



SIoux LOOKOUT
Meno Ya Win
HEALTH CENTRE

Research Compilation 2010-2012

VOLUME 2



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

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Research Compilation 2010-12 **Volume 2**

Sioux Lookout Meno Ya Win Health Centre Northern Ontario School of Medicine

Sioux Lookout Meno Ya Win Research Compilation 2010- 2012

This second research compilation produced at the Sioux Lookout Meno Ya Win Health Centre follows ours first from 2007-2009. We continue to move forward clinically and academically in developing cross-cultural care. The following peer reviewed articles fit well with our challenge to be a Centre of Excellence of Aboriginal Healthcare. This work represents collaboration with other institutions, colleagues and the communities and the patients we serve. The articles are reprinted with the permission of the authors and the publishers.

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Measuring Cross-Cultural Patient Safety: Identifying Barriers and Developing Performance Indicators

Roger Walker, Natalie St. Pierre-Hansen, Helen Cromarty, Len Kelly and Bryanne Minty

Abstract

Medical errors and cultural errors threaten patient safety. We know that access to care, quality of care and clinical safety are all impacted by cultural issues. Numerous approaches to describing cultural barriers to patient safety have been developed, but these taxonomies do not provide a useful set of tools for defining the nature of the problem and consequently do not establish a sound base for problem solving.

The Sioux Lookout Meno Ya Win Health Centre has implemented a cross-cultural patient safety (CCPS) model (Walker 2009). We developed an analytical CCPS framework within the organization, and in this article, we detail the validation process for our framework by way of a literature review and surveys of local and international healthcare professionals.

We reinforce the position that while cultural competency may be defined by the service provider, cultural safety is defined by the client. In addition, we document the difficulties surrounding the measurement of cultural competence in terms of patient outcomes, which is an underdeveloped dimension of the field of patient safety. We continue to explore the correlation between organizational performance and measurable patient outcomes.

Patient diversity is an important factor related to healthcare quality and health status. Mitigation of inequities in health outcomes requires the development of healthcare services that are responsive to the needs of

unique populations. Despite the existence of a multitude of conceptual frameworks and diversity models, there is a paucity of tools that evaluate the impact of these models on patient outcomes.

Both medical errors and cultural errors can threaten patient safety. This article describes the development by the Sioux Lookout Meno Ya Win Health Centre (SLMHC) of an analytical framework to evaluate cross-cultural patient safety (CCPS). The health centre is a provincially funded acute care hospital in northwest Ontario serving a primarily First Nations (Anishnabe) population of 28,000 people. The framework encompasses the constructs of patient safety theory and practice and of cultural safety. Our process involved the identification of issues through a review of SLMHC incident reports; the identification of risk factors contributing to these and other potential incidents; and concept validation of these factors by way of a literature review and surveys of local, national and international healthcare providers.

Review of Incident Reports

A review of the SLMHC incident reports highlighted a number of cases in which cross-cultural competency issues were the underlying root cause of the incident. These events represent tipping points that initiated calls for change to SLMHC's system and practices.

The initial trigger event was a series of three cases in April 2004 involving the care and handling of fetal remains. A regional laboratory's lack of awareness of Anishnabe burial and

ceremonial handling of fetal remains practices led to outrage on a national scale and a call for action by community leaders and elders. Following these events, SLMHC developed both reactive and prospective analytical approaches.

The reactive approach involved an internal investigative process that responds to medical and cross-cultural errors in order to learn from them and to put systems in place to eliminate risk factors and to guide organizational change. The investigative process follows a conventional format while also incorporating a review of cultural factors, consultation with a First Nations health advisor and an Elders' Council on the best way to resolve the issue and preventive education and information (Figure 1). This review process is now entrenched in the organization and has resulted in major changes in how we respond to patient issues. The primary cultural adaptations to conventional approaches to issues management include incorporating the impact that cultural variables may have had in generating the issue, the direct involvement of those with knowledge of the impacted culture in the resolution process and the adoption of culturally appropriate communication and "healing" processes as part of the resolution mechanisms.

