly in a general nursery with low rates of NAS. The time frame of our study marked the initiation of physician diagnosis and treatment of NAS and, therefore, might reflect a degree of under-reporting.

Conclusion

Oxycodone abuse is a growing problem in northwestern Ontario. Obstetric units will need to be vigilant and well

prepared. Assessment tools such as Finnegan scoring and regional treatment protocols will need to be available in order to develop the expertise and comfort levels required for effective treatment of both mothers and infants. Remote First Nations communities might be hardest hit economically, socially, and spiritually.

A comprehensive approach to substance abuse in remote First Nations communities is needed. Because it is an in-community problem, in-community solutions need to be developed and appropriately supported. These could take different directions than traditional Western approaches to addictions, which would require travel to distant treatment centres, thus causing another level of social disruption. Communities will have to decide for themselves if First Nations healing traditions need to be combined with medical withdrawal management so that affected community members can safely stay home for treatment and healing.

Dr Kelly is a rural clinician, a researcher, and Professor in the Division of Clinical Sciences at the Northern Ontario School of Medicine in Sioux Lookout, Ont. Dr Dooley is Chief of Obstetrics at Sioux Lookout Meno Ya Win Health Centre and is Assistant Professor in the Division of Clinical Sciences at the Northern Ontario School of Medicine. Ms Cromarty is Special Advisor on First Nations Health at Sioux Lookout Meno Ya Win Health Centre. Ms Minty is a medical student at University of Manitoba and a research intern at Sioux Lookout Meno Ya Win Health Centre. Ms Morgan is a research intern at Sioux Lookout Meno Ya Win Health Centre. Dr Madden is a rural clinician, a researcher, and Assistant Professor in the Division of Clinical Sciences at the Northern Ontario School of Medicine. Ms Hopman is an epidemiologist and a researcher at Kingston General Hospital and in the Department of Community Health and Epidemiology at Queen's University in Kingston, Ont.

Contributors

All authors contributed to the concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

Competing interests

None declared

Correspondence

Dr Len Kelly, McMaster University, Family Medicine North, Box 489, 79 5th Ave, Sioux Lookout, ON P8T 1A8; telephone 807 737-3803; fax 807 737-1771; e-mail lkelly@mcmaster.ca

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First Nations Menopause

Madden S, St Pierre-Hansen N, Kelly L, Cromarty H, Linkewich B, Payne L. First Nations Women's Experiences and Perspectives of Menopause: A Qualitative Study. *Canadian Family Physician* 2010;56:e331-7.

This qualitative study of 18 perimenopausal First Nations women explores the menopause experiences of First Nations women in Northwestern Ontario. Participants explained that menopause is generally not discussed. Madden emphasizes the need for understanding the different influences on a women's menopause experience and avoid attaching preconceived ideas.

Webster R. Aboriginal Women and Menopause. *J Obst Gynaecol Can* 2002;24(12):938-40.

This article explores the characteristics of menopause in Canadian Aboriginal women. Through an extensive literature review the author found that menopause might have a positive effect by increasing a woman's freedom within their community.

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First Nations women's knowledge of menopause

Experiences and perspectives

Sharen Madden MD MSc CCFP FCFP Natalie St Pierre-Hansen Len Kelly MD MCISc CCFP FCFP Helen Cromarty RN
Barbara Linkewich RN IBCLC CHPCN(C) Lauren Payne MPH

ABSTRACT

OBJECTIVE To understand and describe the menopause experiences and perspectives of First Nations women residing in northwestern Ontario.

DESIGN Phenomenologic approach using in-depth qualitative interviews.

SETTING Sioux Lookout, Ont, and 4 surrounding First Nations communities.

PARTICIPANTS Eighteen perimenopausal and postmenopausal First Nations women, recruited by convenience and snowball sampling techniques.

METHODS Semistructured interviews were audiotaped and transcribed. Themes emerged through a crystallization and immersion analytical approach. Triangulation of methods was used to ensure reliability of findings.

MAIN FINDINGS This study confirms the hypothesis that menopause is generally not discussed by First Nations women, particularly with their health care providers. The generational knowledge gained by the women in this study suggests that a variety of experiences and symptoms typical of menopause from a medical perspective might not be conceptually linked to menopause by First Nations women. The interview process and initial consultation with translators revealed that there is no uniform word in Ojibway or Oji-Cree for menopause. A common phrase is "that time when periods stop," which can be used by caregivers as a starting point for discussion. Participants' interest in the topic and their desire for more information might imply that they would welcome the topic being raised by health care providers.

CONCLUSION This study speaks to the importance of understanding the different influences on a woman's menopause experience. Patient communication regarding menopause might be enhanced by providing women with an opportunity or option to discuss the topic with their health care providers. Caregivers should also be cautious of attaching preconceived ideas to the meaning and importance of the menopause experience.

EDITOR'S KEY POINTS

- North American First Nations women often have different experiences with and perceptions of menopause compared with other Western women; family physicians working in aboriginal areas need to take these differences into account in order to provide effective and comprehensive care for menopausal women.
- The word *menopause* might not exist in many First Nations languages, and physical and emotional symptoms medically attached to the biological process might not be identified as connected to the menopausal experience.
- Some First Nations women come from backgrounds in which menopause is not discussed and therefore might experience discomfort with the subject; however, these women might still experience a desire for information, particularly as communication practices regarding the subject of menopause have changed over time.
- Health care providers can initiate discussion of menopause by referring to "that time when periods stop," paying attention to language barriers and acknowledging the various stages in a woman's life.

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Connaissance de la ménopause chez les femmes des Premières nations

Expérience et perspectives

Sharen Madden MD MSc CCFP FCFP Natalie St Pierre-Hansen Len Kelly MD MCISc CCFP FCFP Helen Cromarty RN
Barbara Linkewich RN IBCLC CHPCN(C) Lauren Payne MPH

RÉSUMÉ

OBJECTIF Comprendre et décrire ce que les femmes des Premières nations du Nord-Ouest de l'Ontario connaissent et pensent de la ménopause.

TYPE D'ÉTUDE Approche phénoménologique à l'aide d'entrevues qualitatives en profondeur.

CONTEXTE Sioux Lookout, Ontario et 4 communautés des Premières nations des environs.

PARTICIPANTES Dix-huit femmes pérимénopausées ou ménopausées des Premières nations, recrutées de façon informelle et par des techniques d'échantillonnage boule de neige.

MÉTHODES Les entrevues semi-structurées ont été enregistrées sur ruban magnétique et transcrites. Les thèmes ont été extraits par une approche analytique de cristallisation et d'immersion. On s'est assuré de la fiabilité des observations par triangulation des méthodes.

PRINCIPALES OBSERVATIONS Cette étude confirme l'hypothèse que les femmes des Premières nations ne discutent généralement pas de la ménopause, particulièrement avec les dispensateurs de soins. Les connaissances que les femmes de cette étude ont acquises de leur milieu laissent croire qu'une variété d'expériences et de symptômes qui, d'un point de vue médical, sont typiques de la ménopause pourraient ne pas être vus ainsi par les femmes des Premières nations. Lors des entrevues et de la consultation initiale avec traducteurs, on s'est aperçu qu'il n'y avait pas de terme uniforme pour ménopause en ojibway ou en oji-cri. Une expression communément rencontrée est « ce moment où les règles cessent » : cette phrase peut être utilisée par les soignants pour entamer la discussion. L'intérêt des participantes pour ce sujet et leur désir d'en savoir davantage semblent indiquer qu'elle souhaitait que leurs soignants soulèvent cette question.

CONCLUSION Cette étude souligne l'importance de comprendre les différents éléments qui influencent la perception qu'une femme a de la ménopause. On pourrait amener les patientes à parler davantage de la ménopause si on leur donnait l'occasion ou l'option d'en discuter avec ceux qui les soignent. Les soignants devraient aussi prendre garde de ne pas associer d'idées préconçues à la signification et à l'importance de l'expérience de la ménopause.

POINTS DE REPÈRE DU RÉDACTEUR

- Les femmes des Premières nations de l'Amérique du Nord ont souvent une expérience et une perception de la ménopause qui diffèrent de celles des autres femmes des Amériques; le médecin de famille qui travaille chez les Autochtones doit tenir compte de ces différences s'il veut prodiguer des soins efficaces et complets aux femmes ménopausées.
- Le terme ménopause pourrait ne pas exister dans plusieurs langues des Premières nations et les symptômes physiques et émotionnels qui accompagnent ce processus biologique pourraient ne pas être vus comme en lien avec la ménopause.
- Certaines femmes des Premières nations viennent de milieux où on ne parle pas de ménopause et sont donc mal, à l'aise avec ce sujet; elles pourraient quand même désirer en être informées, surtout depuis que les façons de faire ont évolué avec le temps.
- Les soignants peuvent entamer une discussion sur la ménopause et parlant « du temps où les règles cessent » tout en tenant compte des barrières linguistiques et en étant conscients des différentes étapes de la vie d'une femme.

Cet article a fait l'objet d'une révision par des pairs.
Can Fam Physician 2010;56:e331-7

Menopause is a universal and individualized experience. It is a complex process, influenced by biological, psychological, and cultural factors.

Research examining cross-cultural symptoms suggests that menopausal experiences vary among societies and groups.¹⁻⁶ It is unclear whether reported menopausal differences among ethnicities relate to variations in occurrence, perception, or reporting of symptoms^{7,8} or to methodologic challenges of cross-cultural inquiry.⁹

This study was initiated by a group of caregivers in northwestern Ontario who identified a lack of both documented and anecdotal information on First Nations women's experiences with menopause.

An anthropologic approach views biological processes, such as menopause, as being mediated through cultural understanding, socioeconomic conditions, and social circumstances.¹⁰ Kaufert, a Manitoba anthropologist, and Gilbert suggest a cultural stereotype of the menopausal experience can shape the individual experience, including the expected symptoms.¹⁰

A greater understanding of First Nations women's experiences with and perspectives of menopause by primary health care providers is imperative to providing effective and holistic care to this underserved population. This study might also have implications for further research in this area among aboriginal groups across Canada.

Literature review

Seven databases (HealthSTAR, HAPI [Hispanic American Periodicals Index], EMBASE, OVID MEDLINE, OVID Nursing Database, AMED [Allied and Complementary Medicine Database], and PsycINFO) were searched to find articles on North American aboriginal women and menopause published in the past 30 years. The search revealed scant findings: 1 literature review, 1 mixed-methods study, and 3 qualitative studies.

The 2002 literature review by Webster¹¹ revealed 4 early studies between 1891 and 1963, which found that menopause had a small and possibly positive effect on aboriginal women's way of life.¹¹ There was documentation of fewer vasomotor symptoms in aboriginal women, but these summarized studies were small and had incomplete methodologies.

A primarily quantitative study of 150 Blackfeet women in Montana examined the timing of menopause. They found early age at menarche and low household income were associated with a delaying effect on menopause.¹²

Three interesting qualitative studies explored the experiences of aboriginal women: In 2000, 23 focus groups consisting of Hispanic, Navajo, and white women (N=158) in New Mexico explored ethnic variations in women's attitudes toward and experiences

with menopause.¹³ The study revealed that women across cultures were much more alike than they were different regarding their attitudes toward menopause, but more traditional women (ie, Navajo women and Latina immigrants) did relate fewer or no menopausal symptoms. Factors differentiating traditional women from modern women included diet, lifestyle, parity, and experience of a ceremony upon menarche. All groups identified a lack of information, wished that women in their families had better prepared them for menopause, and expressed dissatisfaction with doctor-patient communication.¹³

A 2005 study in Nova Scotia employing focus groups with Mi'kmaq women (N=42) revealed that participants "know little about the mechanics of menopause but understand a great deal about holistic change of life."¹⁴ The menopausal time of life was marked by evolving and changing relationships, acceptance of aging and change, a time of rest, an increased focus on self, and a time of freedom from childbearing and the constraints of women's roles. Women's expectations of menopause were shaped by the experiences of women in their families, despite the fact that most family members did not talk about menopause or reproductive change. Misinformation and stories of suffering contributed to negative and fearful expectations. Self-perceptions were described as overwhelmingly positive; women who had entered menopause tended to experience an increased sense of autonomy and were viewed as respected elders. Doctors were perceived as knowing little about menopause beyond symptoms and details of hormone replacement therapy.¹⁴

In 1991, a focus group of 8 Mohawk women in Quebec, who met over an 8-week period, placed menopause in the continuum of life.¹⁵ Conceptions of time were important. These women's menopausal experiences involved a time of shifting priorities from family to self, a desire to spend time meaningfully, and a perception of self along one's life trajectory.¹⁵

METHODS

This study employed a phenomenologic approach using qualitative in-depth interviews. The semistructured interview questions were developed in a bicultural, interdisciplinary setting (Box 1). Additional consultation with a network of 5 interpreters was done to select appropriate wording of interview questions, particularly surrounding translation of the word *menopause*.

First Nations consultation

The National Aboriginal Health Association's research principles of ownership, control, access, and possession were respected and followed.¹⁶ The chiefs of each of the 4 targeted First Nations communities granted the team

permission to interview women in their respective communities. The First Nations Health Advisor to the Sioux Lookout Meno Ya Win Health Centre (SLMHC) was involved in the design and analysis stages of the project and guided the team toward a culturally appropriate process, and also approved the final draft of the manuscript before submission for publication. Health directors of the communities were consulted and provided research support where available. The SLMHC Elders' Council and 10 of the staff interpreters were involved in the project and were given the opportunity to provide feedback to the research team. Ethics approval was granted by the SLMHC.

Data collection

Convenience sampling techniques were used to recruit 18 First Nations women, 9 from Sioux Lookout and 9 from the 4 surrounding First Nations communities. Participants who were either perimenopausal or postmenopausal by way of natural or surgical menopause were asked to participate. Potential participants were identified by the research team, community health workers, community leaders, and by word of mouth.

Box 1. Semistructured questions used in the interview process

1. Can you tell us about the age at which you had your last period?
2. What did you know about it?
3. Did your mother, sisters, aunts, or grandmothers ever tell you about it?
 - a. When was that?
 - b. What did they tell you?
4. Did you know enough about it when it happened to you?
 - a. How did you find out information?
 - b. What did you need to know more about?
5. When it happened to you, what did you experience? How old were you then?
6. When it happened to you, how did you think about it? How did you feel about it?
7. Did you feel good or bad about it?
8. In your circle of friends and family, is it discussed? And what is said?
9. If you were going to explain it to a younger woman, what would you tell her?
10. Is there information that you would have liked to know before it started or during the early stages? Can you tell what sort of things might have been helpful?
11. Is there anything else you would like doctors and nurses to know about this topic?

Each interview was conducted by 2 female researchers, who took field notes and audiotaped interviews. All but 2 interviews were transcribed verbatim; the audio files of those 2 interviews were lost and analyses were based on the interviewers' field notes alone. Interpreters were used as required.

Data analysis

Data were analyzed for thematic patterns. Five researchers independently analyzed the interviews for main concepts and assigned them codes. The collated codes were then organized into thematic categories and overarching themes by 3 researchers using an immersion and crystallization approach.

FINDINGS

The first thing we learned from our initial consultations with our First Nations researchers and elders was that there was no consistent word for menopause in the regional languages of Ojibway and Oji-Cree. It was commonly referred to as "that time when periods stopped." We adopted this terminology and only used the word *menopause* when the participant introduced it. The second finding was that many participants began their narrative about *menopause* by discussing menarche experiences. These stories noted onset of menses with or without traditional ceremonies as well as residential school menarche experiences.

Thematic analysis delivered 3 overarching themes regarding menopause among First Nations women: knowledge, communication, and experience (**Figure 1**).

Knowledge

Sources of information about menopause varied. Nine of the 18 women gained some sort of information from their mothers. One woman described open communication with her mother who also provided her with comprehensive information:

I knew it was the next stage in the woman's stage[s] of life ... because my mother was very open with us like that. I mean talking about the woman, I mean the feminine side, I mean what happens to a female. So we would chat, and [with respect to] that part we knew what my mother was going through.

The other 8 women received information that was limited to the cessation of menstruation at a certain age or a description of the phases of life:

My mom just used to tell me that there's a certain age that I wouldn't get my period anymore. That's about it. There were no stories or anything like that.

She, my grandmother, said, "as I'm sitting here, I have these different symptoms." Again, I didn't understand—I was about 12 or 13 and I was sitting with her, and she said to me, "One day your monthly cycle will go away and your body will just do things that you know [are] going to be different within you." But she didn't describe the different symptoms.

Research | First Nations women's knowledge of menopause

Other sources of information regarding menopause included books, other women (eg, older women, coworkers, and sisters), and health care providers. Some women received either no information or misinformation. One participant thought she was pregnant when her periods stopped and another heard from her aunt that premature menopause was caused by having "so much on your mind, so much anger, or [by being] upset or depressed or something."

For many women information and understanding were limited:

And that time, when I'm feel[ing] sweaty and splash like that—really hot—I just came here and [a nurse] told me that I had the menopause ... and I didn't ask that much, what that mean[t], menopause. I told her "what's that mean, menopause?" [laughter]

The only thing we know is the very first day and then menopause ... it's just not talked about.

I don't really know much, like what to experience ... I just know about having hot flashes. I guess dry mouth too. I don't know.

Oh gosh. It was not something that was talked about. The first time I heard about menopause must have been ... I suppose maybe in my twenties, after I had had children already. I read books in the hospital. My grandmothers never talked about it. My mother never talked about it.

Many women described the need for more information

and enhanced awareness about what to expect, a greater understanding about the process, and information on relevant medications:

It would be more helpful if they read something regarding menopause, and for them to know what it is that they're going through and that it's not going to hurt them, they're not going to get a disease Some of them are probably scared about what's happening to them.

But the medical part of it, I don't really know, like what is it that's happening inside you? And I don't think that's something that is known enough, or talked about enough.

Communication

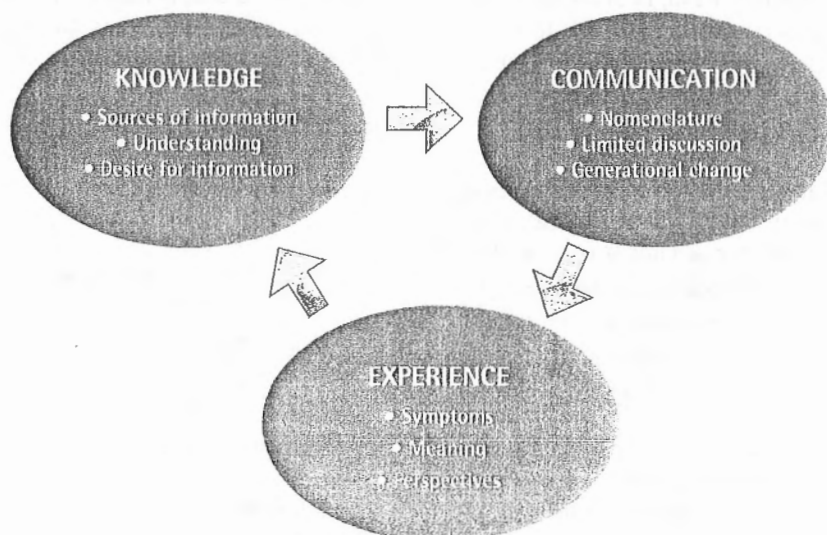
Most participants described menopause as something that was not discussed:

I'm glad [the study is] being done, because it's almost like [menopause is] hidden, hush-hush, especially when it comes to the older women. Some of them will not talk about that kind of thing.

And there's so many of them ... they don't want to talk about it. I guess they feel ashamed with it, especially when they have irregular periods, and also when they have menopause [T]hey don't know what to expect.

No. I'm very quiet, like I just take, take, take it, I don't how to say it ... like I know it's going to happen, I

Figure 1. Themes of First Nations women's menopause perspectives and experiences



don't really want to talk about it, like, I know it's not bugging me or anything about my body. Maybe if it was, I would talk to somebody.

Some women experienced open communication with their sisters and other women:

[W]e would share and comment on how we can help each other. So that nobody's left out as sisters.

Yes, the girls that I work with, I tell them ... I'm getting them ready now.

Many women implicitly identified a generational change in which menopause is increasingly discussed:

I don't know about now—but those years when I was working and most of the women wouldn't talk about it ... because of ... they don't ... they don't even tell when they have a period. Now, today, my girls they're telling every time they're having [a] period.

Now that was her time, now my time ... being a grandma, it's [a] very sacred thing. You talk to your granddaughters or even your grandsons about it.

So, it's all a matter of how you look at it and what generation you were raised to believe.

Several informants described health care provider communication as an element of their menopause experiences. Others identified a need for more information from doctors. A couple of the women expressed a need for doctors to be more holistic. One woman identified the need for doctors to recognize language barriers:

See, I speak English as a second language—I have to translate it up here [points to head] in order for me to understand what the doctor is trying to say to me ... so that way it takes time. But I know that the doctors are so busy and I have that common courtesy not to ask questions with the doctor.

I think doctors, all healers, should understand that it's not just curative. It involves your mental, your emotional ... you know? All that kind of stuff. And to look at it from all angles. They themselves need to understand that in order to be talking to me! [laughing] Because I have feelings, this is my body. This is my experience. Don't just come to me at one angle.

Experience

Many participants viewed menopause in a neutral or positive way. Some did not identify any value attached to the experience and others saw it simply as the cessation of menstruation: "We didn't think nothing of it,

because we were told [about it] when we were young women. We didn't think anything. We expected it." It was described at times as a phase or stage in life. A couple of participants expanded on this concept as a time when women are more respected and seen as sacred:

At that stage too, where women are menopausal, they're very respect[ed] people in the First Nations members, I guess You know, they look at you as a woman with wisdom, especially young girls. So that ... I can see it coming with myself.

So you're considered elderly—not elderly as in old and grey and wrinkled, but old and wise, because you've given birth how many times, and you have that knowledge to teach.

[B]elieving in my traditional ways and beliefs as a woman makes a big difference. I don't think I would have gone through my menopause if I didn't know my beliefs and my practices. Because in our belief, we hold the woman very sacred; she is the life giver.

Six women experienced no symptoms and 6 expressed symptoms as central to their menopause experience. Mood swings and hot flashes predominated:

[I would tell a younger woman] that they'll experience moodiness; you cry easily, but you won't know why they're crying, I think.

[Y]ou have the night sweats and the irritability because you're not rested half the time. So I don't know if it's the menopause or the diabetes, you know your sugars are going out of whack and you're feeling ... I don't know.

Yeah, like a couple days now and today, this morning, [I had hot flashes]. I was kind of scared, like I didn't know what was happening.

I still have this feeling of having your bones become really hot. They feel hot, and it's very uncomfortable, very uncomfortable.

DISCUSSION

In conventional Western culture, *menopause* is a well-known term referencing a woman's multifaceted experience. There is no word for this biological and emotional process in Oji-Cree or Ojibway. It is referred to as "that time when a woman's bleeding or periods stop." Whether this nomenclature references a limited characterization of menopause among First Nations women is unclear.

Symptoms reported included hot flashes and mood swings. Sometimes where medical knowledge was not present, folk knowledge or misinformation resided. Health care providers were characterized as having a role to play; however, they need to understand that no uniform term exists for menopause and that multiple symptoms might not always be viewed as connected to the experience.

We have identified a generational change in the patterns of communication, which might result from the medicalization and Westernization of menopause over time. Although most of the women interviewed received little to no information about menopause from previous generations, several women identified the importance of discussing menopause with future generations. The results of this study speak to the importance of understanding the different influences on a woman's experience with menopause. Many women described thoughts of acceptance of the natural process, yet some did not attach any thoughts or values to menopause at all. Although few women spoke to caregivers, many identified the need for more caregiver information and resources.

Participants in this study told stories that referenced stages of a woman's life. That several of the participants discussed menarche and pregnancies when asked about menopause is interesting. We had never experienced this in similar discussions with nonaboriginal patients in our clinical practices, where menopause can be discussed in isolation. This might speak to a holistic concept of "woman," in which discussion of menopause incorporates the beginning of the woman's story. This might have implications for how clinicians begin such discussions.

Limitations

The convenience sampling technique limits the transferability our findings to other groups, especially outside of the Nishnawbe Aski Nation region of northwestern Ontario. The uniqueness of both the menopause experiences and each of the First Nations communities, respectively, means that these findings might not be generalizable. Results are also limited by the translation of words and concepts across cultures.

Conclusion

Caregivers would be well served to recognize the multiple influences affecting First Nations women's experiences with menopause and to exercise caution when attaching preconceived ideas of the meaning and importance of menopause to a woman's personal

experience. Some First Nations women might be coming from backgrounds in which menopause is not discussed, yet experience a desire for information and a greater understanding of menopause; or, as one participant put it, "answers to questions that might be hidden somewhere, [which we] are afraid to ask."

Dr Madden is an Assistant Professor in the Division of Clinical Sciences at the Northern Ontario School of Medicine (NOSM) in Sioux Lookout, Ont. Ms St Pierre-Hansen is an NOSM research intern in Sioux Lookout. Dr Kelly is an Associate Professor at the NOSM in Sioux Lookout. Ms Cromarty is the First Nations Special Advisor to the Sioux Lookout Meno Ya Win Health Centre in Ontario. Ms Linkewich is Assistant Executive Director of Patient Care Services at the Sioux Lookout Meno Ya Win Health Centre. Ms Payne is a student in the Master of Public Health Program at Simon Fraser University in British Columbia.

Contributors

Dr Madden, Ms St Pierre-Hansen, Dr Kelly, Ms Cromarty, Ms Linkewich, and Ms Payne all contributed to concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

Competing interests

None declared

Correspondence

Dr S. Madden, Northern Ontario School of Medicine, Box 489, Sioux Lookout, ON P8T 1A8; e-mail smadden@slmhc.on.ca

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ABORIGINAL WOMEN AND MENOPAUSE

Robert W. Webster, MD

Department of Obstetrics, Gynecology, and Reproductive Sciences, University of Manitoba, Winnipeg MB

Abstract

Objective: To determine the characteristics of menopause in Aboriginal women, in particular Canadian Aboriginal women.