A prospective analytical approach was also developed to study and learn from both medical and cross-cultural errors. Our approach is based on principles of business quality management strategies of Six Sigma and Lean, which aim to improve the performance of organizations (Schweikhart and Dembe 2009). Of the many Six Sigma tools available, we selected the *failure modes and effects analysis* (FMEA) methodology to identify the crucial parts of the process requiring improvement (Avanthi Goddard and Associates 2007). FMEA is an operations management procedure that uses a systematic method of analyzing error and its consequences.

A subsequent sentinel event shed light on other organization and health system inadequacies and underlined the need to broadly adapt organizational and system-wide programs and services. A letter from a family member of two elderly non-English speaking First Nations patients detailed the system failures that led to the patients receiving inadequate care. From that moment, SLMHC began the transformation of its model of care by identifying and incorporating First Nations values and traditions into its governance and leadership models and its approach to health and healing. Community relationships were strengthened and service and program support changes were made; the new model has gained national recognition as a centre of excellence for culturally attuned First Nations healthcare.

A third recent sentinel event signalled an urgent call for a reassessment of SLMHC's practices and level of cultural competency. The event involved an unexplained death in which communication barriers and stereotyping contributed to substandard care and a possible misdiagnosis of the patient. This case alerted SLMHC to the fact that its actual practice

Figure 1. SLMHC complaints review process



SLMHC = Sioux Lookout Meno Ya Win Health Centre.

was not congruent with the fundamental values and principles guiding SLMHC through its transformation process. The need for identification of the cross-cultural risk factors to patient safety and an assessment tool to measure organizational cultural competence became apparent.

CCPS Conceptual Framework

Cross-cultural patient safety is defined by SLMHC as the safe practice and successful delivery of healthcare services to a diverse population across the barriers to understanding and to the identification of client needs. It includes overcoming obstacles to implementing prescribed remedial or supportive actions.

The focus of SLMHC's model of CCPS is on providing safe patient-centred care by recognizing that culture embodies a separate set of risk factors that threaten patient safety. The unique model is based on the theories and guidelines of both cultural safety and patient safety. Cultural safety involves identifying and obviating actions that disempower the cultural identity and well-being of individuals in situations of diversity. The theory of cultural safety provides SLMHC with a conceptual foundation to work toward patient-centred care by ensuring that culture-based behaviours are not threatened.

Organizational change requires an organizational culture of safety in which individuals recognize that – like infection control and disease management, for example – cultural safety is an integral aspect of overall patient safety and necessary in the provision of equitable care. SLMHC's concept of the Zone

of Cultural Safety (Figure 2) was developed to guide this organizational change. Marginalization or power imbalance positions are reduced or eliminated by moving to progressively higher levels of equity in health service and quality. At the individual level, cultural congruence is the end point whereby individuals internalize diversity-based values and understandings, and consequently manifest equitable, value-based conduct. The organization's adoption of normative standards that

integrate functional cross-cultural practices on an organization-wide basis provides a supportive, integrated context. The reduction of marginalizing behaviours leads to safer practice and ultimately reduces the margin for error.

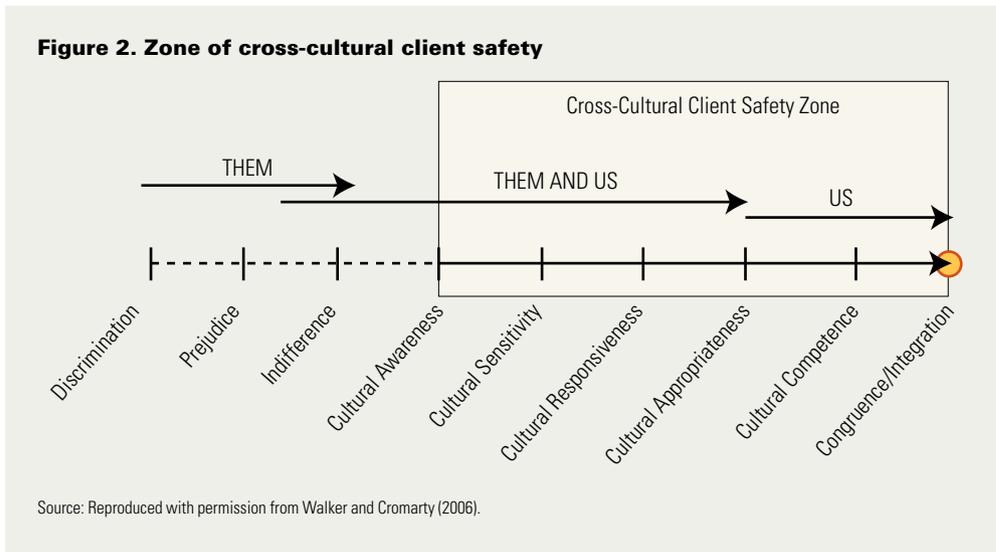
The CCPS framework is used to guide resource allocation and decision-making for organizational structures, programs, services and processes. At the individual level, behaviour changes and enhanced knowledge, skills and understanding can be achieved through staff orientation, training, development and support. At the management level, the framework can be used for performance planning, measurement and accountability.

CCPS Analytical Framework

Through an extensive consultation process with First Nations communities and leaders, SLMHC has developed an analytical framework composed of nine potential core risk factors or barriers to the safe delivery of care in diverse populations, which are outlined in Figure 3 (<http://www.longwoods.com/product.php?productid=21246>). A literature review and survey were conducted to achieve content validity of these risk factors and to contribute to the development of an evaluation tool of intermediate patient outcomes.

Literature Review: Cultural Competency Barriers and Indicators

Racial and ethnic disparities in the provision of care and health status are well documented. The Institute of Medicine, based in the United States, reviewed 175 studies documenting racial/ethnic disparities in the diagnosis and treatment of various conditions (Smedley et al. 2003). Canadian studies have found that social determinants of health and ethnicity have contributed to poorer care and health outcomes (Heaman et al. 2005;



Tonelli et al. 2004, 2005). Cultural competence and diversity models have been widely accepted as strategies to reduce disparities in access to and quality of care. The Aboriginal Nurses Association (2005) of Canada notes that culturally appropriate care leads to patients responding better to care and having better health outcomes.

A review of seven databases (HealthSTAR, Health and Psychosocial Instruments [HAPI], EMBASE, Ovid MEDLINE, Ovid Nursing Database, Allied and Complementary Medicine Database [AMED] and PsycINFO) was undertaken to find articles and documents on cultural competence literature published in the past 20 years. The search was narrowed to include literature identifying barriers to cultural competence or performance indicators for measuring the provision of culturally competent care. Only seven articles identified barriers, and only 10 documents identified performance indicators or patient outcome measures.

Barriers to CCPS

While the literature contains many examples of standards, guidelines, benchmarks and identified domains with which to guide the process toward cultural competence, the identification of barriers to cultural competence is limited (Table 1, <http://www.longwoods.com/product.php?productid=21246>). Some literature focuses on the barriers to the individual caregiver – such as a lack of knowledge, skills or confidence (Taylor 2005) – rather than barriers to the achievement of environment of cultural competence. A possible reason for yielding low search results for the term *barriers* or *risk factors* is that the organizations tend to use a neutral approach, using neutral language. This approach has been criticized by commentators as keeping issues of diversity hidden (Celik et al. 2008) and failing to acknowl-

edge that racism is a social determinant of health (McGibbon and Etowa 2009). Another reason for not using the term *barrier* might be that cultural competence models are process oriented and, therefore, identify targeted areas or domains rather than barriers. For example, the American Bureau of Primary Health Care (Lewin Group 2002) identifies seven components of cultural competence:

1. Values and attitudes
2. Communication styles
3. Community/consumer participation
4. Physical environment, materials and resources
5. Policies and procedures
6. Population-based clinical practice/service-delivery methods
7. Training and professional development

Tripp-Reimer et al. (2001) challenge the very assumption that cross-cultural differences present challenges to the delivery of care. They advance the idea that barriers are associated with the culture of biomedicine rather than the culture of individuals. They suggest that we “invert the problem” and reassess our foundational assumptions that guide the entire healthcare system.

A comparison of the barriers identified in the literature to our taxonomy of barriers and risk factors provided us with one means of validating our factors. While differences in categorization systems and the use of different domains within the literature render this method imperfect, it does provide us with a reference point.