Methods: An extensive review of articles extracted from both medical and non-medical databases was undertaken. The search strategy combined the key word "menopause" with any of the following terms: Aboriginals, Native Americans, Natives, Indians, Métis, Inuit, Eskimo, and Indigenous people.

Results: A total of 29 records were found, 13 of which had results relevant to the objective of the study. These articles suggest that menopause may have a positive effect on the lives of Aboriginal women with respect to increasing their freedom within the community. Aboriginal women appear to experience fewer vasomotor symptoms than other North American women.

Conclusion: More research needs to be done to determine the effect menopause has on Canadian Aboriginal women and their coexisting diseases such as cardiovascular disease, hypertension, and diabetes mellitus. This work will allow health care providers to make more informed decisions on managing Aboriginal women's transition through menopause in areas such as hormone replacement therapy.

Résumé

Objectif : Déterminer les caractéristiques de la ménopause des femmes aborigènes, particulièrement des Aborigènes canadiennes.

Méthode : On a fait une recherche et un examen approfondis d'articles tirés de banques de données portant sur des sujets médicaux aussi bien que non médicaux. L'approche de recherche consistait à combiner le mot clé « ménopause » avec chacun des termes suivants : Aboriginals, Native Americans, Natives, Indians, Métis, Inuit, Eskimo, et Indigenous people.

Résultats : On a trouvé un total de 29 documents, dont 13 présentaient des résultats pertinents pour notre étude. Ces articles indiquent que la ménopause pourrait avoir un effet favorable sur la vie des femmes aborigènes, du point de vue de la liberté accrue dont elles jouissent dans leur communauté. Ces femmes semblent moins souffrir de symptômes vasomoteurs que les autres femmes ménopausées d'Amérique du Nord.

Conclusion : Il faudrait mener plus de recherches pour définir l'effet de la ménopause sur les Aborigènes canadiennes et sur les maladies survenant durant cette période, notamment les

maladies cardiovasculaires, l'hypertension et le diabète sucré. De tels résultats permettraient aux professionnels de la santé de prendre des décisions plus éclairées sur la prise en charge de la ménopause chez les femmes aborigènes, particulièrement en matière d'hormonothérapie substitutive.

J Obstet Gynaecol Can 2002;24(12):938-40.

INTRODUCTION

According to the Society of Obstetricians and Gynaecologists of Canada Canadian Consensus on Menopause and Osteoporosis, the average age of menopause is 51 years.¹ In 2000, approximately 5 million Canadian women (17% of the population) were over 50 years of age.¹ Aboriginal people account for approximately 2.8% of the Canadian population. In 1995, the life expectancy for a "registered Indian" woman was 75.7 years compared to 81.4 years for a non-Aboriginal Canadian woman.² In addition, Aboriginal women are 2 times more likely to suffer from hypertension or cardiovascular disease and 5 times more likely to be afflicted with diabetes mellitus compared to their non-Aboriginal Canadian cohorts.³

The transition into and through menopause is a key point in a woman's life. Health care providers can offer Aboriginal women information with which to make decisions with respect to menopausal symptoms, osteoporosis, cardiovascular disease, sexual dysfunction, urogenital conditions, cancer, and information regarding how menopause will affect pre-existing medical conditions such as diabetes mellitus.

A large number of Aboriginal women in Canada will make the transition through menopause over the next few years, and based on the increased rate of chronic diseases and increased life expectancy, menopause is likely to have a significant impact on their lives. Little is known about menopause in Aboriginal women. The purpose of this review is to determine the characteristics of menopause in Aboriginal women, in particular Canadian Aboriginal women.

METHODS

An extensive review of medical and non-medical databases was undertaken. For each database, the search strategy combined the key word "menopause" with at least one of the following terms: Aboriginals, Native Americans, Natives, Indians, Métis, Inuit,

Key Words

Menopause, North American Indians, attitudes to health

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Eskimo, and Indigenous people. Eleven databases were searched: CINAHL, eHRAF Collection of Ethnography, First Nations Periodical Index, MEDLINE, Native Health History Database, Native Health Research Database, AgeLine, POPLINE, Periodical Contents Index (PCI), Social Science Abstracts Full Text, and the Cochrane Library. All articles were reviewed, and those that provided information with respect to the study objective were summarized and the key points recorded.

RESULTS

The First Nations Periodical Index, Native Health History Database, Social Science Abstracts Full Text, and Cochrane Library did not contain articles relevant to the search criteria. The remaining 7 databases yielded the following number of records: CINAHL, 6; eHRAF Collection of Ethnography, 2; MEDLINE, 8; Native Health Research Database, 2; AgeLine, 4; POPLINE, 3; and PCI, 5.

A total of 7 articles from the non-MEDLINE databases contained information on menopause and Aboriginal women, while MEDLINE yielded 8 articles. Many articles yielded multiple observations regarding symptoms, age of menopause, adverse health effects, endocrinology, information sharing, and women's role in the community. This article presents these chronologically.

The earliest study on menopause in Aboriginal women was published in 1891 and involved physicians working at approximately 30 Indian agencies in the United States.⁴ Researchers were required to ask Aboriginal women numerous questions about their reproductive status, including menopause; but, unfortunately, the total number of women interviewed was not recorded. It was reported that menopause had almost no effect on these women's lives and that the symptoms of menopause affected Aboriginal women less than Caucasian women.⁴ At that time, the age of menopause of American Indian women varied from 40 to 57 years of age, and the duration of the transition into menopause ranged from an abrupt onset to up to 8 years.

The earliest study of menopause in Canadian Aboriginal women, conducted between 1935 and 1936, in the Ojibwa community of Berens River, Manitoba, reported that menopause did not change a woman's role in the community.⁵ A study conducted on an unknown number of Blackfoot women in Alberta during 1939 found that women gained most of their information about menstruation from peers, and only a small part of their knowledge was gained from elders.⁶

In 1961 a study⁷ involving the Iroquois people living in the Six Nations Reserve in Ontario mentioned treatment of symptoms associated with menopause. It was found that the Iroquois women used camomile tea to prevent excessive bleeding during the transition to menopause.⁷ In addition, menopause was described to have had minimal impact on their way of life.⁷ A study⁸ of the Aboriginal people in the commu-

nity of Snowdrift, Northwest Territories, in 1963 also found that menopause had no impact on women's lives. A 1972 study⁹ on the Tlingit people of Yakutat Bay, Alaska, found that societal restrictions that had been imposed on women, such as the ability to fish, were lifted after menopause.

A 1986 study¹⁰ revealed that the Mayan Indian women of Yucatan, Mexico, enjoyed their transition to menopause because it provided "relief from child-bearing, acceptance as a respected elder, and a surrendering of many household chores to the wives of married sons." In addition, this study¹⁰ reported that women experienced little in the way of vasomotor symptoms and that menopause occurs between the ages of 41 and 45.⁶ A follow-up, cross-sectional study^{11,12} on 52 postmenopausal women who did not report menopausal symptoms such as hot flushes, found that the Mayan women's endocrinology was similar to other women with menopausal symptoms, with respect to follicle-stimulating hormone, estradiol, estrone, testosterone, and androstenedione levels. In 1991, 8 Mohawk women, aged 45 to 54, living on a reservation outside of Montreal, Quebec, were interviewed in an exploratory-descriptive study design.¹³ These women stated that menopause affected their lives in a positive way: children were expected to leave home and a woman's own needs became her primary concern.¹³ In a study released in 1995 about Copper Inuit women, a total of 17 women stated that the majority of their information about reproductive health, including menopause, was passed down verbally from elders, usually their mothers and grandmothers.¹⁴ A cross-sectional study, involving 77 women of the Sac and Fox Nation in rural Oklahoma, found that these women lost bone density postmenopausally at a faster rate than Caucasian women, but had higher bone density prior to menopause.¹⁵ The ENDOW (Ethnicity, Needs, and Decisions of Women) project, carried out in New Mexico, was a large multi-centre study that included the issues of menopause and hormone replacement therapy. Using 20 focus groups with an enrolment of over 140 women, this study contained 3 major groups: Navajo, Hispanic, and non-Hispanic white women.¹⁶ The ENDOW project, using the definition of menopause as the absence of menses for 12 consecutive months, found that most women, regardless of their background, did not feel they could openly discuss menopause in everyday life.¹⁶ Navajo women from rural areas and recently immigrated Hispanic women reported few menopausal symptoms such as hot flushes. In contrast, non-Hispanic white women reported that vasomotor symptoms were very common.¹⁶

DISCUSSION

The literature reviewed⁴⁻¹⁶ has numerous limitations. First, all the studies, with the exception of the ENDOW study, failed to define menopause. Thus, it is unknown what definition was being used and whether the term was applied correctly and consistently. Another limitation is the study sample sizes. The early

studies are vague with regard to the exact number of women surveyed, and, where the sample sizes are reported, these are small, yielding limited power. In addition, many of the studies were conducted at a time when very little information about the pathophysiology of menopause was known.

The studies reviewed suggest the transition through menopause seems to have little effect on Aboriginal women's lives,^{4,10,13,16} and that if there is an effect, it seems to be a positive one in that it increases freedom to do activities the women deem important. In addition, while it appears that Aboriginal women experience fewer vasomotor symptoms than their Caucasian counterparts (level II-2 in rural New Mexico¹⁶), it is not known if they experience other symptoms of menopause, such as those related to the urogenital tract or psychological issues. The fact that the difference between Aboriginal and non-Aboriginal women in symptoms such as hot flushes does not appear to be biologically caused suggests culture, tradition, and ethnicity play a role in the reporting of vasomotor symptoms. With respect to the age of menopause in Aboriginal women, there is little evidence to suggest a difference from non-Aboriginal women.

It is important for Canadian physicians to determine if Canadian Aboriginal women do suffer from menopausal symptoms, and, if so, whether it is to a lesser degree than their non-Aboriginal counterparts. If Aboriginal women are troubled by their menopausal symptoms, health care providers need to understand how their symptoms are managed, and whether there is any role for hormone replacement therapy. Additionally, based on the fact that Canadian Aboriginal women have increased rates of cardiovascular disease,³ hypertension,³ and diabetes mellitus³ compared to their non-Aboriginal Canadian cohorts, it is important for health care providers to know what impact menopause has on these conditions; that is, whether or not it is an aggravating factor to these conditions and part of the reason why their prevalence is increased. Further, if hormone replacement therapy is to be considered, the benefit-to-risk ratio needs to be quantified to justify it as a wise choice.

These are but a few of the compelling reasons why health care providers and policy makers need to better study Canadian Aboriginal women and the effect that menopause has on them personally as well as on their overall health. Further studies need to be pursued in either the form of focus groups or questionnaires, to accurately describe postmenopausal symptoms or lack thereof, and determine Aboriginal women's views on menopause in general. Once this is accomplished, physicians and other health professionals will be better able to decide on further research questions and, most importantly, to manage and appreciate the uniqueness of Aboriginal women with respect to menopause and its effect on their health. This review shows the limitations in our current knowledge about menopause in Aboriginal women and indicates the need for further study of Canadian Aboriginal women with respect to symptoms of menopause and the health consequences seen postmenopausally.

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Aboriginal Health Research

Canadian Institute of Health Research. *CIHR Guidelines for Health Research Involving Aboriginal People*. 2007, CIHR: Ottawa. [Excerpt]

These guidelines assist researchers in carrying out ethical and culturally competent research involving Aboriginal people. This document outlines the need for an understanding of Aboriginal worldviews and community jurisdictions. Cultural knowledge and protocols should be respected. Community interests and concerns should also be respected as an important objective of the research.

National Aboriginal Health Association. *Ownership, Control, Access and Possession (OCAP)*. 2007 NAHO: Ottawa.

These guidelines explain the principles of Ownership, Control, Access and Possession (OCAP) as they relate to Aboriginal health research and the goals of self-determination. OCAP involves incorporating Aboriginal practices and values through community involvement. This includes the community's right to control what research is being done in the community and how it is to be carried out.

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OCAP

Ownership, Control, Access and Possession

Sanctioned by the First Nations Information Governance Committee

Introduction

First Nations need to protect all information concerning themselves, their traditional knowledge and culture, including information resulting from research. The principles of Ownership, Control, Access and Possession (OCAP) enable self-determination over all research concerning First Nations. It offers a way for First Nations to make decisions regarding what research will be done, for what purpose information or data will be used, where the information will be physically stored and who will have access. This piece of work was sanctioned by the First Nations Information Governance Committee (FNIGC) and the First Nations Regional Longitudinal Health Survey (RHS).

In First Nations' world view, the Regional Health Survey (RHS) and its processes and principles of OCAP "come from the people". Rooted in self-determination and inherent rights, within the context of data and information management, the cultural framework of this project was the foundation from which many tools, documents, theories and mechanisms emerged and developed. The success of the work, past, present and into the future, is directly attributed to and dependent on the support, investment and vigilance of First Nations people at the grass-roots and leadership levels. Without this, no success would ever have been achieved and no foundational principles would have been developed to challenge the status quo in research, data collection, data holdings and stewardship. This body of thought, along with the obligation to ensure its integrity in the appropriate contextual application, was entrusted to a regionally represented steering committee which transitioned over time into the First Nations Information Governance Committee (FNIGC). This work has had a transformational impact on the status quo; the credit for which needs to remain with "the people". The trust obligation requires FNIGC to ensure that the products that came from the work of the people are attributed rightfully back to the people, in a manner that is recognizable and attached to its initial formulation. It is for this reason that appropriate citation in the written world is credited back to the people through reference to the mandated custodians of this knowledge, the FNIGC. It is also why

sanction is sought from and given by the FNIGC to the veracity and application of these principals and processes in third party documents and applications.

It is because of the strength of the First Nations teachings and the support and encouragement given by the people that this work was accomplished. The work must be appropriately recognized and attributed, as that is the only respectful thing to do.

This guide explains the principles of OCAP and all that they encompass – from regulating the collection of data, to analyzing, managing and storing the data. It also provides some useful models in the form of policies, protocols, or strategies that reflect OCAP and have been adopted by First Nations to regulate all research activities that affect their people and communities. It also outlines key issues and concepts of OCAP, as well as existing barriers and challenges towards its implementation.

OCAP offers a First Nations approach to research, data and information management. It is a way to say "yes" to beneficial research and "no" to research that may result in harm. It is a way to improve research relevance.

Those interested in OCAP may also find the following First Nations Centre (FNC) materials useful:

- **Understanding Research;**
- **Health Surveillance;**
- **Privacy;**
- **Ethics in Health Research; and,**
- **Considerations and Templates for Ethical Research Practices.**

The Origin of OCAP

OCAP, as we call it today, was originally expressed as “OCA”¹ in 1998 by the National Steering Committee² of the First Nations and Inuit Regional Longitudinal Health Survey (RHS).³ As a result of heightened interest in the issue of First Nations ownership of information, the OCAP principles were developed during the inception of the RHS. The OCAP principles apply to all research, data or information initiatives that involve First Nations.

The RHS is a survey of health in First Nations communities. It is the only national research initiative in Canada under complete First Nations control.

Recognized as the “First Nations Survey of Choice”, the RHS has gained tremendous credibility in First Nations, among First Nations leaders, in academic and government circles, and internationally. Providing information that is both scientifically and culturally validated, the RHS contributes to effective health promotion, planning and program development. The survey also provides First Nations leaders and decision makers with the knowledge they need to advocate on behalf of First Nations. Finally, the RHS helps communities take control of their health information, while serving as a model of First Nations Information Governance in all areas of research, data and information management.



The RHS is recognized not only as OCAP-compliant but also as the primary innovator and driver of emerging OCAP policies, data sharing protocols, research practices and appropriate questionnaire content for use in First Nations communities.⁴ Capacity development is also an important outcome of the RHS. It promotes building long-term research and data management capacity within First Nations communities and organizations, not only on an individual level.

The RHS has done a great deal to advance the assertion of OCAP principles and has led to

the rebuilding [of] trust and belief of First Nations in research processes. [It] has produced important innovations in data sharing protocols, training, research ethics, methodology, and culturally appropriate questionnaire content. Most significantly, it has highly invested in individual and institutional capacity development at the community, regional and national levels (nation building). This capacity has not only demonstrated its effectiveness in undertaking survey research, but also in generating and disseminating knowledge, and in influencing health and social policy development.⁵

“RHS origins are rooted in the assertion of First Nations self-determination, self-governance and nationhood... [It] is based on the values of trust and respect for First Nations peoples, communities and Nations.”⁶ This has ultimately contributed to a renewed sense of pride in First Nations Research!

Research Legacy

Research involves gathering, organizing and interpreting the information around us. Everyone engages in some form of research on a daily basis. For instance, before purchasing a car, the buyer might research the vehicle by reviewing its features, comparing costs or asking friends and family what they’ve heard about the car. Research guides us in making more informed decisions and generally helps us to understand the world around us.

OCAP is about doing research the First Nations way—for First Nations, by First Nations. Before we look at OCAP itself, it is useful to consider how previous research involving First Nations has been done.

Good research has the potential to create valuable new knowledge or substantiate what we already know. It can also foster positive change or confirm that things are working well.

Research has been used by First Nations to:

- access funds for programs and services;
- assess community health and evaluate the effectiveness of health interventions;
- develop strategies or plans for community services and programs;
- lobby for policy changes or the creation of new policies;
- preserve and revive traditional languages;
- appropriately document and preserve traditional information and ceremonies;
- support land claims and Aboriginal rights court cases; and,
- prevent projects or developments that would negatively impact on traditional land use and the environment.

In the past, research was usually conducted in ways that excluded the people it aimed to understand. In general, an outside researcher would initiate a research project while the community and its members were simply the research subjects. Communities were seldom consulted with and had very little, if any, control over the research process. The Report of the Royal Commission on Aboriginal Peoples, Vol. 3 (RCAP) addressed this point:

The gathering of information and its subsequent use are inherently political. In the past, Aboriginal people have not been consulted about what information should be collected, who should gather that information, who should maintain it, and who should have access to it. The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters.⁷

Social research was used as “an instrument of oppression, imperialism and colonialism.”⁸ Negative experiences have led First Nations to feel distrustful and reluctant to participate in social research. Past research practices were often disrespectful, damaging

and stigmatizing to First Nations people. Examples of such research include: cultural ceremonies that have been misunderstood; the disturbance of sacred burial grounds to collect human remains and cultural artifacts for display in museums; and the stereotypical portrayal of First Nations.

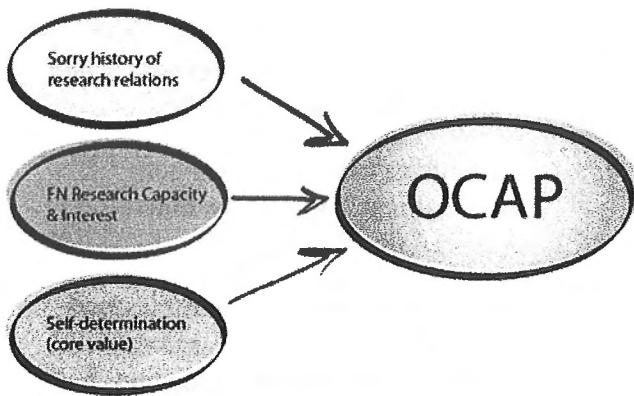
Many Aboriginal people feel that research has been “one-sided [and] that researchers enter communities for motives of personal career enhancement, academic publishing, and/or financial economic incentives, [rather] than supporting community development in improving health and well-being.”⁹ Moreover, First Nations have protested that they have been over-researched.

In recent years First Nations have voiced many concerns about the negative aspects of externally driven research. These include:

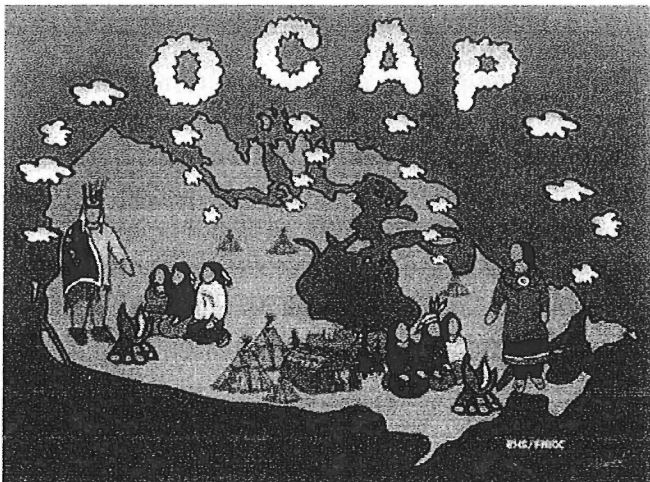
- lack of meaningful community involvement in the research process;
- lack of individual and community benefit from research (irrelevant research, lack of compensation to participants and no local hiring);
- lack of informed community consent (communities not informed of potential risks to health and safety or negative impacts of research);
- pressure to support a project (e.g., “Your people really need this research. How can you deny it to them?”);
- research agendas dictated by personal or academic interests rather than First Nations priorities or interests;
- lack of community ownership of data and research results (no control over analysis, interpretation or reporting; no review or say in who has access to data);
- community stigmatization and stereotyping of First Nations; and,
- lack of respect towards First Nations culture and beliefs, including misinterpretation of traditional knowledge and practices.

The principles of OCAP are, in part, a political response to the “sorry history of research relations between Aboriginal peoples and Canada”,¹⁰ a history based on colonial, oppressive and exploitative research. This response converged with two other historically important elements:

- 1) an increase in First Nations research capacity and involvement; and,
- 2) a widely shared core value of self-determination.



These three things came together to create the conditions for OCAP to resonate and travel quickly across the country like a smoke signal. OCAP is paving the way for the acknowledgement and application of First Nations research processes and models. This will result in more useful, respectful and beneficial research.



What is OCAP?

The principles of OCAP are one aspect of First Nations aspirations towards self-determination and self-governance. The principles represent a comprehensive framework developed by First Nations to bring self-determination into the realm of research and information management. OCAP applies to all research, data or information initiatives that involve First Nations, and encompasses all aspects of research (including funding and review), monitoring, statistics, cultural knowledge and so on. By insisting on the application of the OCAP principles, First Nations are asserting their authority over all research concerning their communities. This includes the right to make decisions about what, why, how and by whom information is collected, as well as how it will be used and shared.

The RHS affirms that the principles of OCAP best express the “necessary authorities, structures and processes for First Nations self-determination and self-governance over their individual and collective data, information and knowledge.”¹¹ Moreover, the RCAP Report highlighted that “capacity building and control in the areas of research and information are clearly linked to Nation re-building, the implementation of self-government and the assertion of First Nations rights to self-determination.”¹²

OCAP is a way to participate in a First Nations created environment that promotes the pursuit of beneficial research and its ethical application.

The OCAP principles are defined as follows:¹³

Ownership: Refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship [or possession].

Control: The aspirations and rights of First Nations to maintain and regain control of all aspects of their lives and institutions include research, information and data. The principle of control asserts that First Nations Peoples, their communities and representative bodies are within their rights in seeking

to control all aspects of research and information management processes which impact them. First Nations control of research can include all stages of a particular research project – from conception to completion. The principle extends to the control of resources and review processes, the formulation of conceptual frameworks, data management and so on.

Access: First Nations people must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.

Possession: While ownership identifies the relationship between a people and their data in principle, possession or stewardship is more literal. Although not a condition of ownership per se, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party is in the possession of another, there is a risk of breach or misuse. This is particularly important when trust is lacking between the owner and possessor.

How OCAP Can Benefit Your Community

Insisting on the OCAP principles is a way to turn a good research idea into a good research process. The increasing assertion of OCAP principles is causing researchers – especially external researchers – to be more open-minded and flexible in their research plans.

Research must respect the privacy, protocols, dignity and individual and collective rights of First Nations. It must also derive from First Nations values, culture and traditional knowledge.

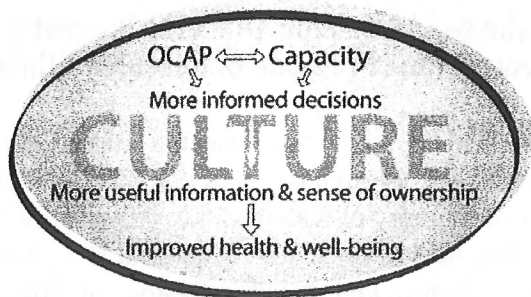
OCAP allows First Nations to not only judge the merits of a proposal, but also to put forward conditions so that good research ideas can be done in a good way. All stakeholders in a research project stand to gain from OCAP-compliant research:

The application of OCAP principles promises to deliver significant benefits to governments, researchers, First Nations Peoples and their communities. Research and information management practices also stand to benefit.¹⁴

OCAP can benefit your community by:

- insisting that First Nations rights in the realm of research be recognized (community empowerment);
- rebuilding trust in research;
- creating a more holistic approach to research;
- improving data quality, relevance and value to the community;
- supporting meaningful capacity development and empowerment among First Nations;
- ensuring community consent to and control over the research process (including the interpretation and reporting of results);
- insisting on community ownership of the research results and data;
- supporting appropriate compensation and recognition for all project participants and contributors;
- protecting First Nations and their communities against stigmatization and stereotyping; and,
- protecting traditional knowledge.

The following figure illustrates culture permeating every aspect of an OCAP-based research process. The model suggests that OCAP and capacity are mutually reinforcing, and that they lead to more relevant research results. This, in turn, empowers communities and individuals to make more informed decisions that ultimately lead to improved health and well-being for community members.



OCAP and capacity development go hand-in-hand. Research capacity enhances a community's ability to assert OCAP, which, in turn, creates new opportunities for capacity development. In this perspective, the development of a community-driven First Nations health research infrastructure is seen as a long-term benefit of OCAP.



Those who promote and believe in OCAP are sometimes known as Data Warriors. The FNC offers three-day training on the effective use of health data for community planning. The sessions are popularly known as "Data Warrior Training".

How First Nations Can Assert OCAP

Many First Nations have begun to assert control over all research concerning them in order to ensure that it is done in an ethical manner—one that reflects and respects their community values and processes. They are initiating steps to manage research by putting in place the necessary regulations, procedures and oversight mechanisms, often including some kind of research committee.

One approach that has gained momentum is the development of community research protocols, policies or ethical guidelines such as a community code of research ethics.¹⁵ These documents typically regulate all research concerning the community and its members. A well developed, respected and enforced code of research ethics can be an important tool in asserting self-determination over research. It can prevent inappropriate research and the misuse of existing data while also encouraging positive

research. Research can be very good, and in the health field, good research can improve health.

A community code of research ethics and related processes can increase public awareness of First Nations rights in relation to research, influence change, and improve the culture and practice of research in general. The result should be better, more useful and relevant research—the kind that promotes positive change for the benefit of the community. FNC's *Considerations and Templates for Ethical Research Practices (2006)* provides a template for developing a code of research ethics, as well as other tools.

A variety of strategies have been effective in asserting the OCAP principles. Some useful practices include:¹⁶

- 1) Holding community consultations to find out the issues and research priorities of the community; Speaking with Elders and leaders.
- 2) Becoming informed of what other communities are doing and what strategies they are adopting. Build on successful First Nations initiatives and processes.
- 3) Setting up a committee to develop research guidelines and protocols.
- 4) Developing culture-based frameworks, methods, tools, training, review and reporting strategies.
- 5) Developing a community code of research ethics, guidelines, policies or by-laws to guide all research activities and researchers.
- 6) Developing criteria for evaluating research proposals. (See the attached *Appendix A* for a list of useful questions to ask when reviewing research proposals.)
- 7) Establishing a Research Review Board to review research proposals.
- 8) Negotiating the research relationship and management of the research project, including the goals and objectives, methodology, data collection process, control and access of the data, data stewardship and analysis, dissemination of the research results and their publication.

(First Nations may wish to decline participation in research processes that do not respect OCAP or their research protocols.)

9) Building research skills among people in your community or organization.

A checklist of suggested actions is provided in *Appendix B* to assist First Nations communities in asserting their OCAP rights.

Initiatives that Reflect OCAP

Whether they refer specifically to OCAP or not, the number of policies and processes that reflect the principles continues to grow. The following are just a sample.

The RHS Code of Research Ethics

The RHS Code of Research Ethics (2005), developed by the First Nations Information Governance Committee, establishes a framework of principles and procedures to guide all partners of the RHS in accomplishing the mandate and objectives of the survey. The *Code* outlines the responsibilities of each partner through all aspects and phases of the survey (and spin-off research) to its conclusion. The policy statement echoes the cornerstone of OCAP, and recalls the recommendations of the RCAP:

It is acknowledged and respected that the right of self-determination of the First Nation includes the jurisdiction to make decisions about research in their communities.¹⁷

It further states:

the benefits to the communities, to each region and to the national effort should be strengthened by the research. Research should facilitate the First Nation communities in learning more about the health and well being of their peoples, taking control and management of their health information and to assist in the promotion of healthy lifestyles, practices and effective program planning. The First Nations Information Governance Committee promotes making the most of the funding opportunity on behalf of First Nations. We will reclaim the original foundations of our health and healing.¹⁸

Kahnawá:ke Schools Diabetes Prevention Project (KSDPP) Code of Research Ethics

The KSDPP's Code of Research Ethics (1996) guides the research partners: the Kanien'kehá:ka community of Kahnawá:ke, community based researchers of the Kateri Memorial Hospital Centre, the Kahnawá:ke Education System, and researchers from McGill University and the Université de Montréal.

Embodying the principles of community-based participatory research, the Code ensures that the community is a full partner throughout the entire research process. It outlines the obligations of each of the partners in all phases of the project, from the design of the research through to the publication of results. The Code recognizes and respects the "sovereignty of the Kanien'kehá:ka of Kahnawá:ke to make decisions about research in Kahnawá:ke."¹⁹

The Code further states that the "benefits to the community as a whole and to individual community volunteers should be maximized by the researchers. Research should empower the community to support community goals of health and wellness, to promote healthy lifestyles, improve its self-esteem and to fulfill its traditional responsibility of caring for the Seventh Generation."²⁰

Mi'kmaq Ethics Watch Model

The Mi'kmaq Ethics Watch Model: Principles and Guidelines for Researchers Conducting Research With and/or Among Mi'kmaq People (2000) was developed by the Grand Council of the Mi'kmaq to protect Mi'kmaq peoples and their knowledge. These principles and protocols, including a formal review process, help to ensure that outside organizations follow the highest standards of research, with sensitivity and respect to Mi'kmaq people and their communities. They will also ensure that the right of ownership of Mi'kmaq knowledge and heritage rests with the appropriate Mi'kmaq communities.

Assembly of the First Nations of Quebec and Labrador Research Protocol

The First Nations of Quebec and Labrador Research Protocol, published by the Assembly of the First Nations of Quebec and Labrador, was developed in cooperation with various regional organizations. The research protocol is a tool for First Nations and organizations to support them in activities related to research. It promotes the development of research skills. It aims to “promote a precise and well-informed ethical form of research, whose whole process respects the will of the First Nations involved.”²¹

The American Tribal Participatory Research Approach

In the United States, the Indian Health Service offers funding for Native American Research Centers for Health (NARCH). These centres include participation from American Indian/Alaska Native (AIAN) organizations, including scientists and health professionals, responsible for securing funding, building capacity and strengthening partnerships. Taking a Tribal Participatory Research (TPR) approach, this American funding program provides funding directly to the Tribal organization and not an academic institution. The TPR approach

*facilitates the active involvement of AIAN communities in the research process, from conceptualizing the issues to be investigated to developing a research design, and from collecting, analyzing, and interpreting the data to disseminating the results. [It] emphasizes the inclusion of community members and the social construction of knowledge.*²²

OCAP is a Way Forward!

There have been some concerns about OCAP, mainly expressed by non-First Nations researchers and government representatives.

“...protect [your community’s traditional knowledge] and ensure that it reaches only people who will appreciate its worth, meanings, and uses. People have a right to protect their intellectual property.”

(Masuzumi and Quirk, 1993)

Some perceive OCAP as being an obstacle to doing research and gaining entry to First Nations. Certainly, OCAP affirms the right of First Nations to accept or refuse research concerning their communities. However, it is not simply a means for automatically saying “no”. Instead, OCAP is a way to turn a good research idea into a good research process and allows beneficial research to happen in a beneficial way. It affirms the right of First Nations to exercise their voice and control over research, as well as make decisions on research that affects their communities.

OCAP helps to identify worthwhile research and ensure better research processes. It asserts the right of First Nations to decide not only whether research should happen, but also how it should be done for the benefit of their communities. To the overall mainstream research community, this may take some getting used to. It challenges researchers to change their accustomed ways of conducting research with First Nations. For example, they must carefully consider community research protocols, conflicting worldviews, and the time needed to build trusting relationships, all of which are fundamental in successful research undertakings with First Nations.

Some may argue that research and knowledge do not belong to anyone and can therefore be collected freely. Yet, some practitioners of science carefully guard data and refuse to share it with the individuals or groups from whom they collected it. Moreover, at the conclusion of the research, researchers have released results publicly without full regard for the privacy and other rights of the people who supplied the data.

While academic freedom is an important principle, it does not amount to free rein. Canadian laws establish many kinds of protections and conditions for the ownership, safeguarding, dissemination and use of data and intellectual property. In asserting OCAP principles, First Nations are hardly being unreasonable; they are simply being assertive, particularly in safeguarding their information and their knowledge. For some, this assertiveness will take some getting used to. Through OCAP, First Nations remind the practitioners of science that ‘free knowledge’ is a guiding principle and not an absolute.

Under Canadian law, individuals have privacy rights that include protection of their personal information and data. The FNC's Privacy tool kit provides detailed information. OCAP rights are *in addition* to individual rights. OCAP-based policies can protect collective or community information in much the same way that privacy policy and legislation protects individuals. This is sometimes referred to as "collective privacy".

Collective privacy can be asserted through policies that formally require community consent for data collection, data access and disclosure, sharing or reporting of data or results. Collective privacy applies to data already held in government or academic databases, as well as to new research.

Personal privacy provides individual protection. Collective privacy is for the community or Nation. It is a jurisdictional issue, consistent with cultures that value both individual and collective self-determination.

Lastly, First Nations have been unfairly criticized as lacking the research capacity and formal credentials to perform high quality and scientific research. On the contrary, Western assumptions about quality research often filter out precisely those research approaches that would be effective and relevant in First Nation settings. In fact, research that relies on Indigenous knowledge and ways of knowing is usually stronger methodologically because the bias from outside (i.e. non-Indigenous) interpretation is lessened. For this reason, First Nations researchers are often the best choice to research their own peoples. Community-based researchers have a greater understanding of their communities, and can contribute much knowledge, strength and validity to the research.

First Nations are demanding that they are actively involved throughout the entire research process, from the design phase to the analysis and dissemination of the findings. They want to make decisions and have more control over the research that affects them. Although it is difficult for many external researchers to adapt to this new way of doing research with First Nations, it is a reality they must accept. Through OCAP, First Nations not only have a stake,

but they are demanding a key role in the whole research process!

OCAP is a way to say "yes" to beneficial research and "no" to research that is not relevant or results in harm.

What Lies Ahead for OCAP?

Researchers and governments today are increasingly recognizing that if they want to do research involving First Nations, they have to respect OCAP. OCAP is here to stay. The term OCAP is now heard not only in First Nations meetings but also in classrooms, at conferences and within federal, provincial and territorial government offices. Expectations of First Nations are changing quickly and university researchers are updating their ways of doing business. A growing number of academic research centers are beginning to recognize and acknowledge OCAP. In June 2005, the RHS National Coordinator articulated the following goals for strengthening OCAP and improving First Nations research over the next few years:²³

- enhanced research capacity in all First Nations;
- First Nations communities and organizations being identified as authors or co-authors in publications;
- research funding criteria changed to facilitate community access;
- establishment of First Nations research ethics review processes; and,
- First Nations research conducted from within a cultural framework and university curricula incorporating cultural framework training.

Other people have other ideas as well. What do you think is needed? Where should we go now? Although the OCAP road may be bumpy at times, the prospect of more respectful and useful research makes the ride worthwhile.

Glossary of Terms Related to Research and OCAP²⁴

Accountability: The obligation to demonstrate and take responsibility for performance in light of agreed upon expectations.

Aggregate data: Data that is presented or collected in a grouped or a summarized form (e.g., community average income as opposed to each individual's income).

Capacity building:²⁵ Increasing the ability of individuals, communities and nations to learn and to do. Capacity building implies the capacity to work with external agencies, organizations, institutions and governments to share knowledge and experiences. Capacity building in health planning can involve developing and applying governance models, making informed decisions, strategic planning, identifying and setting priorities, evaluating, managing human and fiscal resources, and assuming responsibility for success and failure of health programs and interventions.

Collective privacy: Personal privacy provides individual protection, while collective privacy is for the community, nation or group. Keeping certain traditional cultural practices private is a long-standing practice based on an understanding of collective privacy. Collective privacy can be asserted through policies that formally require community consent for data collection, data access and disclosure, sharing or reporting of data or results. Collective privacy applies to data already held in government or academic databases, as well as to new research.

Collective rights: The concept that the members of a community, nation or other group have rights as a collective, in addition to their rights as individuals. In the context of First Nations research and information, these rights may include ownership, control, access and possession of First Nations research and information, as well as cultural and Indigenous (traditional) knowledge and intellectual property rights.

Data: Facts, observations or measures that have been recorded, but not put into any meaningful context.

Data linkage: Also called "data matching." A method of bringing together the information contained in two or more databases. For example, mortality data might be linked to hospital records.

Data steward: A manager or trustee who has responsibility or is in possession of data banks/repositories of personal information.

Data warrior: Term used to describe those dedicated to protecting First Nations information and upholding the OCAP principles.

De-identified data: Data that excludes any information that can personally identify the research participant/subject. For example, data from which the names, addresses, date of birth and health care numbers have been removed. The data may still include information about individuals, but the individuals cannot be identified.

Health:²⁶ A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

Indigenous (traditional) knowledge:²⁷ An ancient, communal, holistic and spiritual body of information and understanding that encompasses every aspect of human existence. Indigenous knowledge can be unique to a specific culture, collectivity, nation and territory. Knowledge is passed on through traditional teachings, ceremonies, healing practices and everyday living.

Information: Data that have been arranged in a systematic way in order to yield order and meaning. While counts of hospital visits each day might be considered data, knowing that the number on weekdays is higher than the number on weekends is information.

Inherent right:²⁸ A right that abides in a person and/or a collectivity and can not be given or taken away. Aboriginal rights are inherent to all Aboriginal peoples in Canada and are passed down from generation to generation.

They stem from the recognition that Aboriginal peoples are the original occupants of this land, and are often broadly defined as the right of independence through self-determination in respect of governance, land, resources and culture.

Knowledge: Information in the mind in a context that allows it to be transferred into action (see Information).

Participatory research: Participatory research is a systematic inquiry that includes the active involvement of those who are the subject of the research. Participatory research is usually action-oriented, where those involved in the research process work together to define the research, collect and analyze the data, produce a final product and act on the results.

Personal information: Information about an individual(s) that directly identifies the individual(s), or contains personal details that indirectly reveal their identity.

Raw data: A set of information or data that has not been statistically manipulated or analyzed.

Research ethics: A system of rules or standards which distinguish between acceptable and unacceptable research practices. Health research ethics guidelines usually deal with issues such as: the nature of the relationship between the researcher and the subject; ownership of and access to data; conflict of interest; consent to research; privacy and confidentiality; and measures to preserve human dignity.

Research partnership agreement: A document that represents a formal summary of rights, responsibilities and good faith between the parties entering into a partnership to jointly conduct research. Information explaining the roles and responsibilities of all partners in all aspects of the research is outlined in the agreement. All parties involved in the research partnership sign the agreement.

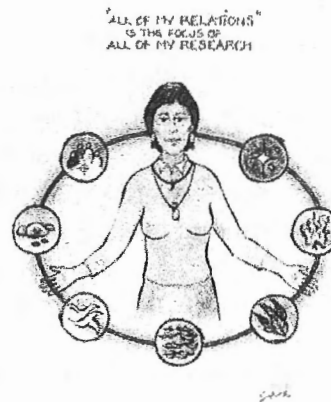
“Right to Dissent”:²⁹ Partners in a research project can agree on a “right to dissent” clause in their research agreement. This clause ensures that all

partners have an equal voice in the oral and written communication of research results and is helpful in cases where there is disagreement. It gives the disagreeing partner the right to include a description of why they disagree, and/or an alternative interpretation in the publication or communication. This also allows the public to read both interpretations and decide for themselves which one they agree with.

Self-determination: The opportunity and ability to direct one’s own life, without the interference of an external entity. For an individual, it includes the freedom and the resources to make economic, health and personal decisions in one’s own best interests. For a community, it is the ability to create an environment that supports the well-being of its members. For a nation, it is sovereignty over its lands, resources and its citizens, including the ability to govern itself according to its values, culture, and traditions, and based on its legal, political, social, economic, and cultural systems, in order to create an environment that supports the well-being and prosperity of its citizens. Evidence suggests that individual self-determination is a determinant of health.

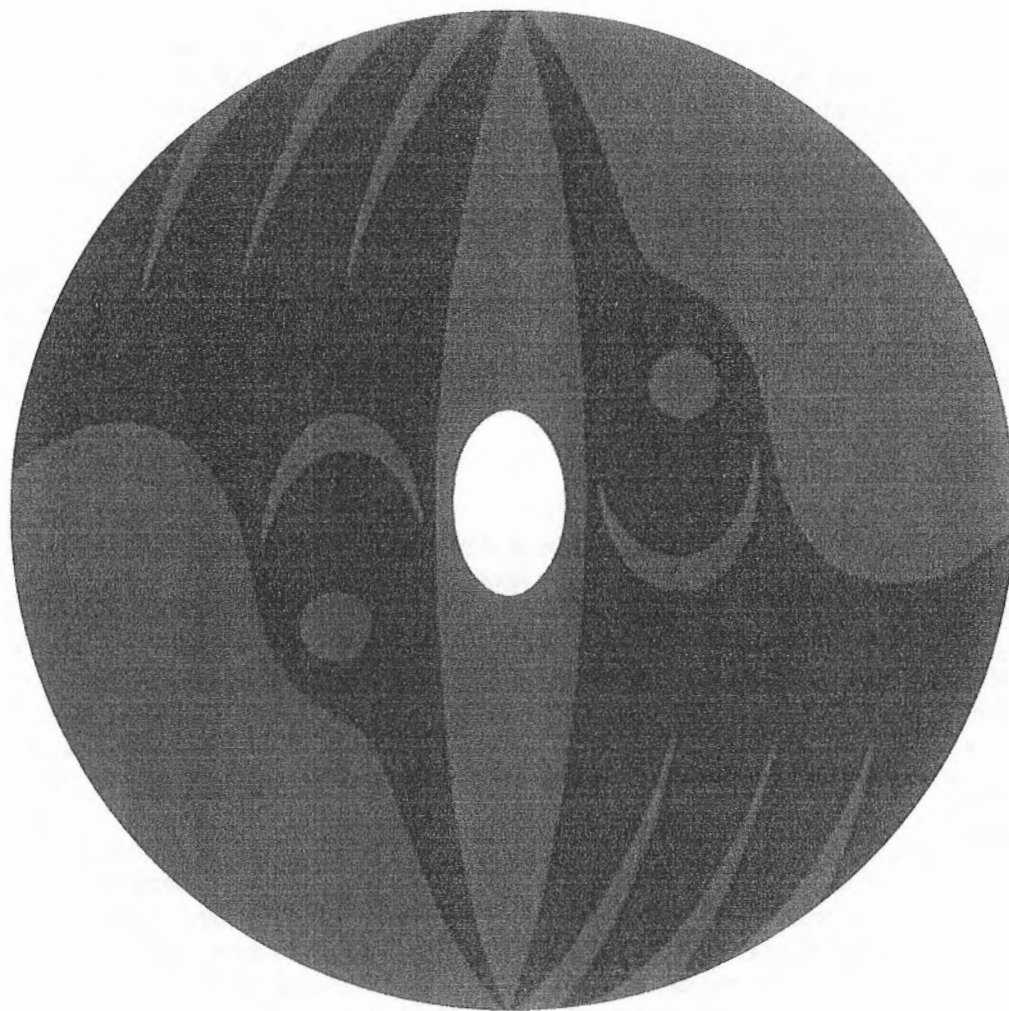
Sovereignty:³⁰ Supreme power or authority of a people over their interests and territories, independent of the control of other governments or other external entities.

Self-government: The ability of a people or a nation to govern themselves according to their values, cultures and traditions, and based on their legal, political, social, economic and cultural systems.





CIHR GUIDELINES FOR HEALTH RESEARCH INVOLVING ABORIGINAL PEOPLE



EXECUTIVE SUMMARY

Purpose and Application

These Guidelines have been prepared by the Ethics Office of the Canadian Institutes of Health Research (CIHR), in conjunction with its Institute of Aboriginal Peoples' Health, to assist researchers and institutions in carrying out ethical and culturally competent research involving Aboriginal people. The intent is to promote health through research that is in keeping with Aboriginal values and traditions. The Guidelines will assist in developing research partnerships that will facilitate and encourage mutually beneficial and culturally competent research. The Guidelines will also promote ethics review that enables and facilitates rather than suppresses or obstructs research.

These Guidelines are applicable to researchers carrying out research to which CIHR has made a financial contribution. The reader should note that these Guidelines are not regulations nor are they meant to be of general application. Rather, they are guidelines that should be followed by anyone who carries out research involving Aboriginal people in Canada if the research is funded by CIHR. The obligation on the researcher to abide by the Guidelines is contractual, i.e. it is voluntarily assumed by the researcher in return for the funding provided by CIHR.

As these guidelines primarily address the special considerations that arise when carrying out research involving Aboriginal people, researchers must also refer to, and comply with, other Tri-Council and CIHR policies, as well as any applicable legislation and, for those to whom it applies, the *Canadian Charter of Rights and Freedoms*. Other agencies of government may impose additional regulatory or other requirements.

Background

CIHR established the Aboriginal Ethics Working Group (AEWG) in March 2004 as part of a broader national endeavour to develop research ethics guidelines for Aboriginal people. The AEWG was representative of Aboriginal interests and academic disciplines in providing advice and support for the development of the Guidelines. The AEWG met to deliberate, discuss and draft the Guidelines over the course of two years. A series of commissioned background papers and contributions from the Aboriginal Capacity and Developmental Research Environments (ACADRE) network informed the deliberations of the AEWG. It followed a hands-on, active approach to the development of the Guidelines and adopted ethical principles to guide its work.

A comprehensive, nation-wide strategy for consultation with Aboriginal communities, researchers and institutions was built on the ACADRE network. The ACADRE network is a unique university-based resource with links to academic research communities and partnerships with regional First Nation, Inuit and Métis communities. Proposals for research ethics collaboration were accepted from the ACADRE centres; each proposal was unique to the centre. Early ACADRE activities focused on work with communities to translate traditional values and ethics into guidance for health researchers; this formed the foundation for the Guidelines.

The first draft of the research ethics Guidelines was completed in May 2005. Initial vetting of the Guidelines took place through the ACADRE centres and their community partners to determine cultural appropriateness

and acceptability. Then, feedback was sought from the wider academic community. Consultations and vetting throughout Aboriginal and research communities were initiated in the fall of 2005 and continued through March 2006; these sessions were conducted by the ACADRE network.

The Ethics Office along with the National Council on Ethics in Human Research conducted workshops and consultations with Aboriginal communities, researchers and members of research ethics boards to obtain feedback on the draft Guidelines. The document was electronically posted by CIHR and its partners to enable widespread access and awareness, and to solicit comments prior to final revision. Two timeline extensions for feedback were granted to accommodate the high level of interest by the Aboriginal and research communities and requests for additional workshops and consultations. This inclusive and adaptive approach to the development of the Guidelines helped achieve a workable balance on specific issues, given the multiple and diverse perspectives expressed. The Guidelines were then edited by CIHR's Ethics Office, in consultation with Health Canada and Justice Canada, to optimize internal consistency, and to ensure that the Guidelines reflected CIHR's mandate.

These Guidelines will contribute to the Tri-Council process established to revise Section 6 of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, which addresses research involving Aboriginal people.

Summary of Articles

Article 1 A researcher should understand and respect Aboriginal world views, including responsibilities to the people and culture that flow from being granted access to traditional or sacred knowledge. These should be incorporated into research agreements, to the extent possible.

The first principle of these Guidelines is premised on a need for researchers to understand and respect Aboriginal world views, particularly when engaging in the sphere of traditional and sacred knowledge, and the corresponding responsibility that possession of such knowledge entails. Researchers should understand the broader senses of accountability in order to understand the responsibility they have when entering into a research relationship with Aboriginal people.

Article 2 A community's jurisdiction over the conduct of research should be understood and respected. This article should be read in the context of the discussion in Section 1.5, which addresses the application of this document.

Some Aboriginal communities manage and control matters dealing with health. Where this is the case, a researcher should comply with any by-laws, policies, rules or procedures adopted by the community. For example, an Aboriginal community may have its own Research Ethics Board and/or community research protocols.

Article 3 Communities should be given the option of a participatory-research approach.

Genuine research collaboration is developed between researchers and Aboriginal communities when it promotes partnership within a framework of mutual trust and cooperation. Participatory research enables a range of levels and types of community participation while ensuring shared power and decision-making. Such partnerships will help to ensure that research proceeds in a manner that is culturally sensitive, relevant, respectful, responsive, equitable and reciprocal, with regard to the understandings and benefits shared between the research partner(s) and Aboriginal community(ies).

Article 4 A researcher who proposes to carry out research that touches on traditional or sacred knowledge of an Aboriginal community, or on community members as Aboriginal people, should consult the community leaders to obtain their consent before approaching community members individually. Once community consent has been obtained, the researcher will still need the free, prior and informed consent of the individual participants.

A process to obtain the free, prior and informed consents from both the community affected and its individual participants should be undertaken sufficiently in advance of the proposed start of research activities and should take into account the community's own legitimate decision-making processes, regarding all the phases of planning, implementation, monitoring, assessment, evaluation and wind-up of a research project. The requirement for community consent is distinct from the obligation of researchers to obtain individual consent from research participants.

Article 5 Concerns of individual participants and their community regarding anonymity, privacy and confidentiality should be respected, and should be addressed in a research agreement.

The researcher, the individual participants and the community should have a clear prior understanding as to their expectations with regard to the anonymity of the community and of the individuals participating in the research project, and the extent to which research data and results will remain confidential to the researcher. If anonymity is not possible, or if there are necessary limitations to anonymity or confidentiality, these should be clearly communicated.

Article 6 The research agreement should, with the guidance of community knowledge holders, address the use of the community's cultural knowledge and sacred knowledge.

Article 7 Aboriginal people and their communities retain their inherent rights to any cultural knowledge, sacred knowledge, and cultural practices and traditions, which are shared with the researcher. The researcher should also support mechanisms for the protection of such knowledge, practices and traditions.

Any research involving Aboriginal people will involve the sharing of some cultural knowledge, practices and/or traditions even when these are not the subjects of the study, as they provide necessary context. The recording of knowledge, practices and traditions in any form (written notes, audio, video, or otherwise) should only be done with explicit permission and under mutually-agreed terms that are set out in advance of the research with the guidance of appropriate Elders and knowledge holders. All uses and wider dissemination of cultural knowledge, practices and traditions should also be by permission.

Article 8 Community and individual concerns over, and claims to, intellectual property should be explicitly acknowledged and addressed in the negotiation with the community prior to starting the research project. Expectations regarding intellectual property rights of all parties involved in the research should be stated in the research agreement.

Not all information and knowledge can be protected by existing intellectual property laws, given the strict eligibility criteria defining these legal rights. Understanding and communicating what does and does not qualify as intellectual property under current Canadian and international laws is the joint responsibility of the researcher and communities involved. Research with explicit commercial objectives and/or direct or indirect links to the commercial sector should be clearly communicated to all research partners.

Article 9 Research should be of benefit to the community as well as to the researcher.

A research project should lead to outcomes that are beneficial to the participating Aboriginal community and/or individual community members. Benefit sharing vis-à-vis a community should be interpreted from the community's perspective. This may include tangible and intangible benefits, including those arising from altruism.