The identification of systemic barriers was prominent in the literature. All of the articles identified barriers or factors that correspond with our definition of systemic barriers (Table 2, <http://www.longwoods.com/product.php?productid=21246>). Linguistic and racism/discrimination barriers were identified by the majority of the articles. Genetics barriers were not identified by any of the authors of these studies but are supported by extensive clinical and cross-cultural literature. The other five barriers were identified by some of the articles. This review indicates that our set of barriers is sufficiently inclusive as there were no new barriers revealed in the literature that could be considered adjunct to our set. Further evaluation will be required to determine if our model is overly broad.

Measuring Outcomes: The Impact of Cultural Competence

While the importance of cultural competence in healthcare systems has been widely accepted, challenges and disagreement surround the methods for measuring and evaluating the impact of cultural competence programs on patient care. It has been suggested that the basic assumptions associated with both identifying barriers and measuring cultural competence be

challenged (Kumas-Tan et al. 2007; Tripp-Reimer et al. 2001).

Suggested shifts in assumptions and approaches include viewing the culture of biomedicine rather than the culture of the individual as a barrier (Tripp-Reimer et al. 2001), and focusing on the problems associated with the advantages of the dominant group instead of the disadvantages of the minority group (Kumas-Tan et al. 2007). Also identified as problematic is the narrow focus on discriminatory attitudes rather than on the actions or inaction that works to maintain a system of inequality (Kumas-Tan et al. 2007). Cultural safety and cultural humility advocate also to identify the weaknesses of the models that carry these assumptions – particularly their tendency to increase stereotyping behaviours – and instead prescribe a constant process of challenging one’s own assumptions and world views.

The majority of evaluation approaches found in the literature are based on an assessment of cultural competency curriculum and the measurement of the provider’s cultural knowledge, attitudes and experience. The validity of this approach has been criticized for many reasons. There is a notable absence of input from patients (McGibbon and Etowa 2009). The self-rating process is subject to social desirability effects. These instruments simply capture the participant’s ability to learn what was taught; therefore, they fail to establish a link between a cultural competence program and the quality of cross-cultural interaction (Kumas-Tan et al. 2007). Even less clear is the impact on patient outcomes. Our literature review revealed a paucity of instruments to measure clinical cultural safety: only 10 approaches were found (Table 3, <http://www.longwoods.com/product.php?productid=21246>).

Many of the instruments reviewed are limited to patient and family satisfaction surveys; while these are important measures of quality of care, the relationship between consumer satisfaction and health outcomes remains unclear. A 2005 American study ($n = 4,700$) found a correlation between patient satisfaction and reported health status change; however, when a multivariate was conducted, there was little evidence of health status change (Franks et al. 2005). Advocates of a quality-focused approach to improving the health status of diverse populations suggest a patient-centred approach that directs care to *how* patients are treated rather than *who* is treated (Kairys et al. 2002; Owen et al. 2002). Critics of this approach call for directed attention to power relationships and models that challenge racism through broad-based socio-political and structural changes (McGibbon and Etowa 2009).

An extensive body of foundational conceptual and descriptive literature exists on cultural competency and diversity models. The lack of rigorous research evaluating the impact of these models on outcomes has been attributed to the newness of the field (Taylor 2005); the complexity of the diversity process, which involves dynamic constructs and processes (Kairys et al. 2002); the challenges of controlling for additional varia-

bles (Brach and Fraser 2000); and the difficulty in collecting outcome or impact measures, which often require sophisticated techniques (Lewin Group 2002).

Consequently, it appears that there is considerable opportunity to develop, validate and disseminate cultural safety performance indicators to determine the extent to which a particular issue or problem exists and the degree to which resources are required or being consumed in response to that issue, and to assess the effectiveness and outcomes of interventions. The framework outlined in Figure 3, (see <http://www.longwoods.com/product.php?productid=21246> provides key dimensions around which such indicators can be developed.

SLMHC Survey

As a means of validating our nine risk factors, we designed an electronic survey to investigate the barriers to care seen by people working in diverse settings. The survey was sent to two separate groups of healthcare providers: the 1,400 members of the CLAS-talk listserv and the 300 staff members of SLMHC. (The CLAS-talk listserv is an international network of participants from healthcare organizations, government, business, academia, national and community-based organizations and philanthropy who discuss culturally and linguistically appropriate services [CLAS] and other diversity-related practice, policy and research issues.) Participants of the survey were asked to identify the extent to which they have observed or experienced each of the nine barriers to the safe and reasonable delivery of care in a cross-cultural setting. Optional questions provided participants with the opportunity to provide examples of barriers, to suggest performance indicators that may be used to show the success of interventions related to its respective factor/barrier and to identify additional barriers.