Article 10 A researcher should support education and training of Aboriginal people in the community, including training in research methods and ethics.

Researchers should work to foster capacity building among Aboriginal people to enhance their participation in research projects and improve the overall interactions between Aboriginal governance mechanisms and public educational institutions.

Article 11.1 A researcher has an obligation to learn about, and apply, Aboriginal cultural protocols relevant to the Aboriginal community involved in the research.

Article 11.2 A researcher should, to the extent reasonably possible, translate all publications, reports and other relevant documents into the language of the community.

Article 11.3 A researcher should ensure that there is ongoing, accessible and understandable communication with the community.

Aboriginal communities often have cultural protocols involving interactions within the community. It is important that researchers learn about these and respect them. When providing a research project report to the community, the researcher should, at a minimum, provide an executive summary in the language of the community unless the community has expressly waived this. The reports or other communications of results should use language and terminology that are readily understood by the community.

Article 12.1 A researcher should recognize and respect the rights and proprietary interests of individuals and the community in data and biological samples generated or taken in the course of the research.

Article 12.2 Transfer of data and biological samples from one of the original parties to a research agreement, to a third party, requires consent of the other original party(ies).

Article 12.3 Secondary use of data or biological samples requires specific consent from the individual donor and, where appropriate, the community. However, if the research data or biological samples cannot be traced back to the individual donor, then consent for secondary use need not be obtained from the individual. Similarly, if research data or biological samples cannot be traced back to the community, then its consent for secondary use is not required.

Article 12.4 Where the data or biological samples are known to have originated with Aboriginal people, the researcher should consult with the appropriate Aboriginal organizations before initiating secondary use.

Article 12.5 Secondary use requires REB review.

These guidelines set out basic principles for the collection, disclosure, use and transfer of data and biological samples. The details of safeguards protecting the privacy and confidentiality of data and biological samples

should be negotiated as part of the research process and specified in a research agreement. Subject to the community's views on traditional or sacred knowledge, co-ownership of data between researchers and communities is recommended because the Aboriginal community and the researcher are both integral to the production of data.

If there is to be transfer of data or biological samples to a third party, this should be done only with the consent of the researcher, the individual participants and the community. If the third party is to engage in secondary use of the transferred data or biological samples, then a further consent to that use must be obtained. The consent should address how confidentiality and privacy will be respected.

In any case, secondary use of data or biological samples requires new consent unless such use is specifically agreed to in the research agreement. Notwithstanding the above, individuals retain the right to access data about themselves.

In cases where the research is a governmental activity, other standards for protecting privacy may apply, flowing, for example, from the *Canadian Charter of Rights and Freedoms* or privacy legislation.

Article 13 Biological samples should be considered "on loan" to the researcher unless otherwise specified in the research agreement.

Subject to the terms of the research agreement with their community, biological samples from Aboriginal participants should be considered "on loan" to the researcher, analogous to a licensing arrangement, and this should be detailed in the research agreement.

Article 14 An Aboriginal community should have an opportunity to participate in the interpretation of data and the review of conclusions drawn from the research to ensure accuracy and cultural sensitivity of interpretation.

Research involving Aboriginal people is susceptible to misinterpretation or misrepresentation when information about the group is analyzed without sufficient consideration of other cultural characteristics that make the group distinct.

The opportunity for review of research results by the Aboriginal community should be provided before the submission of research findings for publication, to ensure that sensitive information is not inappropriately divulged to the public and that errors are corrected prior to wider dissemination.

This should not be construed as the right to block the publication of legitimate findings; rather, it refers to the community's opportunity to contextualize the findings and correct any cultural inaccuracies.

Article 15 An Aboriginal community should, at its discretion, be able to decide how its contributions to the research project should be acknowledged. Community members are entitled to due credit and to participate in the dissemination of results. Publications should recognize the contribution of the community and its members as appropriate, and in conformity with confidentiality agreements.

A sample research agreement and charts describing the step-by-step procedures of the research process are included as preliminary guides in Section III and in the Appendix.

Supportive Care: doulas, partners

Ballen L, Fulcher A. Nurses and Doulas: complimentary roles to provide optimal maternity care. *J of Obstetric, Gynecologic and Neonatal Nursing*. 2006;35(2):304-11. This article seeks to correct misconceptions about the doula's role and offers suggestions on improving communication between health care providers and doulas.

Campbell D, Lake M, Falk M, Backstrand J. A randomized control trial of continuous support in labour by a lay doula. *J of Obstetric, Gynecologic and Neonatal Nursing*. 2006;35:456-64.

This study compared labour outcomes in women accompanied by an additional support person (doula group) to women who did not have this support. Using a randomized control trial of 600 nulliparous women carrying a singleton pregnancy who had a low-risk pregnancy at time of enrolment, identified a female friend or family to act as their lay doula. They found that providing low income pregnant women with the option to choose a female friend who has received lay doula training shortens the labour process.

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Nurses and Doulas: Complementary Roles to Provide Optimal Maternity Care

Lois Eve Ballen and Ann J. Fulcher

Staff in maternity-care facilities are seeing an increase in doulas, nonmedical childbirth assistants, who are trained to provide continuous physical, emotional, and informational labor support. The long-term medical and psychosocial benefits are well documented. In this article, misconceptions about the doula's role are corrected, and suggestions are offered on ways to improve communication between health care providers and doulas. Together, nurses and doulas can provide birthing women with a safe and satisfying birth. *JOGNN*, 35, 304-311; 2006. DOI: 10.1111/J.1552-6909.2006.00041.x

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To the relief of some busy nurses, and the consternation of others, trained childbirth assistants called doulas are increasingly present in labor rooms across the United States. In response to the need for one-on-one advocacy and support for a safe and satisfying birth, more and more women are choosing to use doulas, and a rising number of hospitals are developing doula programs. The DONA International, (originally Doulas of North America), one of the largest doula-certifying associations, reports that within its 1st decade, membership grew seven-fold from 750 to 5,221, and the number of doulas certified by DONA increased from 31 to 2,504 during the same period (DONA International, 2005).

However, the role of the doula has not been widely embraced in current obstetric care because of lack of awareness, lack of understanding of the doula's role, and some bad press on interactions between a few

doulas and hospital staff. The purpose of this article is to clarify the positive effects of doula support in labor, clarify some misconceptions about the doula's role, and discuss ways that nurses and doulas can work effectively together.

Benefits of Continuous Labor Support

A growing and unambiguous body of literature demonstrates medical benefits and an increase in patient satisfaction with continuous labor support to both mother and infant and the cost savings to be gained by the use of doulas (Abramson, Altfeld, & Teibloom-Mishkin, 2000; Hodnett, Gates, Hofmeyr, & Sakala, 2003; Sauls, 2002). The Cochrane Library published an updated systematic review on continuous labor support in 2003, concluding "Women who had continuous intrapartum support were less likely to have intrapartum analgesia, operative birth or to report dissatisfaction with their childbirth experiences. Continuous support during labour should be the norm, rather than the exception" (Hodnett et al., 2003).

From the perspective of the health care system, safety is the top priority in childbirth (Miltner, 2002). From the woman's point of view, birth is a life passage in which both safety and satisfaction have great significance (Lavender, Walkinshaw, & Walton, 1999). The woman's perception of her experience is so important that it affects her self-esteem, parenting, breastfeeding skills, and immediate birth outcomes (Kroeger & Smith, 2004; Sauls, 2002). A woman's satisfaction with childbirth is influenced more by the quality of support she receives, feeling in control of herself, and feeling that she was actively involved in decisions than by her degree of pain, the number of interventions she experiences, or even the medical

outcomes (Goodman, 2004; Hodnett, 2002; Lavender et al., 1999). A mother may have an uneventful vaginal delivery and reflect negatively on the experience, or she may suffer complications and consider her birth a satisfying experience. "The goals for all childbearing women are safe, esteem-building, satisfying birth experiences that launch them into motherhood with a sense of competence and self-confidence" (Simkin, p. 7, 2003).

The Role of the Doula

Doulas and Hospital Staff

Traditionally, women birthed with support from other women: a family member or an experienced woman from within the community. Today, this woman is often called a doula; what is different now is how the doula fits into the medical environment. Her role has evolved along with the institutionalization of childbirth and perhaps even because of it. The goal of the nurse is to ensure the safe outcome of childbirth. The goal of the doula is to ensure that the woman feels safe and confident. Knowing the connection among labor and birth experience, a woman's self-esteem, and her medical outcomes (Hodnett et al., 2003; Sauls, 2002), the doula's mandate is to work in tandem with health care staff to support a woman in having a safe and satisfying childbirth experience.

The goal of the nurse is to ensure a safe outcome. The goal of the doula is to ensure that the woman feels safe and confident.

For nurses to value doulas, they must understand what a doula does and does not do and how she complements the nursing care and family support. They must also recognize the beneficial outcomes of doula care. Table 1 outlines the major distinctions between nursing care and doula care.

The doula's sole responsibility is attending to the emotional and comfort needs of a laboring woman and staying by her side continuously throughout labor, birth, and the immediate postpartum period (Klaus, Kennell, & Klaus, 2002). Nurses work on shifts and have clinical responsibilities, paperwork, and may have other patients. The hallmark of doula care is her continuous, rather than intermittent, presence (Klaus et al., 2002; Rosen, 2004; Scott, Berkowitz, & Klaus, 1999).

The doula's care includes direct hands-on physical care and comfort and the use of positioning techniques that

keep the mother comfortable and aid rotation and descent of the baby (Klaus et al., 2002). She keeps the laboring woman informed about her progress in labor and helps the whole family understand each stage (Hodnett, 1996; Klaus et al.). She helps explain medical terminology used by health care staff. If the plan of care changes, the doula facilitates the mother's adjustment to the new plan (Gilliland, 2002; Klaus et al.). She does not speak for or make decisions for the mother or family (Gilliland).

The doula also helps create a satisfying birth memory by making a postpartum visit. Simkin (1991) found that aspects of childbirth that were negative for the woman became more negative over time, whereas positive memories enhanced a woman's long-term self-esteem. The doula allows the woman to reflect on her experience, fills in gaps in her memory, praises her, and sometimes helps her reframe upsetting or difficult aspects of the birth.

Models of Doula Care in the United States

Three primary models of doula care have developed over the past decade: hospital-based programs using volunteer or paid doulas, community-based programs, and private practice doula. Each model of care has advantages and disadvantages.

Hospital-Based Programs. An Internet search quickly uncovers links to several dozens of the more than 100 hospital-based programs in the United States in both private and teaching hospitals and numerous listings for private doula services. The hospital-based program offers doula access to all women. The doulas are familiar with the particular hospital setting, policies, and procedures; the nurses and doulas get to know one another and develop working relationships; and the hospital screens doulas. Disadvantages of the hospital-based model include difficulty maintaining full-time doula coverage, especially if using volunteers, the continual need to recruit and train new doulas, and funding issues to maintain a doula program.

Hospital-based programs are funded by hospital budgets, grants, or a combination of both. University of North Carolina (UNC) BirthPartners, in Chapel Hill, North Carolina, is funded by the Department of Nursing. The University of California (UCSD) Hearts & Hands Volunteer Doula Program in San Diego is primarily grant funded. Both programs use a combination of volunteer scheduled on-call doulas and referral doulas who meet their clients in advance. Doulas are offered to anyone but largely attend underserved mothers including low-income women, teenagers, women laboring alone, incarcerated women, and others with special needs. Since 2000, volunteers have attended over 1,400 births in the in-house Birth Center and the Labor and Delivery Unit at UCSD Medical Center and over 800 births at UNC.

The Cambridge Doula Program in Cambridge, Massachusetts, started in 1995 with seed money from the Boston Foundation. These paid doulas collectively speak 10

TABLE 1
Contrasting the Nursing and Doula Roles

<i>Role of the Nurse</i>	<i>Role of the Doula</i>
Clinical tasks—vitals, monitoring fetal heart tones and contraction pattern, medications, intravenous access, vaginal examinations, assesses for potential complications.	Supportive role—no clinical functions.
Consults with physician or midwife.	No clinical responsibilities or decisions.
Intermittent presence—leaves for meal breaks, to care for other patients, and at change of shift.	Continuous presence—Leaves patient's room only for bathroom breaks.
May have more than one patient.	Stays with one patient throughout labor and birth.
Keeps patient informed of the progress of labor, explains what is normal, and what to expect.	Keeps patient informed in lay terms of the progress of labor, what is normal, and what to expect.
Advocates by communicating patient's desires to physician or midwife.	Advocates by helping the patient identify her questions and by helping her to communicate with health care staff. Does not offer direction regarding the woman's approach to labor.
Provides intermittent comfort measures and reassurance.	Provides one-on-one, continuous comfort measures and reassurance, including massage and touch, positioning for comfort, and to facilitate fetal rotation and descent.
Documentation responsibilities.	No documentation as part of patient's chart. May keep own records or write "birth stories" for clients.
Has legal responsibility for own actions.	Follows a Code of Ethics; may be certified.
Usually no contact with patient once she is transferred to postpartum unit.	Follow-up postpartum visit, either in the hospital, in-home, or by phone.

to 12 languages. They offer a prenatal visit, attendance at the birth, and up to 15 hours of postpartum care. After seeing the effects of doula care, Cambridge Hospital included funding for the doula program in the annual budget.

Community-Based Programs. Doulas recruited from the community being served offer care that is culturally sensitive because the doula and woman share values and language. Such programs have demonstrated improved outcomes with underserved and high-risk populations, including low-income women, teenagers, and drug users (Abramson et al., 2000). Difficulties may include funding challenges and the doulas' lack of familiarity with the hospital and health care staff.

The Chicago Health Connection (CHC) collaborates with agencies to train doulas recruited from the community being served. In this model, the doula gives extensive support, visiting the woman prenatally, supporting her with birth, and visiting postpartum for up to 12 weeks. The CHC helps other communities adapt the model to varied underserved populations. CoMadres, in rural North Carolina, recruits Spanish-speaking women from within the local Latina community. These doulas meet the pregnant woman prenatally and accompany her to the hospital for her labor, ensuring that the woman has a culturally competent presence.

Doulas in Private Practice. In the private practice model, the birthing woman and her partner have the opportunity to develop a trusting relationship with the doula prior to birth. She is available around the clock, and the relationship may continue after the birth providing postpartum support. The privately hired doula generally spends many hours with the pregnant woman. Contact increases as her due date nears, and the woman has more questions, excitement, and anxiety. The doula is on 24-hour call, attends the entire labor, and follows up with postpartum attention.

The private practice doula is available only to women who can afford to pay for this service, although some insurance companies now reimburse for private doula services (Falcao, R., n.d.). The doula may not be familiar with the nursing staff or the hospital environment, and there may be uncertainty on the part of nurses about whether questions, birth plans, or requests come from the birthing mother or the doula.

Misconceptions About Doula Care

As a modern adaptation of an old idea, doula care is still relatively new and unfamiliar in some maternity-care settings. While many nurses and physicians have nothing but

praise for the doulas in their midst and an increasing number of hospitals have in-house doula programs, controversies and misunderstandings have surfaced as the doula profession gains visibility. A number of misguided assumptions limit recognition of the benefits of doula care.

Misconception 1: Women Laboring With an Epidural Do Not Need a Doula

While the doula's forte is in providing nonpharmacological comfort measures, she also provides valuable care and support for women using analgesics or anesthesia. She provides physical support in early labor and during placement of the epidural and continued informational and emotional support to both the mother and her partner for the rest of the labor and delivery. When women were randomized to receive an epidural or support from a doula along with an epidural if they chose to have one, the cesarean rate was 3.1% in the doula group versus 16.8% in the epidural group. Women in the two groups rated the decrease in their pain level as equivalent whether they received epidural analgesia or were supported by a doula (McGrath & Kennell, 1998).

There are several benefits to having the doula stay with women using epidurals (Simkin, 2003). If the anesthesiologist is not immediately available, the laboring woman's coping skills often diminish as she waits. The doula helps the woman cope while waiting for the epidural and can help her keep a positive perspective if she feels disappointed in herself for opting for medications when she had hoped not to. The doula helps the woman regularly turn from side to side to facilitate fetal rotation and descent, and is available should breakthrough pain arise (Simkin). Once she no longer feels pain, her partner may wish to sleep or leave the room for a meal or break. The doula stays with the laboring woman so she is never alone, and her assistance during pushing, delivery, and recovery remains valuable.

Having a doula present improves medical outcomes, even when a partner is present for labor and birth.

Misconception 2: Women Who Have Supportive Partners Do Not Need Doulas

When asked about the partner's presence, most American women report that the partner's presence increased the meaning of their labor and delivery experience and strengthened their relationship. Even if partners do not participate actively, women view their mere presence as special to birth (Lavender et al., 1999; Mosallam, Rizk, Thomas, & Ezimokhai, 2004). Yet, women ranked dou-

las, midwives, and other family members over their partners in terms of the quality of support they received (*Listening to Mothers survey*, 2003). Numerous studies show that having a doula present improves medical outcomes, even when a partner is present for labor and birth (Gagnon, Waghorn, & Covell, 1997; Hodnett & Osborn, 1989; Kennell & McGrath, 1993).

There are many reasons why partners may feel unable to meet all the needs of a laboring woman. Labor may be a stressful experience if they are uncomfortable in the hospital setting or are uncertain about their support role and the well-being of their partner (Klaus et al., 2002). The doula acts as a role model, showing partners specific ways to help the laboring woman. Many express relief at the prospect of having a doula to share the coaching duties for which they feel unprepared.

Differences between doula and partner behavior have been observed during labor. Bertsh, Nagashima-Whalen, Dykeman, Kennell, and McGrath (1990) showed that doulas stayed within a foot of the woman 85% of the time, while fathers were that close 28% of the time. Doulas spent significantly more time touching the woman (rubbing, stroking, and holding) than partners, whose touching was often limited to hand-holding (Bertsh et al., 1990; Kennell, Klaus, McGrath, Robertson, & Hinkley, 1991).

The doula allows partners to take breaks, provides answers to nonmedical questions, and gives anticipatory guidance regarding what is normal during birth. When comparing the obstetric outcomes of women who birthed with their partner to those who birthed with a partner and a doula, the cesarean rate decreased from 27.9% to 14.7% for those who had the addition of a doula (Kennell & McGrath, 1993).

Misconception 3: Nurses Already Give Labor Support to Birthing Women

The obstetric nurse is familiar with the hospital setting, is already present, and is part of the health care team. However, it is the continuous one-on-one aspect of doula care that has been identified as key to the improved outcomes. Observations of nurses' work patterns have found that nurses spend 6.1% to 31.5% of their time giving support to laboring women. The rest of the time is spent in other patient-related activities such as administering medications, monitoring the mother and baby, documentation, and consulting with physicians or midwives (Gagnon & Waghorn, 1996; Gale, Fothergill-Bourbonnais, & Chamberlain, 2001; Miltner, 2002).

Obstetric nurses who are trained as doulas and provide labor support in addition to their clinical nursing duties have not had the same effect on birth outcomes as when a woman has both a nurse and a doula. "Continuous labor support by nurses had no effect on the cesarean delivery rates or other medical or psychosocial outcomes" (Hodnett et al., 2002). Nurses may not be able to give continuous labor support due to staffing patterns, lack of knowledge

of labor support techniques, or the organizational culture (Rosen, 2004; Sauls, 2002).

The highly technical function of today's clinical nurse lessens her ability to give the type of continuous social support that will impact outcomes. Though many nurses say that they chose their profession out of a desire to care for laboring women, they note that clinical and administrative duties in the current environment preclude their ability to provide such care on a continuous, one-on-one basis. Management of technology, such as electronic fetal monitors, intravenous pumps, and epidurals contributes to distancing nurses from their patients. They are physically removed from the intimate touch that fetoscopes and labor support once involved (Tumblin & Simkin, 2001).

Challenges and Solutions

Controversies and challenges sometimes arise as new working relationships are formed. Given the proven benefits of doula care, there is a need to determine how best to address the problems and develop solutions to incorporate doulas as a valuable and accessible resource.

Challenge 1: Territorialism and Turf

Some nurses have described themselves as "territorial" about their patients, and doulas have reported feeling that there are "turf" issues in the labor rooms, especially when the nurse and doula have not met before. A survey of labor and delivery nurses' perceptions of doulas showed more territorialism when nurses were less experienced in their jobs and had less exposure to doulas. One nurse commented that the doula is helpful if her presence makes the patient less needy; but if the doula questions a lot of things, it is like having two patients. Others have commented that doulas are "taking the fun part of my job" and noted that the doulas and medical providers often "get all the thanks" (O. Swigart, personal communication, November 30, 2005).

In our experience as managers of doula programs, we have seen that success of a hospital-based doula program depends on nurses' exposure to doulas, which helps them understand the doula role. In a tertiary-care teaching hospital in the south, attitudes of the nursing staff were surveyed before and 6 months after a doula program began. During the first 6 months of the doula program, understanding of the doula role and belief that birthing women benefit from doula services increased from 65% to 90% (Ferrari, 2001).

Doulas can be both advocates who help women voice their needs and desires and allies of the medical facility.

Critics of hospital-based doula programs have voiced concern about whether these doulas merely encourage women to accept the routine care given in the hospital or are able to be true patient advocates. As program managers, we have seen that doulas can be both advocates who help women voice their needs and desires and allies of the medical facility.

Challenge 2: Doulas Working Outside of Their Scope of Practice

Nurses have reported feeling that doulas sometimes try to "run the labor," giving medical advice and asserting their own opinions and desires, and that patients sometimes turn more to the doula for recommendations than to the provider or nurse. In January 2004, a front-page article in the *Wall Street Journal* brought to light a growing concern among some doctors and nurses regarding such clashes with doulas (Hwang, 2004).

Sometimes a woman hires a doula hoping she can avoid certain standard protocols and hoping the doula will help forward her agenda. This is not the doula's role. An experienced doula may be instrumental in guiding such women in communicating with their providers, understanding what is negotiable and what is not, or in some cases suggesting they seek a birth setting that better suits their needs or wishes.

Doula associations have standards of practice. The DONA International states that "the DONA-certified doula does not perform clinical or medical tasks such as taking blood pressure or temperature, fetal heart tone checks, vaginal examinations, or postpartum clinical care" (DONA International, 2005). When a doula is acting outside of her defined role, direct discussion and feedback outside of the patient's room may be needed. Nurses should acquaint themselves with avenues available for recourse regarding extreme cases. Professional doula associations have published grievance policies and want to resolve this type of conflict.

Several organizations provide training and certification of doulas. Typically, certification includes observing a child-birth education series; readings ranging from two to eight books; and a 2- to 3-day training workshop or distance learning with a curriculum covering anatomy and physiology of pregnancy and birth, nonclinical comfort measures, and nonpharmacologic pain management methods. Certification has additional requirements, such as evaluations by the client, nurse, and midwife or physician; essays; a written examination; and commitment to a Scope of Practice and Code of Ethics for their doulas. Sources of additional information about doula practice are listed in Table 2.

Benefits of Nurses and Doulas Working Together

Working together, nurses and doulas each play a role in maternal/fetal outcomes. They can even increase each other's

job satisfaction as well as the patient's satisfaction. In addition to her nonclinical care for the laboring woman, the doula can provide an extra pair of hands for busy nurses. Doulas can help the staff by supporting partners and family members during the long hours of labor and often can help with the initiation of breastfeeding.

It has been noted that an experienced nurse has attended many more deliveries than most doulas, but that an experienced doula has observed more continuous hours of labor than many nurses or providers (Gilliland, 2002). If the doula knew the patient prenatally, or has been with the patient during the previous shift, she may have information to share with the nurse about preferences and coping strategies for this particular woman.

Recommendations for Enhancing the Working Relationship

Good two-way communication and mutual understanding of the roles of everyone attending births are important. Guidelines can be developed for staff to address issues related to doulas.

It is helpful if nurses initiate communication with doulas and especially with less-experienced doulas. Introductions outside the labor room should be a standard practice when a doula arrives and at the change of nursing shifts. Whether in private practice or within a hospital-based program, doulas who become familiar to the staff have the advantage of getting to know which of their efforts are most appreciated by the nurses and how to avoid stepping on toes or being in the way. The nurse can clarify with the doula how she can help and what would be considered a hindrance.

Some nurses enjoy the opportunity to teach doulas, especially those interested in studying nursing, midwifery, or medicine. Doulas appreciate guidance, feedback, and especially collaboration. An experienced doula values conversations with staff, which can quickly clear the air if necessary and lead to an atmosphere of collegiality and partnership. Recognizing that doulas have a body of knowledge regarding labor support that complements and that is different from the nurses' knowledge will lead to mutual respect. A team approach allows both nurse and doula to do their jobs well and to best serve the individual birthing mother.

TABLE 2
Resources on Doulas and Labor Support

<i>Major U.S. Associations That Train and Certify Doulas</i>		<i>Organizations and Books for Nurses Regarding Labor Support</i>	
<i>Name</i>	<i>Web Address</i>	<i>Name</i>	<i>Web Address or Source</i>
ALACE (Association of Labor Assistants & Childbirth Educators)	www.alace.org	CIMS (The Coalition for Improving Maternity Services), a collaborative effort of individuals and organizations to promote a wellness model of maternity care to improve birth outcomes and reduce costs.	http://www.motherfriendly.org
CAPPA (Childbirth and Postpartum Professional Association)	www.cappa.net	ANACS (Association of Nurse Advocates for Childbirth Solutions), an association for professional obstetric nurses committed to promoting evidence-based practice and positive birth experiences.	www.anacs.org
DONA International	www.dona.org	<i>The Doula Book: How a Trained Labor Companion Can Help You Have a Shorter, Easier, and Healthier Birth</i> , by Klaus et al. (2002).	Perseus Publishing
ICEA (International Childbirth Education Association)	www.icea.org	<i>The Birth Partner: Everything You Need to Know to Help a Woman Through Childbirth</i> , 2nd edition, by Simkin (2001).	Harvard Common Press.
Lamaze International	www.lamaze.org	<i>The Labor Progress Handbook: Early Interventions to Prevent and Treat Dystocia</i> , by Simkin and Archuleta (2000).	Blackwell Science Ltd.

Conclusions

Doula care is an intervention that complements today's clinical obstetric nursing care. Though the integration of these nonmedical labor assistants into the medical environment has not always been smooth, doula care has been shown to be an evidence-based practice that enhances childbirth outcomes. Understanding, acceptance, and appreciation of each other's roles increase, as health care staff and doulas get to know one another and develop working relationships.

Continued research on the effects of doula care in the current medical environment and the long-term effects of doula care on parenting and breastfeeding would be beneficial. Studies are also needed to determine the models of doula care that are most effective in specific settings and the approaches that best blend doula care into standard obstetric care.

In the meantime, doula care should be an option for all birthing women. Childbirth is not simply a medical event. The type of care a woman receives is as important as the medical outcomes. Pregnancy, childbirth, and parenting are all part of the life continuum, and how support is provided for each of these is perhaps a mark of any culture's advancement.

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- Lois Eve Ballen, RN, CNM, MSN, IBCLC teaches nursing at Durham Technical Community College and is Program Manager of UNC BirthPartners, Volunteer Hospital-Based Doula Program, at University of North Carolina, Chapel Hill, NC.*
- Ann J. Fulcher, CD, CLE, is a program manager of the UCSD Hearts & Hands Volunteer Doula Program, University of California, San Diego (UCSD) Medical Center.*
- Address for Correspondence: Lois Eve Ballen, RN, CNM, MSN, IBCLC, 2 West Haven Place, Durham, NC 27705. E-mail: Lballen@unch.unc.edu or Loballen@earthlink.net*

A Randomized Control Trial of Continuous Support in Labor by a Lay Doula

Della A. Campbell, Marian F. Lake, Michele Falk, and Jeffrey R. Backstrand

Objective: To compare labor outcomes in women accompanied by an additional support person (doula group) with outcomes in women who did not have this additional support person (control group).

Design: Randomized controlled trial.

Setting: A women's ambulatory care center at a tertiary perinatal care hospital in New Jersey.

Patients/participants: Six hundred nulliparous women carrying a singleton pregnancy who had a low-risk pregnancy at the time of enrollment and were able to identify a female friend or family member willing to act as their lay doula.

Interventions: The doula group was taught traditional doula supportive techniques in two 2-hour sessions.

Main Outcome Measures: Length of labor, type of delivery, type and timing of analgesia/anesthesia, and Apgar scores.

Results: Significantly shorter length of labor in the doula group, greater cervical dilation at the time of epidural anesthesia, and higher Apgar scores at both 1 and 5 minutes. Differences did not reach statistical significance in type of analgesia/anesthesia or cesarean delivery despite a trend toward lower cesarean delivery rates in the doula group.

Conclusion: Providing low-income pregnant women with the option to choose a female friend who has received lay doula training and will act as doula during labor, along with other family members, shortens the labor process. *JOGNN*, 35, 456-464; 2006. DOI: 10.1111/J.1552-6909.2006.00067.x

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Introduction

The beneficial effects of the supportive care of women in labor by another woman have been demonstrated and replicated by researchers over the past several decades. Meta-analyses of randomized clinical trials have demonstrated that women who have continuous support during labor have a reduction in the Cesarean delivery rate, length of labor, the need for analgesia, operative vaginal delivery, and 5-minute Apgar scores less than 7 (Hodnett, Gates, Hofmeyr, & Sakala, 2005; Scott, Berkowitz, & Klaus, 1999; Zhang, Bernasko, Leybovich, Fahs, & Hatch, 1996). Though the providers of support in these trials have varied from health care professionals to lay family members, the care provided is often modeled after the concept of a "doula," a word of Greek origin that roughly translates as a "woman caregiver." A doula is not a physician, nurse, or midwife; she does not provide any medical interventions in the labor room nor does she supplant the role of the male partner or other family members who may also be in attendance. However, she does provide continuous uninterrupted emotional and physical support throughout labor. This continuity of care, provision of human presence, and social support is unique to the role of the doula and sets her apart from any other model of support for the laboring woman (Gilliland, 2002; Hunter, 2002).

Most women in the United States are accompanied in labor by their spouse or male partner, and women value their partner's presence as extremely important and helpful (Klaus, Kennell, Robertson, & Sosa,

1986). The role of the female companion has been and is an additional support to the laboring couple. Her role is not to replace or usurp the father's role in the birth process. Research indicates that male partners and female companions provide different types of support to laboring women (Bertsch, Nagashima-Whalen, Dykeman, Kennell, & McGrath, 1990). Independent observers found that in the couples where a doula was present, the male partners were noted to be more affectionate and tender toward their partner when compared to couples who did not have a doula.

The services and benefits of a doula are not universally available to women in the United States. Gordon et al. (1999) noted that it was time to reassess what effect a labor companion may have on improving perinatal outcomes since the advances in technology have failed in that aspect. Occasionally, doula programs are available through hospital-based programs or through community service agencies. However, health care systems that serve low-income women may not have hospital-based programs in place through which the women they serve can receive continuous support in labor by a doula. It is the authors' opinion that developing and maintaining such a program may be costly and problematic for a health care agency in terms of a bottom line cost-benefit analysis.

The services of professional doulas are available in many parts of the country. The cost of the services of a professional doula in the authors' tristate region ranges from approximately \$300 to \$1800. Although grant funded programs may exist that offer subsidization of fees for doulas, in most cases doula services are paid for directly by the woman. The majority of underinsured low-income women cannot afford these services.

In previously reported investigations of continuous support in labor, the person providing the support was usually someone with a health care background (nurse, midwives, student midwives) or someone who had received training as a doula. A friend or family member of the parturient has not traditionally carried out the role of provider of continuous support in labor. Prior to the report by Madi, Sandall, Bennett, and MacLeod (1999), there had been no randomized controlled trial of continuous support in labor provided by a female friend or family member of the mother.

The current study was designed with the benefits of continuous labor support in mind as well as the need for a cost-effective affordable program to provide those services for low-income women.

Review of the Literature

Physiological Benefits of Labor Support

The physiological benefits on the outcome of support during labor (by a doula) are most likely derived from the role of catecholamines. The human response to stress has

been documented as the flight-or-fight response expressed through the sympathetic nervous system by production of epinephrine and norepinephrine (Cannon, 1932; Taylor et al., 2000). The opposite of this is the parasympathetic system regulated by the hormone oxytocin and endorphins (Klaus, Kennell, & Klaus, 2002; Lieberman, 1992; Simpkin & Ancheta, 2000). Endogenous catecholamines (epinephrine, norepinephrine, and dopamine) are released when a woman experiences pain, anxiety, and fear during labor (stress). The smooth muscle cells of the uterus contain both alpha and beta adrenergic receptors. Stimulation of alpha receptors result in uterine contraction, while stimulation of beta receptors cause the uterine muscle to relax (Lipshitz, Pierce, & Arntz, 1993). Epinephrine's predominant effect on uterine activity is through stimulation of these beta adrenergic receptors, with a resultant decrease in uterine activity (Klaus et al., 1986; Zuspan, Cibilis, & Pose, 1962). Norepinephrine is linked to alpha adrenergic receptor stimulation in uterine muscle resulting in increased contractility. By infusing various concentrations of both epinephrine and norepinephrine into gravid women who were either in "advanced prelabor" or spontaneous labor, Zuspan et al. (1962) were able to demonstrate this uterotonic effect of norepinephrine and tocolytic effect of epinephrine.

While it is clear that both norepinephrine and epinephrine increase as a result of the pain, anxiety, and physical exertion of labor, each neurotransmitter may be influenced by different factors (Dimsdale & Moss, 1980). By sampling subjects during periods of both physical activity and psychological stress, Dimsdale and Moss were able to demonstrate that while norepinephrine levels rose more dramatically during physical activity and less so during psychological stress, epinephrine levels rose significantly higher during periods of anxiety and less so during physical activity.

Further support of the relationship between epinephrine, emotional stress during labor, and its influence on labor progress is reported in work by Lederman, Lederman, Work, and McCann (1985). Plasma epinephrine and norepinephrine levels as well as self-reported anxiety and observed stress levels were collected from a group of 73 women at several points during labor. There was a positive correlation in phase 1 of labor (3-6 cm dilatation) between epinephrine levels and the level of stress, anxiety, and duration of labor; a negative correlation was seen between epinephrine levels and uterine activity as measured by Montevideo units (Lederman et al., 1985).

Both animal and human research has demonstrated that catecholamine levels increase during labor and that these rising levels reduce blood flow to the uterus and placenta and are associated with a decrease in uterine contractions, slower dilation rates, and longer labors (Adamsons, Mueller-Heubach, & Myers, 1971; Barton, Killam, & Meschia, 1974; Lederman et al., 1985; Lieberman, 1992;

Myers, 1975; Simpkin & Ancheta, 2000; Wuitchik, Bakal, & Lipshitz, 1989; Zuspan et al., 1962). The role of the doula or trained female companion is to soothe, praise, and encourage the laboring woman continuously allowing her to feel more self-assured, confident, and less fearful. Support during labor reduces the incidence of abnormally long labor patterns and improves neonatal well-being (Cogan & Spinnato, 1988; Klaus et al., 2002; Simpkin, 1986) and reduces the amount of hospitalized labor time (Hemminki et al., 1990). All of this research suggests that one of the primary positive effects of female companionship during labor is its influence on the cycle of maternal anxiety, catecholamine levels, and the progress of labor.

Researchers have recently hypothesized that the female response to stress is more "tend and befriend" than the classic flight-or-fight response. The female response is characterized by "tending" to offspring and protecting them from harm and "befriending" by affiliating with other females to manage stressful conditions (Taylor et al., 2000). Taylor et al. (2000) proposed that previous animal and human studies suggest that oxytocin and endogenous opioids may be the basis for this gender specific response to stress. Massage, stroking, and support provided by the doula (who is female) meets the pregnant woman's need to befriend during this highly emotionally charged time of childbirth. The doula encourages the woman to relax, which reduces her stress response resulting in an increase in the release of oxytocin. This release strengthens the uterine contraction, improves the pattern of labor, and potentially decreases the total length of labor (Klaus et al., 2002). These studies contribute to the scientific rationale that female support in labor may result in improved obstetric outcomes.

Trials of Labor Support

The influence of supportive care during labor has had the benefit of investigation by a number of randomized clinical trials beginning in 1980. The studies have taken place in the United States, Europe, and in developing countries. Zhang et al. (1996) published the 1st meta-analysis of the then available five randomized clinical trials evaluating the effect of continuous labor support among primiparous women. Four of those five studies involved underinsured low-income women with otherwise uncomplicated pregnancies who delivered in hospitals that did not allow any companions in the labor room with the mother and were randomized to either a group who were accompanied by a labor attendant for most or all of her labor or to a control group whose members received "routine intrapartum care" (Hofmeyr, Nikodem, Wolman, Chalmers, & Kramer, 1991; Kennell, Klaus, McGrath, Robertson, & Hinkley, 1991; Klaus et al., 1986; Sosa, Kennell, Klaus, Robertson, & Urrutia, 1980). The training of the labor attendants was inconsistent, ranging from

being what the authors described as "well trained" to having no training. It was on the basis of those four studies that the authors noted continuous support by the labor attendant significantly shortened labor duration, doubled the rate of spontaneous vaginal birth, and reduced by half the rate of Cesarean delivery, forceps delivery, and oxytocin use (Zhang et al.).

An updated review of Caregiver Support for Women During Childbirth in 2005 (Hodnett et al., 2005). This review included published results from 15 randomized trials comparing continuous support during labor with usual care. The studies took place between 1986 and 2002 and involved over 12,000 women. Labor support in these trials was provided by a variety of individuals including student midwives, hospital employees, and lay women with and without training. Of note is one trial (Madi et al., 1999) in which the support was provided by an untrained close female relative. Madi et al. reported significance at a $p < .05$ for the following results: fewer cesarean sections (6% vs. 13%), less intrapartum analgesia (53% vs. 73%), and less use of synthetic oxytocin (13% vs. 30%) in the experimental group with female labor support (Madi et al.). Actual percentages noted in the other 14 studies vary, but overall continuous support in labor was associated with a reduced likelihood of cesarean birth, operative vaginal birth, regional anesthesia/analgesia, and receipt of any anesthesia/analgesia (Hodnett et al.).

In six of the 15 trials in the *Cochrane Database Review*, no additional support people or family members other than the person associated with the study were allowed to accompany the laboring woman. The positive effects of continuous support in labor were more robust in these settings where no other support person was allowed to attend the mother (Bréart et al., 1992; Hofmeyr et al., 1991; Kennell et al., 1991; Klaus et al., 1986; Langer, Campero, Garcia, & Reynoso, 1998; Madi et al., 1999).

The Listening to Mothers Survey (Sakala, Declercq, & Corry, 2002) states, "Although doulas and midwives were the best rated sources of supportive care in labor, they were the least-used sources of supportive care (5% and 11% respectively)." Early research had demonstrated a reduction in the cesarean delivery rate with the presence of a doula; yet, continuous support during labor by a registered nurse did not reduce the rate of cesarean delivery (Hodnett et al., 2002). This might have been due, as Sauls argues, to the benefits of support being "overpowered by the effects of birth environments characterized by high rates of routine medical interventions ... the technological, surveillance, and administrative aspects of nurses' jobs leave little time for supportive care" (Sauls, 2002, p. 739). Coffman and Ray (2002) noted that even when there is supportive care by nurses, there is a difference between professional and personal support. They identify a goal of nursing as embracing and encouraging the parturient's

natural support network especially during critical times, such as childbirth.

The objective of this study was to compare labor outcomes in nulliparous women accompanied by a personally chosen, additional support person (doula group) with outcomes in nulliparous women who received standard care (control group). The specific outcomes selected for this study were as follows: Length of labor defined as the time from the onset of regular contractions (either witnessed by the nurse or as reported by the patient to the nurse at the time of admission) to the delivery of the neonate and documented on the medical record as the length of the 1st stage of labor plus the length of the 2nd stage of labor; type of delivery as either spontaneous vaginal, forceps, vacuum assisted, or cesarean; type and timing of analgesia/anesthesia as either nonnarcotic, narcotic, epidural, or spinal; and Apgar scores at 1 and 5 minutes.

Methods

Design

This study was conducted using a randomized controlled design. It was approved by the Institutional Review Board of the hospital where the study took place. Neither the labor room staff nor the participant's caregivers were blinded to group assignment.

Setting

The setting for the study was a women's ambulatory care center located at a tertiary perinatal care hospital in New Jersey. Enrollment took place between 1998 and 2002 when approximately 1,000 underinsured low-income women received comprehensive prenatal care annually at the center. Certified nurse-midwives, nurse practitioners, and resident physicians provided obstetric care.

Procedures

The eligibility criteria were as follows: nulliparous, singleton pregnancy, low-risk pregnancy at the time of enrollment in the study, and able to identify a female friend or family member willing to act as their lay doula. Women with a contraindication to labor (e.g., placenta previa, planned cesarean delivery) were excluded from the study. Study subjects were recruited by the research assistant. The purpose of the study was explained to her and her written consent for participation was obtained. As part of the consent process, all study participants were told that this support person would be with her in labor along with any other support people the mother chose. It was stressed that the doula did not alter or substitute for any other person she had planned on being with her during her labor and birth process. The study hospital allowed laboring women to have multiple people in the birthing room. Some early studies restricted support from a friend or

family member and had women laboring alone if they were randomized to the control group (Klaus et al., 1986; Sosa et al., 1980). This study did not restrict other support for participants in the control group. Participants were prospectively, randomly assigned to either the doula (experimental) group or a control group. A computer generated randomization scheme was utilized. Papers identifying the group assignment were folded and placed in opaque envelopes. After obtaining consent, the research assistant opened the randomization envelope that held the participant's group assignment.

The study facility offered childbirth preparation classes to all clients in the form of a series that met weekly for 5 weeks and were attended primarily by married couples. Although offered free of charge to the clients of the ambulatory care center, historically this population of women rarely attended. This knowledge was kept in mind when developing the procedure for teaching the traditional doula supportive techniques to the parturients and their female companions in the doula group.

Lay doula core curriculum consisted of continual presence, knowledge of anatomic and physical changes, and skills in listening, anticipatory guidance, comfort measures, and coping strategies.

All teaching for the study participants was conducted by the research assistant who was a doula certified by Doulas of North America. She met with from one to two pairs of pregnant women and their doulas at each of the two 2-hour sessions. These sessions were semistructured and took place in a variety of locations from a hospital classroom, to a home, to a local diner. The training was done wherever the parturient desired in hopes of improving compliance with attendance. The curriculum for the program consisted of the following topics: discussions of a pregnant woman's anatomy and physical changes during childbirth, methods to use to assess the mother's progress in labor, as well as coping strategies during labor. In addition the doulas were taught how to provide anticipatory guidance and comfort measures as well as praise and reassurance to their partners. Regardless of where the training took place, the content was consistent for each class. The doulas received printed material to keep as a reference on the following subjects: comfort suggestions, body positions and movements for labor and birth, a skill sheet on listening, and a guide for assisting and supporting during the 1st and 2nd stage of labor.

After enrollment, members of the control group had no further interaction with any member of the study team. Outcome data were extracted by the authors from hospital records after delivery.

Sample

A convenience sample consisted of 600 subjects (300 in the doula group and 300 in the control group). The sample size was calculated on the hospital's primary cesarean delivery rate of 18%, with an alpha of .05 and 80% power. A total of 586 women completed the study (76% power). Twelve women were lost to data collection as they delivered at a different facility (7 in the doula group, 5 in the control group), and 2 participants in the doula group withdrew their consent. The demographic characteristics of the participants are described in Table 1. In general, the groups were non-Hispanic, White females in their early twenties.

Analysis

Data were analyzed using frequency distributions, *t* tests, and Cochran-Mantel-Haenszel statistics to identify differences between the two groups.

Results

Descriptive and outcome data were collected from the intrapartum period by a retrospective hospital record review. The intent to treat analysis of the 586 participants revealed that the doula group had statistically shorter total

lengths of labor, more cervical dilatation at the time of epidural analgesia/anesthesia, and higher Apgar Scores at 1 and 5 minutes. These results are described in Table 2. No significance was noted between the groups in the Cesarean delivery rate, length of the 2nd stage of labor, or epidural rate. Neonatal birthweights were analyzed to ensure that potential differences in the total length of labor or length of the 2nd stage of labor were not influenced by discordant birthweights in the two groups. (No significance noted with the doula group birthweight 3,341 g [\pm 546] and 3,302 g [\pm 553] in the control group.)

An additional analysis of 530 subjects was performed on participants who maintained eligibility for the study based on the inclusion criteria. A total of 56 were excluded from this analysis: 44 from the doula group and 12 from the control group. In the doula group, the reasons for exclusion included those who had incomplete doula training (18 did not attend the two sessions), and 10 who did not have their doula with them during the labor and birth. In the control group, three participants were inappropriately enrolled in a conflicting intrapartum study in which type of delivery was an independent variable. The remaining 25 exclusions included women from both groups who experienced either preterm birth, a medical complication making them a patient at high risk, or had a scheduled cesarean birth due to a breech presentation.

All outcome variables that were significantly different between the doula and the control group in the intent to treat analysis remained significantly different in this secondary analysis. The cesarean delivery rate in the doula group was 10.6% and in the control group was 15.5% ($p = .09$). The primary cesarean delivery rate for the study facility during the enrollment period averaged 17.9%.

Discussion

The beneficial findings of a shorter labor and improved neonatal Apgar scores demonstrated in this study are similar to those found in all the randomized trials of doula support in labor. The women in this study, who were accompanied in labor by a female friend who had focused education on labor support techniques, received measurable beneficial effects from the support, specifically significantly shorter labors (time greater than 1 hour), and higher 1- and 5-minute Apgar scores.

Women who received continuous support in labor by a female support person trained as a lay doula had significantly shorter labors.

TABLE 1
Participant Characteristics^a

Demographic Descriptor	Doula Group (N = 298)	Control Group (N = 300)
Race		
White	56%	56%
Black	36%	29%
Indian	.4%	.6%
Chinese	.7%	2%
Filipino	.4%	.6%
Other	6.4%	12%
Ethnicity		
Hispanic	18%	21%
Non-Hispanic	78%	72%
Other	4%	7%
Age at delivery (mean), range: 14-40 years	22.2 years	22.6 years

^aNo statistical significance noted in any category.

TABLE 2
Intent to Treat Analysis of Study Variables

Variable	Doula Group Possible (N = 291)	Control Group Possible (N = 295)	p Value
Cesarean birth rate ^a	18.9%	17.9%	.7
Length of labor (in hr ± SD) ^b (Vaginal deliveries only)	10.4 ± 4.3	11.7 ± 4.8	.004
Length of 2nd stage ^b (in min ± SD)	58 ± 51	64 ± 57	0.2
Epidural rate ^a	85%	88%	.4
Centimeters dilated at epidural ^b (in cm ± SD)	4.3 ± 1.3	3.9 ± 1.2	.007
1-min Apgar >6 ^a	95%	90%	.04
5-min Apgar >6 ^a	99.7%	97%	.006

^aChi-square (χ^2).
^bt Test.

Unlike many of the previous trials of continuous support, there was no difference in the rate of cesarean birth or rate of epidural anesthesia between the doula and control groups in this study, neither in the intent to treat analysis nor the additional analysis. A careful review of this outcome is warranted. As Hodnett et al. (2005) noted, the previous randomized trials that showed the most powerful influence on cesarean birth rates took place in institutions where family members were not allowed to be with laboring women, and the rates of medical intervention were low.

This study institution is a university affiliated teaching hospital that is a Level III regional perinatal center with an annual delivery rate of over 6,000 during the study years. There is continuous in-house coverage by maternal-fetal medicine specialists and anesthesia. The doula and the control group had a similar rate of continuous labor epidural management (85% and 88%, respectively) and pitocin augmentation (46% and 49%, respectively) as a medical intervention. This study supports the hypothesis that the effects of the birth environment typified by high rates of medical intervention have the ability to overpower the benefits of continuous support in labor (Hodnett et al., 2002).

There were no restrictive visitation policies in place during the study. The laboring woman could be accompanied by people of her choosing. A criticism of the study may be that the health care professionals were not blinded to the study group assignment. In the study institution, it would have been unusual for the laboring woman to be identified as a study participant, as the presence of an additional support person(s) was a common practice. We did not place visiting restrictions on the control group or limit support to a male partner only. Due to this practice, this

study was closer to being "blinded" than any previously reported studies where visitor restrictions clearly identified the control from the experimental group.

Required in the nursing section of the hospital record of our facility was to identify who was in attendance with the mother during labor and birth. Over 44% of the control group had between one and three female companions with them during labor and birth. The authors propose that these participants may have been enlightened as to the potential benefits of a female companion after the informed consent process and chose to seek out and bring a female companion with them after they were randomized to the control group. This may in part explain the lower rate of cesarean birth in both the experimental and control group when compared to the overall hospital rate during the study period and may bear clinical if not statistical significance for perinatal nursing practice.

It has become apparent that the type of person who provides the support during labor is important (Bowers, 2002; Coffman & Ray, 2002; Rosen, 2004). In the recent North American trial evaluating the effectiveness of nurses as providers of labor support, continuous support by highly trained nurses had no impact on the cesarean birth rate (Hodnett et al., 2002). Similarly, the most recent *Cochrane Database Review* found that if the provider of continuous support was a member of the facility's staff, the effects of the support were less pronounced (Hodnett et al., 2005). In this study, where a woman of the mother's choosing, sometimes a friend or sometimes a relative, provided continuous support, there was a measurable beneficial effect from the support in the length of labor and Apgar Scores. These results are similar to those found by Hodnett and Osborn's (1989a, 1989b) early work and the two trials in Finland that failed to demonstrate a

difference in the cesarean birth rate but did report fewer labor interruptions or abnormally long labors (Hemminki et al., 1990).

Suggestions for Future Research

The influence of catecholamines and oxytocin on the labor process has been described previously. This study, along with earlier studies, has demonstrated the beneficial effect of a female companion on the labor process. That effect is presumed brought about by helping to control fear and anxiety in the laboring mother and thus lower the influence of catecholamines and increase the production of oxytocin. A future study measuring these hormone levels at selected times during labor in both a doula and a nondoula group would provide further support to this prevailing theory.

In this study, one certified doula provided all of the education to the female companion. Although this ensured consistency in content and teaching style, her unique style or personality may have influenced the study outcome. Replicating this study with several different doula trainers using a standard teaching plan may help eliminate this potential bias. Additional research is needed to study more diverse populations and to explore cultural variations in the comfort of receiving nonsexual touch and stroking to elicit relaxation.

Implications for Practice

In the majority of randomized trials evaluating continuous support in labor, the person providing the support was either a health care professional, had a health care background or had specific doula education and training. The cost of maintaining a cadre of such women who would be available to provide continuous labor support to a hospital's obstetric population would likely be prohibitive, and Rosen (2004) suggested that hospital affiliated support may not be the best approach. Additionally, the services of professional doulas may not be available in all geographic areas nor will low-income women likely be able to afford the fees for the services of a professional doula. Yet, there is consistent evidence of the benefits of having continuous support in labor.

This study has demonstrated that a relatively low-cost method of providing this support has a beneficial effect for a population of underinsured low-income women. Hospitals, prenatal centers, and childbirth educators should consider the potential benefits of providing a labor preparation program for pregnant women and female companions along with husbands or partners. In less than 4 hours of semistructured teaching, the selected female was provided with knowledge to serve as a lay doula and demonstrate a powerful positive impact on the labor of her friend.

The female friend who served as a doula demonstrated a powerful positive impact on the labor of her friend.

The process of selecting a female friend to accompany the pregnant woman and providing education to become a lay doula should be considered as the standard of care during the prenatal period. This could be offered in a variety of settings in addition to the traditional health care delivery systems. Community agencies, local and state departments of health, and parish nurses could all become involved with offering this information and providing doula education. The financial outlay for such a program would be minimal and could potentially become standard of care for the antepartum client.