Preliminary Results

Preliminary survey results are based on the response rates to date. The survey sent to the international group retrieved 51 completed surveys – 92% of which were from the United States, 4% from Canada and 2% from New Zealand.

In both groups, over 50% of the respondents reported either observing or experiencing medical literacy, linguistics, cultural differences, context or structure and systemic barriers. Medical literacy and linguistics barriers were particularly present among the international respondents as more than 50% reported frequently or almost always experiencing or observing these barriers. Practice differences were present in the international group but not significantly present in the local group. In both groups, the majority of respondents reported genetics, racism/discrimination and power, history and politicization barriers as occurring either never or rarely.

As indicated by the shaded areas in Tables 4 and 5 (<http://www.longwoods.com/product.php?productid=21246>), the

overall response patterns of the two groups were similar, but there are significant differences. The group accessed by listserv rated several of the barriers as occurring more frequently than did the local group. These included medical literacy, linguistics, cultural differences, practice differences, context or structure and racism/discrimination. This is likely due to broader scope of experiences being reported by the larger and more diverse listserv group. The area of greatest difference between the two groups is practice differences: two thirds of the listserv reported this as a common barrier, while only one third of the local respondents indicated practice differences as a regular occurrence. More of the local group reported “genetics” as an issue than did respondents in the listserv group.

Both sets of respondents indicated difficulty associating the reality of genetics issues with the more sociological or anthropological constructs of “culture.” Since this is an area of observable difference related to underlying correlates of cultural difference (race, ethnicity etc.), we believe that it should be maintained as part of the taxonomy as one basis for better understanding CCPS.

Several respondents also suggested adding *religion* to the list of cultural barriers. Accordingly, the description of cultural differences in Figure 3 has been modified (from the description given in the survey) to include “spiritual or religious beliefs” as part of the definition.

Based on the reported experience and observation of the survey groups, including the multiple examples given and extensive discussion of each of these nine factors, the key conclusion we drew from these results is that the factors may be considered to be a valid framework for analyzing obstacles to CCPS.

The validation of risk factors requires the involvement of patients who directly face these barriers to care.

Survey Limitations

The survey is limited by low response rates and the use of complex definitions. Despite the low response rates, the results provide us with baseline data with which to establish content validity. The results are not meant to be representative of the populations surveyed but to provide an identification of barriers relative to each other. It is also recognized that validation of risk factors requires the involvement of patients who directly face these barriers to care. Further validation of the framework will include this input.

In addition, the survey is limited by the way questions are framed, which may impact various healthcare provider roles differently. For example, a person who is not directly involved in the provision of care may have knowledge of the presence of

barriers but may not directly experience or observe them.

Suggested Indicators

Although the primary purpose of the survey was to validate the SLMHC analytical framework, participants were provided with the option of suggesting performance indicators for each of the barriers. Suggestions from the surveys included the following:

Medical literacy

- Number of medical errors
- Number of calls for clarification from a patient
- Medication compliance rates: blood sugar levels, blood tests for medication
- Use of diagrams or visual aids
- Frequency with which interpreters are provided for incoming calls from limited English proficiency (LEP) patients and families compared with frequency of calls from all patients and families
- Percentage of consumer groups accurately interpreting content as intended
- Percentage of consumer groups rating materials as culturally and linguistically responsive to their needs and resources

Linguistics

- Post-communication surveys to determine degree of understanding of concepts
- Performance measures on screening patients for preferred language
- Documentation of whether a patient receives a language service
- Measures on timelines
- Percentage of patients receiving services
- Patient satisfaction surveys
- Culture and language addressed in mission and strategic plans

Cultural differences

- Caregiver testing of health beliefs of cultural groups in their catchment
- Extent to which health beliefs and practices are incorporated into treatment plans

Practice differences

- Caregiver testing of practices of cultural groups in their catchment
- Percentage of time that provider consults the elder or other person when planning care
- Traditional beliefs asked about on intake or assessment forms
- Conventional safety indicators (e.g., adverse events)
- Rate of declined or incomplete procedures or treatment