Perinatal nurses have an enormous opportunity to improve the emotional and physical well-being of their pregnant clients as they prepare for the birth of their child. All health care personnel participating in prenatal and intrapartum care should be knowledgeable about the current state of the science regarding continuous support in labor. Information about the benefit of a female support friend should be dispensed at the 1st prenatal encounter and reinforced at each visit. The empowerment a prenatal program such as this could provide may be especially important for low-income women. A secondary study was done with this population to examine maternal perceptions of infant, self, and support from others by performing a follow-up telephone interview within 8 weeks postpartum. The benefits of continuous female support may continue past the actual process of birth.

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Della A. Campbell, RN, CNA-BC, APRN-C, is a research coordinator for the Study on Sleep & Functional Performance in Heart Failure at the University of Medicine and Dentistry of New Jersey, School of Nursing, Newark, NJ.

Marian F. Lake, RNC, MPH, CCRC, is a research nurse manager in the Division of Maternal Fetal Medicine at Saint Peter's University Hospital, New Brunswick, NJ.

Michele Falk, MSW, is a research coordinator in the Department of Obstetrics & Gynecology at Saint Peter's University Hospital, New Brunswick, NJ.

Jeffrey R. Backstrand, PhD, is an associate professor, Urban Health Systems, University of Medicine and Dentistry of New Jersey, School of Nursing, Newark, NJ.

Address for correspondence: Della A. Campbell, RN, CNA-BC, APRN-C, University of Medicine and Dentistry of New Jersey, School of Nursing, 65 Bergen Street, Suite 1112, P.O. Box 1709, Newark, NJ 07101-1709. E-mail: della.campbell@verizon.net.

PERINATAL LOSS / FETAL REMAINS

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Culturally Sensitive Support for Grieving Parents

The cultural beliefs of Native Americans, Mexican Americans, and Southeast Asians affect the grieving of these parents following the death of their infant.

LAUREN VALK LAWSON

The devastation that follows the loss of a child makes the family's emotional healing extremely painful and difficult. Expressions of grief vary from person to person, but almost always they are influenced by a person's cultural background. And, no socioeconomic, racial, religious, or cultural group is spared such tragedy. Tailoring grief support to the specific needs of a family who has lost a child to Sudden Infant Death Syndrome (SIDS) or any trauma or disease, warrants a compassionate understanding and acceptance of how cultural traditions influence the grieving process.

Culture has been defined as

LAUREN VALK LAWSON, M.N., C.T.N. (certified transcultural nurse), is the program director of SIDS Northwest Regional Center at Children's Hospital and Medical Center, Seattle, Washington. She has worked with parents who have lost a child to Sudden Infant Death Syndrome (SIDS), and information in this article is based on her experience in the program. She thanks Catherine Fleshman, M.P.H.; Alice Tew; Bernadette McBride, R.N.; Kit Bakke, M.N., M.P.H.; Sharayne Shiu-Thronton; and Nora Stern for their help preparing the manuscript.



the "values, beliefs, rules of behavior, and lifestyle practices that guide a designated group in their thinking and actions in patterned ways" (1). Traditions are learned from other group members, and influence how people interact within and outside their families. Culture also guides people in their daily life, affecting, for example, food choices, time and space orientation, and attitudes toward health and illness.

Cultural influences on how members of a family grieve include:

-the meaning a death (especially an infant's death) has for the group

-the customs surrounding death and funerals

-family-life patterns, such as the lines of authority, the roles of various family members during periods of grief, and the amount of help available, and

-the family's expectations of health professionals during death and periods of grief.

Language is critical in understanding culture. Working with persons whose native language is not English necessitates an interpreter, not only for exchanging information, but for understanding finer shades of meaning. The following description of a visit to provide health care to a Spanish-speaking family illustrates that point.

While explaining the cause of their infant's sudden death to the family, the nurse used the term "SIDS." The parents became extremely agitated. Through an interpreter, the nurse learned that the Spanish acronym for AIDS is SIDA (síndrome de inmunodeficiencia

adquirida). The family thought the nurse was telling them that their infant had died of AIDS. Through the interpreter, the nurse was able to reassure the family and correct the misunderstanding that had occurred.

Cultural Assessment

The first step toward providing culturally sensitive support to a grieving family is to explore your own attitudes about grief. Ask yourself what death means to you, how the death of an infant affects you, and how you expect a person to grieve. Think about what your own family does when a member dies and decide who you'd turn to for help if you were grieving.

Once you've identified your own feelings about grief, consider accepting the parents' beliefs within the cultural context of their own grief. To do so, you need to separate your own values and expectations about death from how you provide care to parents of other cultures.

First, ask family members the following questions about their feelings:

-What do you think may have caused your infant's death?

-Since your infant died, what has been happening to you and to your family?

-What do you think might help you? (2).

Keep in mind that diagnoses we consider acceptable from a nursing perspective (such as Sudden Infant Death Syndrome) may not necessarily be similarly viewed in other cultures. For example, one Native American group explains death in spiritual terms. An infant is considered more susceptible to death while his fontanelles are still open, and if the infant's spirit is not happy with the conditions of life, it can depart through those openings. That is how that group understands sudden infant death. Any physiological explanations are not likely to have the same meanings. When providing such information, try to understand the spiritual rationale for the death as the parents do and appreciate their grief from their point of view.

Expect that the parents' degree of identification with a cultural group not only influences their expressions of grief, but may become more

intense in times of crisis. If the family are migrants or refugees, they are already grieving what they've lost through social, economic, and cultural relocation. The death of an infant can overwhelm their already limited resources. Or, the parents may have assimilated characteristics of American culture, depending on how long they've lived in the United States. Have they a social network of peers from a culture similar to their own? Do they live in urban closeness or rural isolation from peers? All these factors affect how closely parents' grief reactions will follow the cultural norms of their group.

Although it is essential to avoid stereotyping or expecting that a "cookbook" approach will work for each member of a particular cultural group, acquainting oneself with the characteristics of cultural groups, especially as they relate to death and dying, will prove invaluable. Synopses of three cultural groups—Native American, Mexican American, and Southeast Asian—follow.

Native Americans

The term "Native Americans" encompasses many tribal groups, each with its own distinctive characteristics and style. Native Americans compose a culture in flux, and it is difficult to assess what degree of influence the prevailing American culture has on Native American groups.

Family life. Most tribal groups consider children of great value. Among impoverished groups, the birth of a child may indeed be all that can provide the parents with a sense of achievement. Because families extend far beyond the nuclear concept, grief tends to be family- and even community-oriented, with all members assuming roles in the grieving process.

Religion and healing. Among Native Americans, religion and healing are inseparable. Tribal religions are based on living in harmony with nature; their healing ceremonies focus on restoring that harmony. The entire family takes part in such ceremonies, which are led by tribal healers. Parents may thus find native healers and counselors more acceptable than a biomedical approach.

Death and grief. Burial practices vary among tribal groups.



Some mandate burying the deceased within 24 hours. Others forbid leaving the deceased alone and stipulate that a family member remain in attendance until the burial. Many tribal groups hold long, somber wakes where food and memorial gifts are distributed. Some hold a memorial service at the first anniversary of the death.

Expressions of grief range from quiet and stoic to dramatic and hysterical. Private grief may be misinterpreted as denial of the infant's death, when, in fact, the parents feel that talking about the death detracts from its spirituality and may bring bad luck. Native Americans value the integrity of the body after death and do not expect that an autopsy (which violates that integrity) will help explain death.

Interaction with health professionals. Native Americans may be suspicious of people of European descent. Initial reluctance, however, may dissipate when a health professional respects parents and demonstrates a sensitivity to their point of view. Caregivers must avoid "interviewing" parents in order to gain information from them. Often, simply listening helps.

Mexican Americans

The term "Mexican Americans" includes people who migrated from Mexico to the United States and their descendants. Spanish, their first language, is usually spoken with the family at home.

Family life. Mexican Americans consider children essential components of the family. Loss of a child represents loss of hope and expectations for the future. Because immediate and extended family and close friends are primary sources of social support, tangible aid, information, and advice, directing services toward the entire family is absolutely essential.

The family structure is patriarchal. The father makes the decisions, while the mother directs the affairs of the home, including diagnosing an ill family member and seeking necessary care. Parents who are separated from family and other contacts feel a sense of isolation, which may be quite severe.

Health and healing. The concepts that Mexican Americans have of health are based on both folk and biomedical

models, and typically both models are sought in illness. Health is viewed as a harmonious relationship between social and spiritual realms. Somatic complaints often reflect the emotional imbalance of grief.

Death and grief. Concepts of death and the after-life are deeply rooted in Roman Catholicism. Religious practices, such as saying the rosary (a series of prayers) for the dead, are integral parts of mourning. Mexican Americans consider death and hardship "God's will," and expressions of grief tend to be demonstrative.

Interaction with health professionals. If Mexican Americans are reluctant to become involved with official-looking personnel, it may be because they fear having to prove legal status. In a crisis, a good interpreter is essential. In addition, if a person can speak a language, it must not be assumed that he can also read it.

Southeast Asians

The term "Southeast Asian" includes people of many nations, ethnic groups, and religions, each speaking any of about 20 languages. The four most prominent groups of Asians in this country are Vietnamese, Cambodian, Laotian, and H'mong. They arrived in the United States in greatest numbers after the fall of Saigon in 1975 and the Vietnamese invasion of Cambodia in 1979.

Family life. For most Southeast Asian people, the family is the basis of society. They value large families and are proud of their children.

Social support, resources, and tangible aid are sought first from extended family and peers of similar background. Parents who are cut off from that type of support feel profoundly isolated.

Families are traditionally patriarchal, with the oldest male making decisions about health care. It is essential to acknowledge the key role of the eldest and to direct all interventions toward the family as a whole.

Religion and healing. The major religions among Southeast Asians are Buddhism, Taoism, and Confucianism, but Animism, Spiritualism, and Catholicism are also practiced. Religious beliefs influence all aspects of life; therefore, Southeast Asians



ANNOTATED BIBLIOGRAPHY

consider religion an essential part of health and healing. They tend to consult an ethnic healer, monk, or priest first, but often in conjunction with Western medical practices.

Death and grief. The death of an infant is deeply mourned. Expressions of grief vary widely from one group to another. Traditionally elaborate funeral ceremonies were once the norm for marking a soul's passage to the afterlife. To adapt to American living, some had to forego traditions (such as playing loud musical instruments), creating a further loss for the family.

Mourning families may wear white clothing or headbands for a specified period of time. Vietnamese and H'mong bury their dead; Cambodians and Laotians prefer cremation. Because mental illness is considered a disgrace to the family, Southeast Asians more often express depression and grief as somatic complaints.

Interaction with health professionals. Among Southeast Asians respect is shown by agreeing with another person. Thus, smiling and nodding do not necessarily reflect true understanding or agreement. Again, a good interpreter, skilled in the specific Southeast Asian language that the parents understand, is essential, especially during a crisis. Find out what language the family speaks at home, not what language is primarily used in their country of origin. (For example, the Laos-born H'mong do not speak Laotian.)

Socioeconomic background and education vary among Southeast Asians, as do their familiarity with Western thought and their command of English. Many recent refugees, already steeped in personal loss, have had no previous contact with Western thought and Western culture find American health care systems baffling.

Caring Within a Cultural Context

Once health professionals understand what parents expect of them within the context of cultural beliefs about death and grief, caregivers will be able to function more effectively.

Explain what help can be given, but also acknowledge limitations in meeting some needs. Advocate for the family in terms of the traditions that are important to them, and encourage them to use traditional healers when appropriate. Help parents to identify supports and resources within their own families and in the community. At the same time, remind them gently of their own strengths.

Exotic skills are not necessary to provide culturally sensitive care to grieving parents. What is required is only to accept each grieving parent's unique qualities and means of expression and to demonstrate a willingness to listen and support parents through so tragic a loss.

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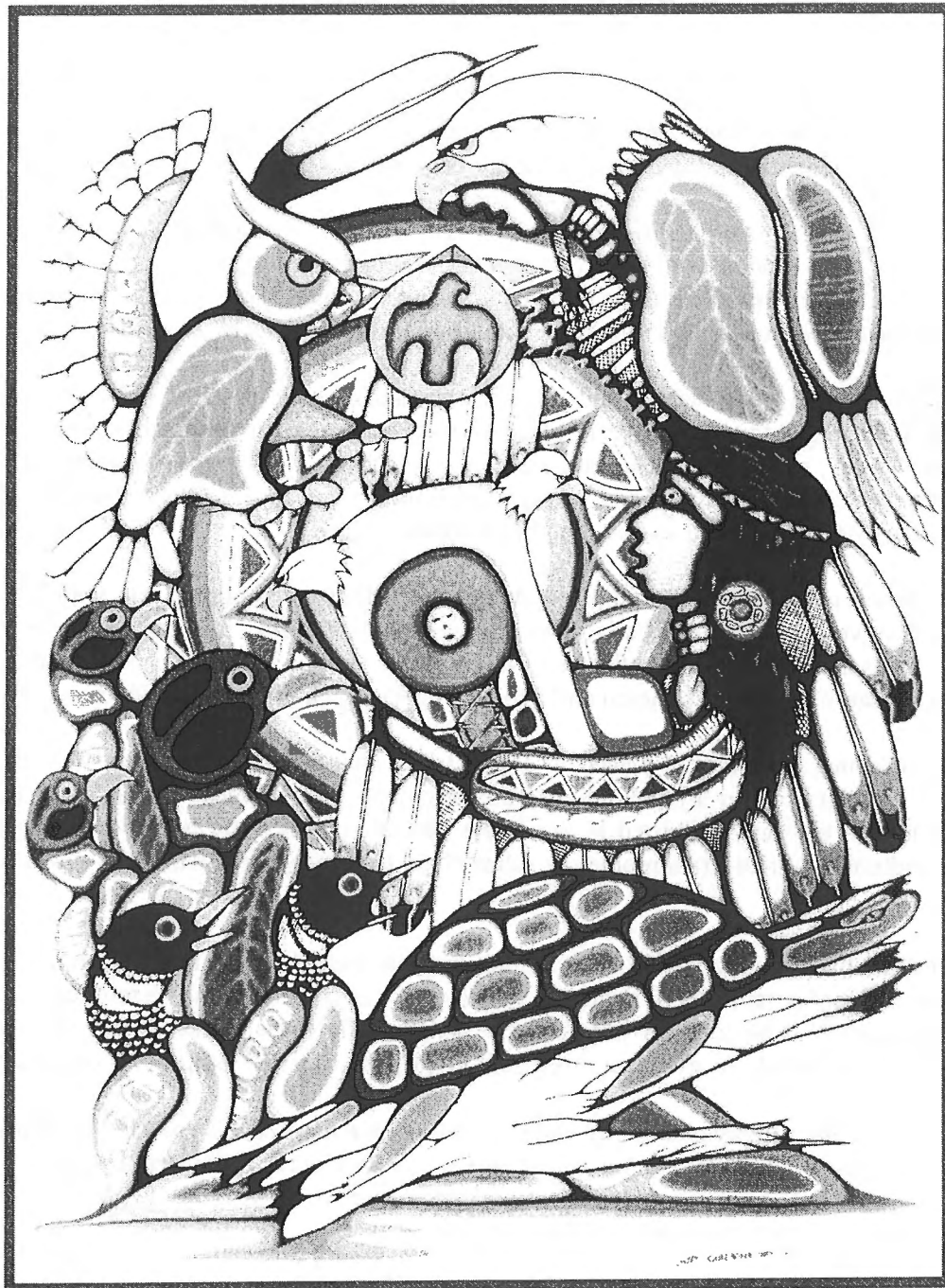
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THE CARE AND HANDLING OF FETAL REMAINS



Sioux Lookout Meno Ya Win Health Centre

DOCUMENT 4

Traditional Aboriginal Customs and Beliefs on Life, Pregnancy, Miscarriages and Stillbirths

Traditional Anishnawbe customs surrounding pregnancy are rooted in two key beliefs: that all life is a sacred gift from the Creator, and that this gift of life begins at the time of conception.

Because all life is such a precious gift, anytime it is lost, whether it be before being born, as a child, or as an adult, the deceased is treated with respect and care and is buried appropriately. If a mother suffers a miscarriage or stillbirth, regardless of gestational age, she has lost a baby. The mother requires appropriate care and the deceased warrants the same respect and burial processes as all other life.

Pregnancy is considered a very sacred and spiritual time and as such treated with respect. Women who are expecting are encouraged to take good care of themselves and it is often advised that the mother not perform heavy physical work, especially during the early stages of the pregnancy, as it puts a strain on the child. The partner and family are encouraged to pick up some of the responsibilities of the home and as the pregnancy progresses, the mother can assume more duties.

There are different customs surrounding miscarriage and stillbirths, and they can vary from community to community. If a woman miscarries early on in the pregnancy, the baby is commonly sought out among any blood clots. In some First Nations, the baby is carefully wrapped and placed high in a tree using long wooden poles. These bundles are sacred and people, especially children, are asked not to go near them.

In other communities, the baby is placed in a small box and buried in the same way an adult would be buried. This is often done in a small and private ceremony, many times with an elder to say prayers. In some communities, the baby is buried in the forest. In others, the baby is buried in the same grave as a deceased grandmother, great-grandmother or other close family member who will act as a guardian to the baby.

In the event of a miscarriage or stillbirth, a mother has lost her baby, and it is important that she be treated with the same care and sensitivity of a woman who has lost an older child. The mother will be experiencing grief and her spirit will be low. It is important that the grief be addressed, and she may need to seek counseling. All staff should be aware of this grief and provide care and support accordingly.

"How you speak to the mother and family about the loss of the baby and the steps being taken by the hospital is very important. Please act as you would like to be treated if you were the one experiencing the loss both in meeting the patient's needs and in dealing with the remains of the baby. Your respectful, considerate response will be a great comfort to the family."



**Interview with Nora Ross (aged 77)
and Agnes Ningewance (aged 70)
Kejick Bay, Lac Seul First Nation
Interview and translation conducted
by Renee Southwind, September 2005**

"As soon as a young mom knows she's missed her period, there is life. If in case of early stage miscarriage, 3 weeks on, there would be a blood clot(s), and they would find the baby amidst the blood clots. They hung it, they wrapped up the baby and hung it on a tree. If it was 2, 3, or 4 months, they put it in a box and bury it like a normal death.

They hung the baby in the tree. When I worked as a CHR (Community Health Representative), the families would take care of the dead baby to bury. Life begins at the time of conception. If a miscarriage happens in the hospital, it must be treated as a death.

Long ago, Anishnawbe had respect for all life and took care of it. With regard to the treatment of a lady who miscarried, she feels as if "it was my baby". The mother feels strongly about this. She feels low in spirit, and there is grief. The grief needs to be taken care of, sometimes she needs to see a counselor. The nurse needs to know how the mother feels and take care of her once she knows how the mother feels.

Upon miscarriage (if at home), the mother finds the baby in the clots, wraps it and hangs it in the tree. A recent miscarriage an elder went to bury it in the bush with the mother and the family and said some prayers. Upon the birth of a baby, it was difficult, had to get another midwife.

After a miscarriage, a woman is given herbs, a drink after delivering the child to heal the mother. The herbal drink is for easy delivery for the baby's sake. "Jimunwabawed awe abinoonjiish" – cleansing for the baby, soothing cleansing and pureness."



Interview with Alice Littledeer
Interviewed and translated
by Renee Southwind, September 2005

"In olden days, when a pregnant woman knew her baby was dead inside the womb, a midwife would find herbs to give to her, the herb was given to help the dead unborn baby to come out safely in a natural way. Or the midwife would place their hands on the womb area and help the dead unborn child come out without hurting the mother. Like a mother who gives birth to a baby, and she needs caring, this is how you treat the mother who has had a miscarriage. You show respect to the dead child, you bury it the same way as would be done for a dead person.

In Aboriginal law, life begins as the time of conception, not down the road as doctors believe today. I had a miscarriage in a hospital once. Today, I still do not know what they did with my dead child. I had another miscarriage (4 or 5 months), later on the reserve. My brother made a coffin and we buried it, like a funeral for a dead person. You treat it with respect. Nurses need to be careful and show respect.

To pregnant women and fathers, a pregnant woman should not work hard physically. This puts strain on a child. Care should be given toward a pregnant lady. Mothers need to listen to these kinds of teachings or whoever is told these teaching."

There are sacred aspects to the birth. The cord is attached to a moose hide bundle which is attached to the tikinagan and is the baby's pillow. The placenta, as stated before, is placed in the forest. Life is sacred from the time of conception."



**Comments of Janet Mekanak
Wunnumin Lake First Nation
At the Meeting of the Meno Ya Win Board of Directors
Translated by Doug Semple, Spring 2004**

“Mrs. Mekanak was asked for her thoughts on this issue. Mr. Semple translated for her. Mrs. Mekanak stated she had heard about the three cases and it gave her cause for concern. In the north, pregnancies are treated with great respect. In the case of a miscarriage, the baby is moved on with proper ceremonies. In the case of a live birth, the placenta is wrapped in a bundle and placed in the trees with long poles. They are sacred and symbolic and people are told not to go near the bundles, especially children.

She asked the board members to pray for the three women who had experienced miscarriages. She said for the future to remind the leaders of the communities to do certain things to bring back the sacredness of giving birth. When the nursing station tells a woman she is pregnant, the staff should get in touch with the spiritual leaders to pray for the new pregnancy.

The leadership should speak with the woman's partner and tell him to look after the woman to help prevent a miscarriage. The family should be encouraged to tell the mother to take good care of herself. She should not work in the early stages of pregnancy. The partner and family should pick up the responsibilities of the home. As the pregnancy progresses, the mother can assume more duties of the home.

She stated that at the time of conception, God started what the person will look like later on.

There are sacred aspects to the birth. The cord is attached to a moose hide bundle which is attached to the tikinagan and is the baby's pillow. The placenta, as stated before, is placed in the forest. Life is sacred from the time of conception.”

Submission from Josias Fiddler

Teachings Around Women, Pregnancy, Fetuses and Afterbirth

Prepared by Marlyn Cook

The time of childbearing in a woman is a very sacred time. This is what we have been brought into this physical plane for and that is to give life. Women are powerful beings. The Creator has given them the capability to give life.

During pregnancy, the most important thing for a woman to do is "quieten" herself. She is quiet, not doing outrageous things or pushing herself too hard. She eats well and rests a lot. She sleeps. Soon there will be a baby and sleep will be hard to come back. At all times, she remembers her baby. Everything that she does affects her baby. Everything that she eats and drinks affects her baby. All her emotions, the baby feels. This is why it is so important to be "quiet". Meditate, pray, connect with nature and the Creator. Love, nurture, be at peace.

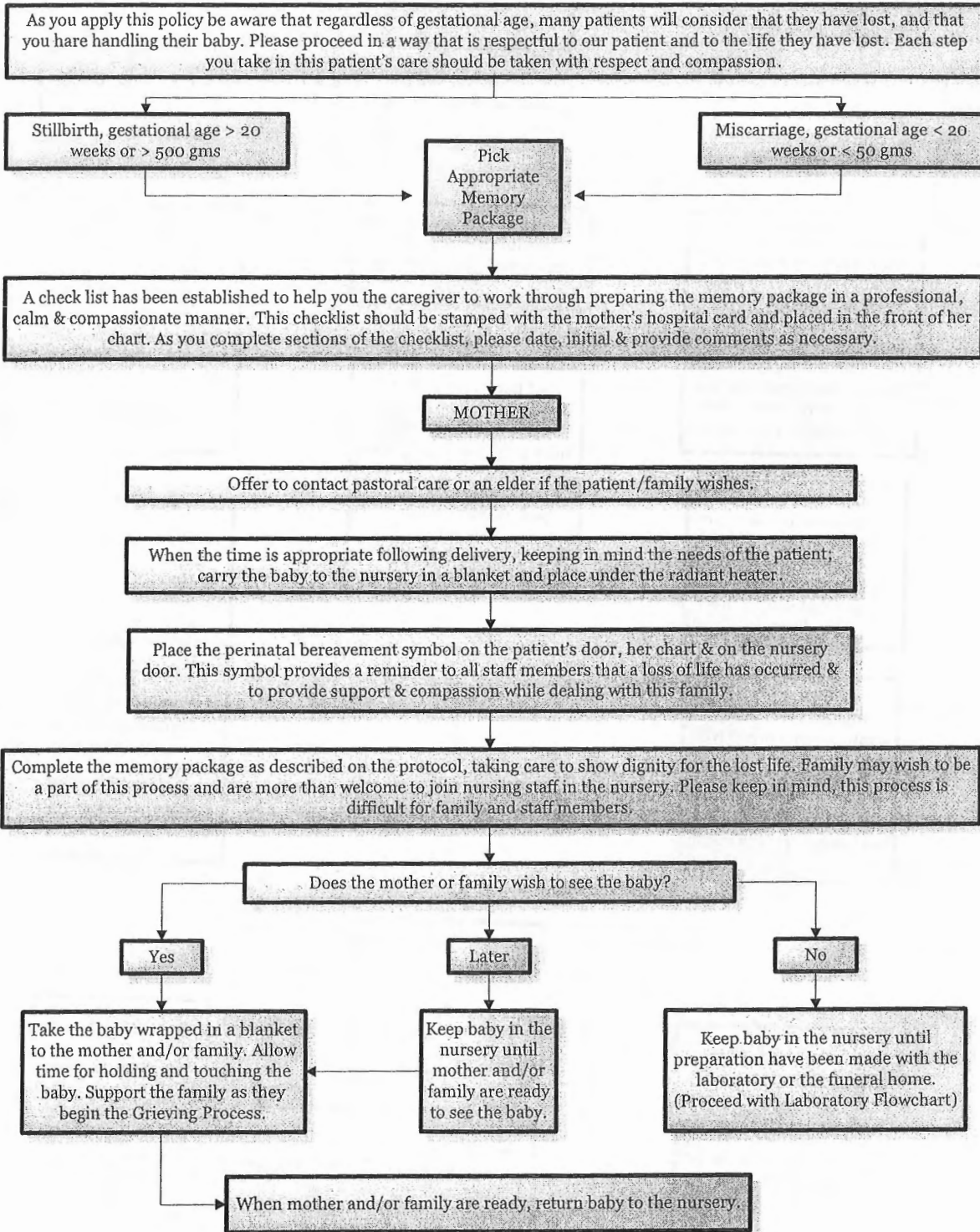
When it comes to the delivery, it is important for female family members to be there to give the support. The father needs to be close by. The baby should be sung to at delivery; this will be his or her song. If at all possible, the baby should be greeted by the parents and family members in their native tongue with the baby's native name.

If a woman has a miscarriage, the fetus needs to be retained for proper ceremonial burial. The baby/fetus needs to be named in their native name if all possible. The ceremony and naming will make the grief easier to bear. At all times, the fetus is handled with respect. At all times, the mother is handled and treated with respect and love.

When it comes to the afterbirth, it is important that this be retained by whoever is in the delivery room with the mother. The afterbirth is saved (put in a container and frozen) until a ceremony can be done. The ceremony may vary but always involves burying the afterbirth in Mother Earth. The feast for the baby, the baby's name, and the burial of the afterbirth can all be done at the same time.

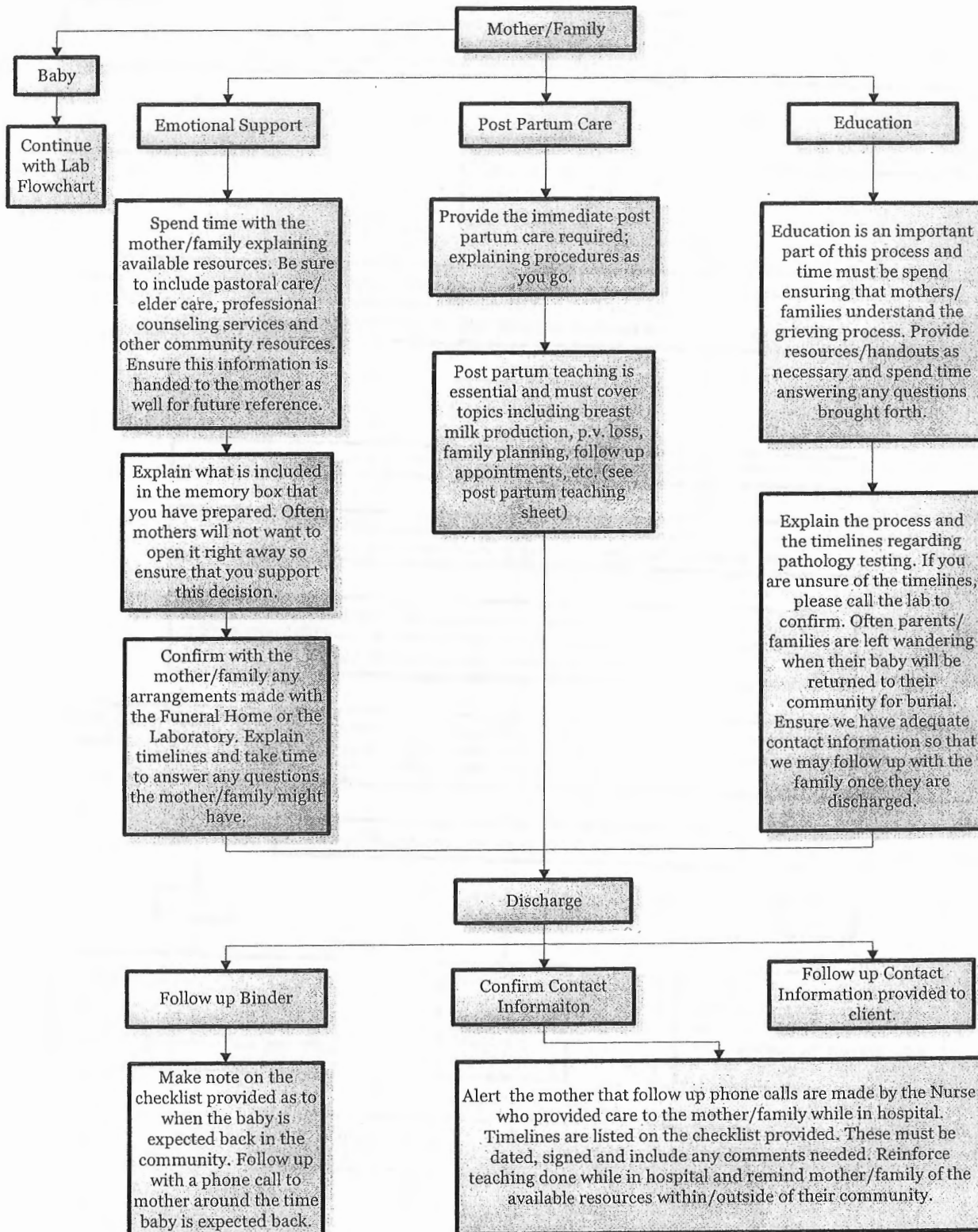
The sacredness of woman is becoming more and more important to me. In doing the work that I do, I have the opportunity to work with the young, the pregnant, and the old. That cycle into womanhood, giving birth, then teaching is so important. I do many complete physical exams on women and do many pelvic exams. I was told in a dream one night that in working in that area of women was an honour and that the pelvic area is a very SACRED PLACE as this is where we come into Mother Earth's physical plan! We women now need to realize our sacredness and not allow the abuse, the violence, and the disrespect of our beings! We are teaching our girls how to be treated and teaching our boys how to treat women. We have an important job to get that teaching done in a good way!

Perinatal Bereavement Flowchart



Discharge Planning Continued on Next Page

Perinatal Bereavement Flowchart (Continued) Discharge Planning



PERINATAL BEREAVEMENT CHECKLIST

Addressograph

Type of Loss:

Miscarriage Stillbirth

Name of Patient: _____

Admission / Delivery Date: _____

PATIENT CARE		
Action	Comments	Initial
<input type="checkbox"/> Patient's Room Labeled with an Angel		
<input type="checkbox"/> Patient's chart flagged		
If infant born alive		
<input type="checkbox"/> Admitting notified <input type="checkbox"/> Start infant chart		
Informed that baby is dying / has died		
<input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Others		
Discussed possible appearance of the baby		
<input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Others		
Saw Baby		
<input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Others		
Touched / Held Baby		
<input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Others		
Offered Private time with Baby		
<input type="checkbox"/> Accepted <input type="checkbox"/> Refused		
Offered Pastoral Care		
<input type="checkbox"/> Notified Name: _____		
<input type="checkbox"/> Visited		
<input type="checkbox"/> Declined		
Offered visit from an Elder		
<input type="checkbox"/> Notified Name: _____		
<input type="checkbox"/> Visited		
<input type="checkbox"/> Declined		

Discussed naming baby <input type="checkbox"/> Yes <input type="checkbox"/> No Baby Name: _____		
Baby Baptized and/or Traditional Ceremony		
Digital Photographs taken		
Memory Package: <input type="checkbox"/> Foot prints <input type="checkbox"/> Hand prints <input type="checkbox"/> Lock of Hair <input type="checkbox"/> ID Bands <input type="checkbox"/> Clothing <input type="checkbox"/> Crib Card <input type="checkbox"/> Photograph <input type="checkbox"/> Baptism Certificate <input type="checkbox"/> Declined, If declined: stored for 6 months at: _____		
Burial <input type="checkbox"/> Informed of need for burial/cremation (>500g or >20 wks) <input type="checkbox"/> Informed of the options (500g or <20 wks) <input type="checkbox"/> Funeral Home: _____		
Discussed Grief Process <input type="checkbox"/> Yes <input type="checkbox"/> No		
Resource Information Given <input type="checkbox"/> Empty Arms <input type="checkbox"/> Other: _____		
Follow-Up by Phone Call – Nurse <input type="checkbox"/> Yes <input type="checkbox"/> No		
ADMINISTRATIVE REQUIREMENTS		
Action	Comments	Initial
<input type="checkbox"/> Laboratory alerted and arrangements made		
<input type="checkbox"/> Operating Room alerted and arrangements made		
<input type="checkbox"/> Birth/Death Certificate Completed		
<input type="checkbox"/> Coroner notified by attending physician <input type="checkbox"/> Yes <input type="checkbox"/> No		
<input type="checkbox"/> Autopsy requested by physician <input type="checkbox"/> Yes <input type="checkbox"/> No		
<input type="checkbox"/> Autopsy consent signed by parents <input type="checkbox"/> Yes <input type="checkbox"/> No		
<input type="checkbox"/> Autopsy declined by parents		
<input type="checkbox"/> Further discussion requested		

O: June 2009

References

Bowles, Stephen V., James, Larry C., Solursh, Diane S., Yancey, Michael K., Epperly, Ted D., Folen, Raymond A., Masone, Maryann. Acute and Post-traumatic Stress Disorder After Spontaneous Abortion. *American Family Physician*. 2000 March 15.

Callister, Lynn Clark. Perinatal loss: *a family perspective*. *Journal of Perinatal & Neonatal Nursing*. 20(3):227-34; quiz 235-6, 2006 Jul-Sep.

Abstract

Perinatal loss is a profound experience for childbearing families. Examples of perinatal loss include miscarriage, ectopic pregnancy, stillbirth, neonatal death, and other losses. Perinatal loss engenders a unique kind of mourning since the child is so much a part of the parental identity. Societal expectations for mourning associated with perinatal loss are noticeably absent. Gender differences in response to such loss, as well as sibling and grandparent grief have been identified in the literature. Descriptive studies provide information on cultural responses to perinatal loss. Nursing interventions have been refined over the past two decades as research studies have been performed, in order to more fully promote health and healing in the face of perinatal loss. These include helping to create meaning through the sharing of the story of parental loss, the facilitation of sociocultural rituals *associated with loss*, the provision of tangible *mementos*, *sensitive* presence, and the validation of the loss. Outcome evaluations of such interventions are recommended.

Chichester M. Multicultural issues in perinatal loss. *AWHONN Lifelines*. 2005 Aug-Sep; 9(4): 312-20.

Abstract

Infant loss is frequently invisible to the rest of society. Parents may become frustrated when they are denied mourning time or asked why they are not "over it" yet. Nurses' demonstration of cultural sensitivity during perinatal loss facilitates grieving by validating each family's "right" way to mourn their infant's death.

Cote-Arsenault D, Freije MM. Support groups helping women through pregnancies after loss. *Western Journal of Nursing Research*. 26(6):650-70, 2004 Oct.

Abstract

Pregnancies following perinatal loss are full of fears and anxieties. Standards of care or interventions are not generally available; however support groups exist across the country. This study explored several pregnancy-after-loss support groups. Data were collected through participant observation of meetings, individual interviews, questionnaires, and artifacts. Five paradoxes were identified reflecting conflicts between common cultural expectations and the women's own perspectives about pregnancy: birth/death, pregnancy equals/does not equal baby, head/heart, public/private, and hope/fear. According to participants, the groups helped members recognize their commonalities, remember their earlier babies who died, develop caring relationships, and learn new coping skills. Key outcomes included "making it through" their pregnancies, finding ways to reconcile the cultural paradoxes, and relating better with their current, live babies.

Davis DL, Stewart M, Harmon RJ. Perinatal loss: Providing emotional support for bereaved parents. *Birth* 15(4):242-246, 1988

Abstract

This paper focuses on parents' emotional needs after perinatal loss and ways in which health care professionals can meet those needs. Parents must be educated about the grieving process and have their feelings acknowledged and validated. Health professionals can support parents by being available and listening, giving clear medical information, addressing parents' concerns, acknowledging the special situation, limiting the use of tranquilizers, providing follow-up, making referrals to support groups or for psychologic counseling, and learning what is helpful to say to bereaved parents. To be able to approach parents and offer support, health professionals must be aware of their own reactions to the death of a baby, loss, and grief. Receiving staff support better enables them to offer effective emotional support to bereaved parents.

DeFrain J. Millsbaugh E. Xie X. The psychosocial effects of miscarriage: Implications for health professionals. *Families, Systems and Health*. 14(3)(pp 331-347), 1996.

Abstract

The loss of a baby can have profound effects on parents and surviving siblings. It is common to hear the loss minimized in our culture as 'just a miscarriage,' but the analysis of more than 4,000 pages of written testimony collected from 172 mothers and 21 fathers indicates that losing a baby due to miscarriage can be a devastating experience. Disturbing flashbacks and nightmares are common in the aftermath of the loss; a high percentage of both mothers and fathers report feelings that they thought they might be 'going crazy'; 11.4% of the mothers said they had considered suicide as a result of the loss, and 1.8% did try to kill themselves. Divorce, however, was uncommon after the miscarriage; many mothers and fathers turned to their partners as major sources of support. Health professionals can play a critically important role in helping families begin the long and difficult journey to recovery, and suggestions for professional intervention are offered.

DeMontigny F, Dumas L, A Baby Has Died: The impact of perinatal loss on family social networks. *Journal of Obstetrics, Gynecologic & Neonatal Nursing* 28(2):151-156, 1999

Abstract

Objective: To describe the impact of a baby's death on the family's social network and to design nursing interventions to support families and their networks. **Design:** Descriptive, with a qualitative approach. **Setting:** An urban area of western Quebec. **Participants:** Twenty parents (mothers and fathers) who had experienced a perinatal loss (abortion, miscarriage, in-utero death, stillbirth, or death of a newborn within the 1st week of life) within the last 6 years. **Main Outcome Measures:** Self-administered questionnaires developed by the authors were completed by each parent. **Results:** Family members' quality and quantity of ties with their network were profoundly affected by the perinatal loss. Some families experienced reinforcement of their bonds with their social network, but most suffered permanent losses of relationships with friends, colleagues, or extended family members.

Conclusions: The quality and quantity of ties with one's network are associated with improved health status and life satisfaction. Considering the changes participants noted in their relationships within their network, further studies of the impact of these changes on family members' grieving process would be useful to guide nursing interventions

Douglas BD A Baby Has Died: All I've Got is a Bucket of Ashes: Spiritual needs of eight bereaved mothers. http://www.ctsnet.edu/degree_programs/advanced_degrees/DouglassDMinProjectO5.pdf

Abstract

Grief is typically treated as a psychosocial phenomenon, but it is a significant spiritual condition as well insofar as relationships with God, self, and others are impaired. However, there is little in the literature that acknowledges grief as spiritual in nature and its notable how seldom parents engage, or are engaged by, faith communities as they grapple with their faith concerns. From interviews of eight mothers of a perinatal loss, three key spiritual concerns are identified and discussed: faith crisis, isolation, and forgetting. This study hopes to better resource clergy and faith communities as they provide for the spiritual needs of bereaved parents.

Estok P, Lehman A. Perinatal Death: Grief support for families. *Birth* 10(1):17-28, 1983

Fletcher SNE. Cultural implications in the management of grief and loss. *Journal of Cultural Diversity*. 2002 Fall; 9(3): 86-90.

Abstract

As culturally unique individuals, our culture impacts and even dictates our responses to normal events of daily living. We are frequently unaware of the way we value time, perceive spatial boundaries, and communicate with others. Health care professionals must be culturally sensitive to all individuals. Culturally diverse nursing care acknowledges the individual's cultural uniqueness and incorporates a variety of approaches to provide culturally sensitive care. This paper will discuss culturally diverse health care with a client experiencing grief and loss.

Jonas-Simpson, C., & McMahon, E. (2005). Practice Applications. The language of loss when a baby dies prior to birth: Cocreating human experience. *Nursing Science Quarterly*, 18, 124-130.

Abstract

When a baby dies prior to birth, a woman and her family begin a life long journey of living and transforming with loss. The language used with families during times of devastating loss is important to reflect upon since, language has the potential to either intensify suffering or enhance the family's experience of grieving. Words that affirm the meaning the baby holds for the family can provide comfort as families engage with the reality of lost hopes and dreams. Recognizing that healthcare professionals do not intend to harm families whose babies die prior to birth, the current authors offer this column as a vehicle for reflecting on the meanings of words used during this particular time of loss and grief. The authors further explore the role that the arts have to play in expressing loss and in helping others to understand.

Jonas-Simpson, C (author), Friis Karen (illustrator). *Ethan's Butterflies: A spiritual book for parents and young children after a baby's passing*. Trafford Publishing. www.trafford.com/06-0606

About the Book

Spiritual comfort and understanding after a baby's passing was what Christine JonasSimpson was looking for in answering her young sons' difficult questions about their baby brother Ethan's passing. This book takes the parents and young children through the journey of deep sorrow and loss of a baby brother or sister from the moment of expectation of meeting them to the despair of knowing they passed, to the joy of reconnecting with them in another way. This story is about living and feeling the deep loss of a baby as well as transforming this precious loss through connecting and creating new relationships.

Haas F. Bereavement care: seeing the body. *Nursing Standard*. 2003 Mar 26-Apr 1; 17(28): 33-7.

Abstract

Background: Generally, it is now accepted that the long-term outcomes are better for those who are able to see the body of a loved one as it helps people who are grieving to come to terms with the death. **Conclusion:** While the evidence indicates that seeing the body of a loved one helps the grieving process, a recent study into bereavement reactions following neonatal deaths gives disturbing evidence to the contrary, so while it may usually be good practice to encourage viewing, this may be potentially damaging to new parents who have lost a baby.

Hebert, M P. Perinatal bereavement in its cultural context. *Death Studies*. 22(1):61-78, 1998 Jan-Feb.

Abstract

A framework for assessing the cultural influences on patterns of bereavement and for planning appropriate, culturally congruent perinatal bereavement care is presented.

Hughes P. Riches S. Psychological aspects of perinatal loss. *Current Opinion in Obstetrics & Gynecology*. 15(2):107-11, 2003 Apr.

Abstract

PURPOSE OF REVIEW: Parents are attached to their unborn children, and loss around the time of birth is a serious trauma. Parental grief is a normal response, and may last for many months. Clinicians have always sought to implement practices that will help recovery, and for a generation, have advocated that parents have contact with the body of their dead infant, believing that this will facilitate mourning. Review of the literature shows that no previous systematic evidence has ever been offered to support this practice. **RECENT FINDINGS:** Recent research throws doubt on the therapeutic value of the practice of encouraging contact with the dead infant. These findings are outlined and discussed. **SUMMARY:** Following an outline of what is already known about the psychological effects of perinatal loss, the paper focuses on the evidence that aspects of psychosocial management are associated with better outcomes. It goes on to describe the cultural context in which psychosocial management changed and parents were first encouraged to see and handle their dead infant, and explores the distinction between the medical and cultural models which may frame this behaviour in very different ways. Finally, it briefly discusses the ethical position of staff who advise parents about their choice to see or not see their infant's body.

Hutti MH, Social and professional support needs of families after perinatal loss. *Journal of Obstetrics, Gynecologic & Neonatal Nursing* 34(5):630-638, 2005

Abstract

Perinatal loss has been associated with depression, anxiety, obsessive-compulsive disorder, suicide, marital conflict, and post-traumatic stress disorder. Nurses may provide professional support through teaching, role modeling, encouragement, counseling, problem solving, and other interventions. Nurses also may encourage more effective social support by helping significant others to provide willing, well-intentioned action that will produce a positive response in the bereaved couple. Interventions to increase professional and social support after perinatal loss are described.

Lawson LV. Culturally sensitive support for grieving parents. *MCN: The American Journal of Maternal/Child Nursing*. 1990 Mar-Apr; 15(2): 76-9.

Abstract

The cultural beliefs of Native Americans, Mexican Americans, and Southeast Asians affect the grieving of these parents following the death of their infant.

Kavanaugh K, Moro T. Supporting parents after stillbirth or newborn death: There is much that nurses can do. *American Journal of Nursing*. 106(9):74-9, 2006 Sep.

Abstract

The experience of perinatal loss can be devastating for couples who want children. The decision and desire to attempt another pregnancy may be too much for parents to bear, yet the majority of women who experience perinatal loss do become pregnant again soon after the loss. A pregnancy after a perinatal loss can be mentally, emotionally, and physically taxing. The anxiety experienced by mothers during a subsequent pregnancy has been documented consistently by investigators, but less is known about the effects of perinatal loss on parenting subsequent children. Perinatal and neonatal nurses play a critical role in supporting parents during and after a subsequent pregnancy and need an understanding of the research to direct their practice.

Kavanaugh K, Hershberger P. Perinatal loss in low-income African American parents. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*. 34(5):595-605, 2005 Sep-Oct.

Abstract

Objective: To examine the experience of low-income, African American parents surrounding perinatal loss and to describe how other life stressors influenced the parents' responses and caring needs. **Design:** Descriptive, using a phenomenologic approach. **Setting:** All data were collected in person. Interviews were held in parents' homes or, at the request of three parents, in an office in the university between 5 and 21 weeks after the loss. **Participants:** A total of 23 parents (17 mothers and 6 of their partners) were interviewed after a perinatal loss (16 weeks gestation or later) or a neonatal death (first 28 days of life). Follow-up interviews were held with 21 of these parents. **Results:** Four themes were revealed: (a) recognizing problems and responding to the loss, (b) dealing with stressful life events, (c) creating and cherishing memories of the baby, and (d) living with the loss. **Conclusions:** The results of this study reveal experiences not previously reported and provide initial insight on the loss experience in this group of parents. Health care professionals should be aware of the presence of additional stressful events that parents may be experiencing and intervene appropriately to provide culturally competent care in a sensitive manner.

Kavanaugh K, Wheeler S. 'When a baby dies: Caring for bereaved families.' Chapter In C Kenner, *Comprehensive Neonatal Nursing: A Physiological Perspective* WB Saunders Co.:Chicago (2003)

Kennell JH, Klaus MH. 'Caring for the parents of a stillborn or an infant who dies.' Chapter in Parent-Infant Bonding, CV Mosby 1982

McCreight BS. A grief ignored: narratives of pregnancy loss from a male perspective. *Sociology of Health and Illness*. 2004 Apr; 26(3): 326-50.

Abstract

This paper, utilising a narrative approach, aims to describe the experiences of men whose partner had experienced pregnancy loss, based on data from Northern Ireland. The methodology was based upon observation within pregnancy loss self-help groups and indepth interviews with 14 men who attended the groups. The study also included interviews with 32 midwives and nurses, with the intention of examining attitudes within the medical context towards bereaved fathers. The impact of pregnancy loss on male partners has been largely overlooked in academic research. When a baby dies before birth the loss can be devastating for fathers yet, very often, the world that surrounds them tends to discount their loss, and emotional support and cultural rituals that are normally available to other bereaved individuals are often absent for this group of men. Previous research has shown that men are expected to be emotionally strong in order to support their partner. The present study will show that the perception that men have only a supportive role in pregnancy loss is unjustified, as it ignores the actual life-world experiences of the men, and the meanings they attach to their loss, in what may be a very personal emotional tragedy for them where they have limited support available. The study uncovered several recurring themes including self-blame; loss of identity; and the need to appear strong and hide feelings of grief and anger. There is consideration of the need for hospital staff and the wider community to acknowledge the male partner's grief as being a valid response to the bereavement suffered.

Pector E, Smith-Levitin M Mourning and psychological issues in multiple birth loss. *Seminars in Neonatology*, Volume 7, Issue 3, Pages 247-256

Abstract

Grief after the death of some or all multiples differs from mourning for a singleton loss in many important respects. A review of the unique features of grief for a multiple birth loss is followed by practical suggestions for empathic care. Cherished mementos and photos, and disposition options for deceased children are discussed. Counselling needs of parents and siblings are detailed, and management options for many complex pregnancy and infant loss scenarios are presented. The abundant resources listed will help caregivers and families better cope with one of the most difficult complications of plural parenthood.

Saflund K, Sjogren B, Wredling R. The role of caregivers after a stillbirth: Views and experiences of parents. *Birth* 31(2), 2004

Abstract

Background: The clinical role of the caregiver to parents in the event of a stillbirth has yet to be defined. The aim of this paper was to focus on the caregivers' support as revealed by the parents' experiences. **Method:** One or both parents of 31 stillborn infants (> 28 weeks) were interviewed twice, for a total of 57 interviews. The data analysis was conducted using a qualitative approach. **Results:** Parents identified the caregivers' behavior and handling of the stillbirth as important Findings showed

that caregivers should support parents in moments of chaos and at other difficult times. The parents needed *assistance in both facing and separating from the baby*. The six "qualities" that summarized the findings were "support in chaos," "support in the meeting with and separation from the baby," support in bereavement, "explanation of the stillbirth," organization of the care," and "understanding the nature of grief." Findings indicate that the hospital is under an obligation to organize the care and make it possible for parents to see the same caregivers again, and to offer extra ultrasound investigations and checkups without unnecessary bureaucracy. **Conclusion:** We suggest that the "qualities" identified by the study findings should be implemented in clinical care, and could facilitate active guidance and counseling for bereaved parents who have experienced a stillbirth.

Stinson, Kandi M; Lasker, Judith N; Lohmann, Janet; Toedter, Lori J. Parents' grief following pregnancy loss: A comparison of mothers and fathers. *Family Relations*, Vol 41(2) Apr 1992, 218-223.

Abstract

Gender differences in bereavement following miscarriage, ectopic pregnancy, stillbirth, and neonatal death are examined. 56 couples were interviewed using the Perinatal Grief Scale. Women were significantly higher than men on most dimensions of grief at 2 mos, 1, and 2 yrs postloss, except on the dimension indicating the most serious consequences of grief. While men do grieve, at times intensely, they may deny their grief and internalize feelings of loss rather than openly express them, due to American cultural norms that advocate male inexpressiveness.

Szgalaky JB. Perinatal death, the family, and the role of the health professional. *Neonatal Network - Journal of Neonatal Nursing*. 8(2):15-9, 1989 Oct.

Abstract

In order to substantially assist a grieving family at the time of perinatal death, the health care team should have sufficient knowledge of the grief reaction, including the duration, maternal/paternal differences, and perinatal psychodynamics. Immediate support includes bereavement counseling. Predelivery care should be provided, if appropriate. The health care team should be prepared for common questions and know about local cultural traditions. Follow-up care after discharge, including anticipatory guidance, is important. The issues of repeat pregnancies and holiday behavior should be addressed. Siblings must be taken into account. The health care team should be able to detect unresolved grief and identify at-risk parents. A hospital protocol should be in place. It should be kept in mind that parents remember the emotional care given to them rather than the technical or medical care provided.

Thomas J. The death of a baby: guidance for professionals in hospital and the community. *Journal of Neonatal Nursing*. 2001 Sep; 7(5): 167-70.

Abstract

It is now recognized that providing bereavement support and involving parents in the care of their baby after death is good practice and vitally important. The way parents perceive that care varies and depends on how the professionals have provided information at this crucial time. Information regarding post-mortems has not always been clear. Many professionals feel untrained and unprepared to care for these grieving families. The guidance described in this article is based on what bereaved parents have said they need during this time.

Wilson, R E. Parents' support of their other children after a miscarriage or perinatal death. *Early Human Development*. 61(2):55-65, 2001 Mar.

Abstract

OBJECTIVES: This study, which grew out of the author's counselling work with the Edinburgh Stillbirth and Neonatal Death Society, explores the way parents who have recently lost a baby support other children in the family. In view of recent research in America on the continuing but changing bonds with the deceased, the place which the parents give to the deceased baby in the ongoing life of the family was also examined. DESIGN OF STUDY: Data were collected through semi-structured interviews with eight families who had initially contacted the Edinburgh Stillbirth and Neonatal Death Society (SANDS). RESULTS: The kinds of support parents provided and felt was needed fell under three main headings: recognizing and acknowledging the child's grief, including the child in family rituals and keeping the baby alive in the family memory. CONCLUSIONS: While there was some consistency in the kinds of support parents recognized as required, the parents own circumstances and beliefs influenced the way support was given. Further research might explore these factors with a larger sample. There did seem to be recognition by parents, in their longer-term support and the range of family activities, of continuing and changing bonds with the deceased baby rather than the severing of bonds.

York CR. Stichler JF. Cultural grief expressions following infant death. *Dimensions of Critical Care Nursing*. 1985 Mar-Apr; 4(2): 120-7. (11 ref)

Abstract

When a family wants to tie strings to their critically ill baby's foot or wants to take a dead infant home, what should you do? This author looks at cultural grief patterns that help you decide.

End-of-life issues for aboriginal patients

A literature review

Len Kelly MD MCISc CCFP FCFP Alana Minty

ABSTRACT

OBJECTIVE To understand some of the cross-cultural issues in providing palliative care to aboriginal patients.

SOURCES OF INFORMATION MEDLINE (1966 to 2005), CINAHL, PsycINFO, Google Scholar, and the Aboriginal Health Collection at the University of Manitoba were searched. Studies were selected based on their focus on both general cross-cultural caregiving and, in particular, end-of-life decision making and treatment. Only 39 relevant articles were found, half of which were opinion pieces by experienced nonaboriginal professionals; 14 were qualitative research projects from nursing and anthropologic perspectives.

MAIN MESSAGE All patients are unique. Some cultural differences might arise when providing palliative care to aboriginal patients, who value individual respect along with family and community. Involvement of family and community members in decision making around end-of-life issues is common. Aboriginal cultures often have different approaches to telling bad news and maintaining hope for patients. Use of interpreters and various communication styles add to the challenge.

CONCLUSION Cultural differences exist between medical caregivers and aboriginal patients. These include different assumptions and expectations about how communication should occur, who should be involved, and the pace of decision making. Aboriginal patients might value indirect communication, use of silence, and sharing information and decision making with family and community members.

RÉSUMÉ

OBJECTIF Tenir compte des questions interculturelles dans la prestation de soins palliatifs aux patients autochtones.

SOURCES DE L'INFORMATION On a consulté MEDLINE (1966 à 2005), CINAHL, PsycINFO, Google Scholar et l'Aboriginal Health Collection de l'Université du Manitoba. On a conservé les études qui portaient sur les soins de santé interculturels généraux et plus particulièrement sur la prise de décision et les traitements en fin de vie. On a repéré seulement 39 études pertinentes, dont la moitié étaient des opinions anecdotiques de professionnels chevronnés non autochtones; 14 étaient des études expérimentales qualitatives du point de vue de l'anthropologie et des soins infirmiers.

PRINCIPAL MESSAGE Chaque patient est unique. Certaines différences culturelles risquent d'apparaître lorsqu'on dispense des soins palliatifs à des patients autochtones pour qui la famille, la communauté et le respect de l'individu sont des valeurs importantes. Il est fréquent que la famille et la communauté participent aux prises de décision pour les questions portant sur la fin de vie et les cultures autochtones ont souvent des approches différentes pour communiquer les mauvaises nouvelles et maintenir l'espoir chez les patients. L'utilisation d'interprètes et de modes de communication variés ajoute au défi.

CONCLUSION Des différences culturelles existent entre le personnel soignant et les patients autochtones. Mentionnons, entre autres, des croyances et attentes différentes sur la façon de communiquer et ceux qui devraient y participer et sur le rythme de la prise de décision. Le patient autochtones pourrait préférer communiquer indirectement, recourir au silence et partager information et prise de décision avec la famille et les membres de la communauté.

This article has been peer reviewed.

Cet article a fait l'objet d'une révision par des pairs.

Can Fam Physician 2007;53:1459-1465

Terminally ill patients and their family members face difficult decisions. When medical staff members are not of the same cultural background as the patient, communication and decision making take on new challenges.¹ This review was undertaken to see how the published literature could inform care delivery for dying aboriginal patients.

Data sources

MEDLINE (1966 to 2005), CINAHL, PsycINFO, and Google Scholar were searched using various MeSH headings, including *American Indians; communication barriers; traditional medicine; health knowledge, attitudes, practice; terminally ill; right to die; palliative care; decision making; informed consent; advance directives; and organ transplantation*. The Aboriginal Health Collection at the University of Manitoba Library was also searched.

Study selection

Three hundred articles were identified in the search. Most of the articles dealt with specific medical problems (eg, diabetes, tuberculosis, HIV), rather than end-of-life issues. Only 39 articles focused on death and dying or relevant cross-cultural medical caregiving.

The studies reviewed varied in size from fewer than 10 subjects to large population surveys. Of the 39 articles used, 15 were review or opinion pieces, and 14 were qualitative studies using interviews or focus groups. Three quantitative studies used observed interactions or surveys. Population surveys included the 1991 Aboriginal Peoples Survey (N=25 122) and the 2003 Ontario First Nations Regional Health Survey (N=1094). Article characteristics are outlined in **Table 1**.¹⁻³⁹

Most papers were written by nonaboriginal authors exploring various aspects of aboriginal beliefs. Relevant papers covered several of the following topics: palliative care and barriers to such care, end-of-life decision making, coping with death in the family or community, organ and tissue donation, and modern and traditional aboriginal health and healing.

Levels of evidence

Level I: At least one properly conducted randomized controlled trial, systematic review, or meta-analysis

Level II: Other comparison trials, non-randomized, cohort, case-control, or epidemiologic studies, and preferably more than one study

Level III: Expert opinion or consensus statements

Dr Kelly is an Associate Professor of Family Medicine for the Northern Ontario School of Medicine and McMaster University in Sioux Lookout, Ont. Ms Minty is a pharmacy student at the University of Toronto in Ontario.

Most research studies were qualitative. Salvalaggio et al and Macaulay suggest that community-based qualitative methodology might be the most appropriate cross-cultural methodology.^{23,33,34}

Synthesis

Many traditional aboriginal perspectives differ from the viewpoints of other Canadians.²⁷ Authors encountered various attitudes when studying end-of-life issues, demonstrating the variety of beliefs within aboriginal communities. Ellerby et al noted that some aboriginal patients valued the "maintenance of quality of life rather than the exclusive pursuit of a cure" and emphasized that "life is to be preserved and should be pursued whenever meaningful quality can be maintained."⁸ In contrast, Molzahn et al documented that some aboriginal patients believe medical intervention should be minimal and that the Creator determines the time of death.²⁷ Diversity of beliefs might vary between and within aboriginal communities, owing to differences of "traditional, acculturated or religious perspectives."³⁹ While generalizations are often inappropriate, some common themes documented below might be reflected in end-of-life issues.^{20,27}

Respect. Several commentators identified the importance of family, community, and respectful interpersonal relationships to aboriginal culture.^{3,8,13,16} Browne's in-depth interviews of 5 Cree-Ojibway key informants from northern Manitoba found that actively listening and accepting others' decisions were important for successful interpersonal relationships.⁴ Brant, a Mohawk psychiatrist, identified the concept of non-interference in his opinion article.³ He suggested that many aboriginals believe that all people are entitled to make their own decisions. This high degree of respect for personal independence means that advising, persuading, or instructing is "undesirable behaviour."³

Elders might be participants in decision making, as they are highly respected in aboriginal communities. They are valued for their wisdom and experience³ and might be quite knowledgeable about medicinal herbs and spiritual matters.³² This respect for elders and healers can lead aboriginal patients to accept medical advice from physicians without question, out of respect for their parallel role as healer.³

Traditional perspectives. Traditional medicine is often assumed to refer to land-based medicines and plants. Hart-Wasekeesikaw, an aboriginal nurse who did a qualitative research study involving interviews with 42 aboriginal patients, suggests it is probably best understood as a set of assumptions concerning the holistic nature of a person.¹⁰ Both physical and emotional health are seen to stem from balance between the mind, the body, and the spirit, as well as strong interpersonal

Table 1. Articles focusing on end-of-life issues*

AUTHOR (YEAR)	NO. OF PARTICIPANTS (N)	TYPE OF STUDY	LEVEL OF EVIDENCE	COMMENTS
Benoit et al ² (2003)	61	Qualitative	II	Focus groups and interviews, Vancouver, BC
Brant ³ (1990)	—	Opinion	—	Overview, Mohawk psychiatrist
Browne ⁴ (1995)	5	Qualitative	II	Interviews regarding respect, Cree-Ojibway, MB
Browne and Shultis ⁵ (1995)	15 reserves	Survey	II	Matched aboriginal and nonaboriginal communities regarding services, ON
Callender et al ⁶ (1997)	40	Qualitative	II	Organ donation, US minorities
Cree Regional Child and Family Services Committee ⁷ (2000)	—	Participatory research	—	Participatory research, Cree, QC
Ellerby et al ⁸ (2000)	—	Review	III	Discusses aboriginal values, Ojibway
Garro ⁹ (1990)	121	Qualitative	II	Ethnographic field work, Anishinaabe, MB
Hart-Wasekeesikaw ¹⁰ (1996)	47	Qualitative	II	Ethnographic interviews with cancer patients and their families, MB
Health Canada ¹¹ (2000)	—	Opinion	—	General overview
Hepburn and Reed ¹² (1995)	—	Opinion	—	Palliative decision making, United States
Hotson et al ¹³ (2004)	44	Qualitative	II	Patients and medical personnel, MB
IMPACT ¹⁴ (2005)	—	Statistics	II	Death and injury, motor vehicle accident statistics, ON
Iwasaki et al ¹⁵ (2005)	26	Qualitative	II	Focus groups, aboriginal and Métis, MB
Jennings ¹⁶ (1994)	—	Opinion	III	Discussion of patient autonomy, United States
Kaufert and O'Neil ¹⁷ (1989)	—	Qualitative	II	Dying patients in MB and Inuit in NWT
Kaufert and O'Neil ¹⁸ (1989)	25	Qualitative	II	Field observation of inpatients regarding giving consent, MB
Kaufert et al ¹⁹ (1998)	12	Qualitative	II	Observed conflict behaviour and interviews, MB
Kaufert et al ²⁰ (1999)	12	Qualitative	II	Observation and interviews, Ojibway, Cree, Island Lake
Kaufert ²¹ (1999)	40	Qualitative	II	Interviews with patients and family about cancer care, MB
Kelly and Brown ²² (2002)	10	Qualitative	II	Grounded-theory interviews of physicians, Canada
Kelly and O'Driscoll ¹ (2004)	—	Opinion	III	Clinical palliative care issues
Macaulay ²³ (1994)	—	Opinion	III	Ethics guidelines
MacKinnon ²⁴ (2005)	—	Review	—	Political review Romanow
MacMillan et al ²⁵ (2003)	1094	Survey	II	Ontario First Nations Regional Health Survey
McQuay ²⁶ (1995)	—	Opinion	—	Organ donation review, United States
Molzahn et al ²⁷ (2004)	14	Qualitative	II	In-depth interviews, Coast Salish, BC
Newbold ²⁸ (1999)	25 000	Survey	II	Analysis of 1991 Aboriginal Peoples Survey regarding disability care
Paniagua ²⁹ (1994)	—	Opinion	III	Communication guidelines, United States
Preston and Preston ³⁰ (1991)	—	Qualitative	II	25 yrs of ethnography James Bay Cree, QC
Prince and Kelley ³¹ (2006)	216	Survey and nested qualitative	II	13 northwestern ON communities
Reynolds-Turton ³² (1997)	100	Qualitative	II	Foundational inquiry, US Ojibway and Chippewa
Royal Commission on Aboriginal Peoples ³³ (1996)	—	Report	III	Government of Canada report
Salvalaggio et al ³⁴ (2003)	12	Qualitative	II	Interviews with aboriginal patients, Anishinaabe, ON
Sarsfield et al ³⁵ (1988)	—	Opinion	—	Role of community health representatives, MB
Schaeffer et al ³⁶ (1998)	495	Retrospective	II	Organ donation demographics, United States

Table 1 continued...

AUTHOR (YEAR)	NO. OF PARTICIPANTS (N)	TYPE OF STUDY	EVEL OF EVIDENCE	COMMENTS
Smylie et al ³⁷ (2000)	—	Policy statement	III	Society of Obstetricians and Gynaecologists of Canada policy statement
Verble et al ³⁸ (2002)	323	Qualitative	II	Focus groups about organ donation, United States
Westlake Van Winkle ³⁹ (2000)	—	Review	III	American and Alaskan literature review

*Blank cells indicate that information was not available or not applicable.

relationships.^{8,15,24,32} This holistic view means that modern healing practices that focus purely on physical problems are often not immediately accepted by aboriginal patients, particularly elders. They might prefer to be treated by traditional healers, using healing circles, sweet grass, or other spiritual methods. Patients might also wish to involve elders in their care and treatment decisions.^{2,8,37} Kaufert and colleagues suggest that access to a traditional healer in a modern hospital is similar to access to a hospital chaplain.²⁰

Garro encountered an aboriginal perspective that differentiates between "Anishinaabe sickness" and "white man's sickness."⁹ Anishinaabe sicknesses can be caused by such things as "onjine" (bad behaviour) or bad medicine, and can only be cured by medicine men, not by modern doctors. White man's sicknesses, which did not exist until the Anishinaabe people were exposed to white men, require a physician who might be more adept at these treatments.¹⁹

Not all aboriginal patients want traditional healing.^{11,22} During the 44 interviews conducted by Hotson et al in northern Manitoba, "most community informants... did not identify the need for any 'traditional' services for those who are dying."¹³ This topic therefore needs to be cautiously explored with aboriginal families, as those from a Christian tradition might take offence.³⁴

Truth-telling. Jennings, McQuay, Ellerby et al, and Kaufert et al all discuss the concepts of truth-telling and maintenance of hope.^{8,16,19,20,26} Relatives of a terminally ill aboriginal patient might not want their loved one to know the seriousness of the medical condition, as positive thinking is thought to promote health. Discussing terminal illnesses or death can cause the patient to die more quickly. For this reason, some aboriginal patients might accept "uncertainty in prognosis or disease progression" more easily than nonaboriginal patients.⁸ Ellerby et al and Kaufert et al cite instances where this focus on hope led relatives to protect their sick loved ones by acting as proxy decision makers or by discouraging physicians or interpreters from delivering bad news.^{8,19,20}

Use of interpreters. Some aboriginal people do not speak English and rely on interpreters in their health care. In 3 studies using observed interactions with follow-up

interviews, Kaufert and colleagues discussed the particular skills interpreters should have.^{19,20,21} Owing to differences in values and beliefs surrounding medical care, interpreters require good understanding of patients' cultures as well as their languages. Kaufert et al and Smylie et al explain the disadvantage of using a family member as an interpreter, despite the apparent convenience.^{19,21,37} Individual privacy concerns and end-of-life values might conflict between the patients and their family members. This can lead family member-interpretors to consciously or unconsciously alter the doctor's message in order to deliver a message that they think their loved one would want to hear.^{19,21,37} In addition to invaluable cultural and language interpretation, experienced nonfamily interpreters might have links to traditional healers and other services of interest to patients or their families.¹⁷

Trust. Benoit and colleagues studied 36 aboriginal women living in Vancouver, BC, using participant observation, focus groups, and follow-up interviews.² The women liked the informal nature of the services at their urban health centre. They preferred aboriginal staff and wanted more information available in areas of parenting and coping with family illness. They liked the fact that they did not have to give any personal medical information on their first visit. Once they had built trust with the staff, nurses, and physicians, then they could address their specific medical concerns.⁸ Kelly and Brown also found this importance of trust in their interviews with 10 Canadian physicians working with aboriginal patients.²² They learned that it often took years of working in the same community before patients really started to open up and discuss issues.

Similar comments were made in northern Quebec by women involved in a diabetes education program.⁷ They thought the group of researchers should have had more understanding of their Cree community before coming to teach them about gestational diabetes. They also thought more local people could have been involved in organizing the project.⁷

End-of-life decision making. Many authors said aboriginal patients strongly preferred immediate and extended family members to be involved in medical decision making.^{8,13,16,19,20,39} Reviews by Ellerby et al, Brant, Kaufert et al, and Jennings, as well as interviews by Hotson et al

and Kelly and Brown, all demonstrated the centrality of family and community.^{3,8,13,16,19,20,22} When it comes to end-of-life decision making, family members of many aboriginal patients attempt to balance keeping their loved ones informed with still allowing them to maintain hope.^{20,21}

Several authors mentioned the difficulty obtaining advance directives from aboriginal patients.^{12,39} The formal structured approach used by many hospitals might be ineffective with aboriginal patients.^{12,18} Hepburn and Reed, as well as Westlake Van Winkle, recommend trying to determine patients' wishes in a less formal manner.^{12,39}

Kaufert et al and Kelly and Brown also suggested that language barriers, as well as cultural differences in behaviour, might impede a physician's ability to assess the patient's mental competence to make informed decisions.^{20,22}

Family caregiving. Newbold reviewed the Aboriginal Peoples Survey of 1991 (N=25 122) and learned that family or friends often care for disabled aboriginal patients, instead of involving external agencies.²⁸ This might be due to the geographic remoteness of patients, financial barriers, or the personal importance of family. MacMillan et al had similar findings in 2003, analyzing the Ontario First Nations Regional Health Survey (N=1094) compared with the National Population Health Survey (N=4840).²⁵ It is difficult to tell if this caregiving by family members is by choice or out of necessity.²⁵ Most aboriginal patients would like to die at home¹³ but do not.³¹ Aboriginal northern Ontario community members (N=216) cited inadequate resources, training, and time as contributing factors.³¹ Aboriginal patients in remote communities more commonly interact with nurses, social workers, and alternative health care providers than they do with family doctors. Aboriginal patients might, therefore, be more comfortable with nonphysician care providers.

Family involvement with the death of the patient. In the event patients are incapable of making their final wishes known and a substitute decision maker has not been appointed, health care providers might have to determine which family member acts as spokesperson. Hepburn and Reed found that a spokesperson often emerges without any formal intervention by caregivers.¹²

Some aboriginal people see death as a necessary part of the life cycle and are quite accepting.^{12,39} Terminally ill patients might feel that it is very important to say goodbye to loved ones before they pass away.³¹ This might relate to their belief in an afterlife and the importance of maintaining relationships with loved ones upon entering the spirit world.^{18,30}

Once an aboriginal patient has passed away, there might be additional local cultural considerations. In

aboriginal communities, news that someone has died is usually told simply, directly, and promptly.³⁰ Views on the handling of the body vary by community and family. The review by Smylie et al presents several belief systems.³⁷ It might be important for family and community members to be present at the time of death. The patient or family might request that the death take place in the home community. If this is not possible, the family might request to have the body returned to the community soon afterward. The family might ask to be directly involved in the preparation of the body, and some traditions even require that the body not be left alone until after burial or that the body be buried within 24 hours of death.^{26,37}

The process of dying. Many traditional aboriginal cultures consider death to be very natural. For many aboriginal people, a "good death" is one where they meet death with dignity and composure.³¹ Dying this way implies a further experience of an afterlife.¹¹ Focus groups in 10 northern Ontario communities further defined a "good death" as "during sleep, without pain, in a patient who had received proper care."³¹

There are several accounts of aboriginal patients seeming to know when they will die. This can allow them to prepare themselves both physically and spiritually. Some people die while dressed in particular clothing which family members believe were specifically worn as preparation for their journey. This knowledge allows them to say goodbye to their loved ones, thereby maintaining their important positive relationships.³⁰

Most authors point out that dying is a uniquely individual process, and care must be taken to ensure sensitivity toward the specific patient's wishes.

Organ donation. Molzahn and associates conducted interviews with 14 members of the Coast Salish people in British Columbia regarding organ donation. They encountered a belief in the existence of spirits within each person: when aboriginal people die, they should be buried with a complete body and soul so that they are prepared for their next life.²⁷ This concept was also discussed by Kaufert et al in their reviews, and by Verble et al in their study of data collected from routine organ donation meetings (N=323).^{18,20,38} Molzahn et al also discussed the concept of spirit transfer: some of the participants believed that part of a donor's spirit might be transferred to the recipient during an organ transplantation.²⁷

These body-wholeness and spirit-transfer values might be issues for aboriginal patients contemplating organ donation. Molzahn et al mentioned the large number of aboriginal people awaiting transplantation and the low donation rate. The need for an intact body and complete spirit at burial might be met by performing a cleansing ceremony before the procedure.²⁷

Injury is the leading cause of death for aboriginal people, most from motor vehicle accidents.¹⁴ Evidence from United States general population shows that minority ethnicity lowers donation rates across many cultures.³⁶ Molzahn et al pointed out that many aboriginal people do support organ donation but lack relevant information.²⁷ In the United States, Callender and colleagues found that a community-based minority research program in Washington, DC, increased organ donation rates over a 17-year period, addressing awareness and "ethnically similar messengers" with "culturally sensitive messages."⁶ Even among the 14 interview participants of Molzahn and colleagues, there was considerable diversity of beliefs, and the authors acknowledged the paucity of Canadian research on barriers to and beliefs about organ donation in aboriginal communities.²⁷

Grieving. The concept of grieving parallels culturally appropriate care. Aboriginal people express their grief in various ways. Some aboriginal cultures view outward expressions of emotion as inappropriate,²⁰ and the apparent grieving period is often quite short.³⁰ Some families hold sharing circles or other ceremonies to help with their emotional pain.²⁰ A traditional healer is sometimes consulted to help bereaved families spiritually.²⁶ Additional customs sometimes take place during the year following the death of a family member.^{11,30}

Complications and barriers. Hotson et al interviewed 44 key informants including community residents, elders, northern physicians, and nurses.¹³ They identified some of the challenges to providing a high level of health care: geographic isolation, language barriers, and financial barriers. The remote nature of many reserves means less access to medical procedures and professionals, lack of inpatient facilities, lack of permanent nursing staff, and difficulty accessing medications.¹³ Physician turnover and inexperience can also play a role.^{28,35} Brown and Shultis found that nonaboriginal communities had more health care services than aboriginal communities of similar size and geographic remoteness.⁵

Physical distance might force patients to leave their families and communities and go to larger cities for medical treatment. Hospitalized patients often feel isolated and lonely without these supports,^{8,17,34} compounded by the unfamiliar atmosphere of a distant hospital.¹⁷ One author wondered if a history of "inadequate health care and broken treaties" might contribute to an undercurrent of suspicion of Western caregivers.³⁹ Doctors' and aboriginal patients' communication styles often differ. Aboriginal patients might be comfortable with more silence than Western caregivers are.^{11,22,29}

Discussion

This small literature set gave a consistent, incomplete picture of issues that can arise in dealing with end-of-life

EDITOR'S KEY POINTS

- Many aspects of traditional aboriginal perspectives differ from the views of other Canadians. These perspectives might affect decision making and provision of palliative care.
- It is important to note that beliefs regarding end-of-life issues vary within aboriginal communities. The authors caution that the process of dying is uniquely individual. Care must be taken to ensure sensitivity toward patients' specific wishes.

POINTS DE REPÈRE DU RÉDACTEUR

- Les façons de voir traditionnelles des Autochtones diffèrent de celles des autres Canadiens à plusieurs égards, ce qui est susceptible d'influencer la prise de décision et la prestation des soins palliatifs.
- Il importe de noter que les croyances concernant les questions de fin de vie diffèrent d'une communauté autochtone à une autre. Les auteurs rappellent que le processus de mourir est éminemment individuel. On doit être particulièrement attentif aux attentes spécifiques des patients.

care for aboriginal patients and their families. Recurrent themes include the creative tension between individual care decisions and family and community values, the mind-body holistic conceptual framework, and geographic isolation and its effects on medical resources.

These themes have implications for communication issues: style and pace of discussions, use of interpreters, and involvement of family and possibly other community members. Cultural beliefs of respect, trust, and spirituality can also factor into end-of-life discussions.

Several electronic and library databases were accessed to find the studies considered in this review. Other excellent small research projects might not have been catalogued and were therefore not reviewed.

This literature review has been a useful starting point for development of a community-based research project in northwest Ontario in partnership with an aboriginal research institute. We hope to explore some of the issues identified in the literature and see how they apply in our region. This could inform development of culturally appropriate tools for stating end-of-life preferences, patient transfer to medical facilities, level of investigations and care, and organ donation. Community-based regional research might remove some barriers to effective communication about these important end-of-life issues.

Conclusion

Aboriginal patient care might involve unspoken beliefs about end-of-life issues typically unexplored by physicians. These discussions can involve interpreters, family, and other key community members. Family members

as interpreters might not be the best choice in these situations. The interplay of patients' individuality and of community and family concerns presents challenges for caregivers. Generalities might be useful to inform physicians of the potential scope of individual variation in end-of-life discussions, but each patient and family needs to be addressed individually. *

Contributors

Dr Kelly and Ms Minty contributed to concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

Competing interests

None declared

Correspondence to: Dr Len Kelly, Box 489, Sioux Lookout, ON P8T 1A8; fax 807 737-1771; e-mail: lkelly@mcmaster.ca

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Sioux Lookout Meno Ya Win Health Centre
1 Meno Ya Win Way
Sioux Lookout, ON
P8T 1B4