Context or structure

- Patient understanding of diagnosis and treatment plan
- Follow-up appointments before and after use of interpreters
- Treatment adherence
- Percentage of time programs used by health team for patients who are new to the community

Systemic

- Number of emergency room visits by different groups
- Number of deaths
- Occurrences of denial of care
- Number of primary care visits by language or ethnicity
- Access rates
- Participation rates
- Satisfaction surveys
- Portion of candidates receiving preventative care
- Portion of patients receiving health education

Genetics

- Screening rates
- Disease prevalence

Racism/discrimination

- Disease-specific outcomes
- Categorical distribution of participants versus population

Potential Indicators of Magnitude, Input and Outcomes

For purposes of this analysis, our base assumption is that performance monitoring and measurement support improvements (i.e., economy, efficiency, effectiveness) in caregiving processes. Our interest was in finding three kinds of indicators: (1) assessment – indicators that measure or define the magnitude of the problem or issue; (2) activity or input – indicators that measure the extent to which resources are committed to or consumed by efforts to resolve the issue; and (3) outcome – indicators that measure the effectiveness of our efforts to resolve the issue.

Although survey participants provided valuable suggestions that are important to the various dimensions of performance monitoring and measurement, the majority of these suggested indicators are input or activity indicators rather than assessment or outcome measures. Many would not measure CCPS. This parallels the findings of the literature review. The dearth of outcome indicators highlights the difficult nature of identifying and the need to develop and deploy such indicators.

As part of its commitment to incorporate CCPS into its patient safety program, SLMHC has begun to develop a broad set of CCPS indicators. Examples are shown in Table 6 (<http://www.longwoods.com/product.php?productid=21246>).

The initial application of this approach to performance indicators will require modifications of the SLMHC incident

reporting forms and processes to include a broader set of adverse events beyond medication errors, patient falls, nosocomial infections and other standard reportable problems. The expanded set of reportable incidents will be based on the barriers identified in the CCPS analytical framework. Root-cause analysis tools and processes will also be adjusted to include the nine factors outlined in the framework. Patient charts, interpreter logs and other reports will be modified to ensure the capture of other base information required to support this initiative.

SLMHC has consistently used a five-step program and development model for improving processes (Figure 4). Our introduction of CCPS programming and performance monitoring will be based on this model. Over time, practices initiated, elaborated and matured in limited settings within the organization will be integrated on a broad basis and ultimately provide a platform for sharing successes with and learning from other organizations. We believe that the response from the survey indicates that these issues enjoy extensive interest and have wide-ranging applicability.

Discussion

SLMHC is working toward the elimination of adverse incidents due to cultural misunderstandings or errors. To ensure that the foundational values and principles guiding the organization translate to the care provider level, a continuous process of organizational review is required. This is achieved through the assessment of service provision. As the international literature on the topic has indicated, this assessment is fraught with challenges. The development of tools in this field is in its early stages.

Our analytical framework, which involves approaching cultural competence from a patient safety framework, provides a unique method of continuous assessment and an opportunity to learn from our mistakes. As our most recent incident review has taught us, this may involve taking a step back and reassessing our assumptions about the organization and about what it means to be culturally competent. As one author has suggested, the foundational premise that issues arise from cultural differences rather than the culture of the healthcare system itself must also be challenged (Tripp-Reimer et al. 2001). We may in fact be better served asking whether our nine risk factors are simply manifestations of a deeper problem that resides in the culture of biomedicine.

Conclusions

CCPS requires adaptations to all other aspects of clinical patient safety programming. This

research has provided a starting point. Results of the study confirm the validity of the risk factors contained in the analytical framework. The information gleaned from both the literature review and survey may be imported into our local context to further develop and refine the framework. Future steps in the validation of risk factors will include patient involvement using a variety of methods.

The results of this study reaffirm the difficulties surrounding the measurement of cultural congruence in term of patient outcomes. The results from the survey and literature review suggest that CCPS is an underdeveloped aspect of clinical patient safety. Additional research is needed in both the theoretical and practical implications of measuring cultural competence. The adaptation of contemporary patient safety and risk management approaches to incorporate cross-cultural issues into reporting, measurement, monitoring, evaluation, prevention and prospective programming is strongly supported by this research. **HQ**

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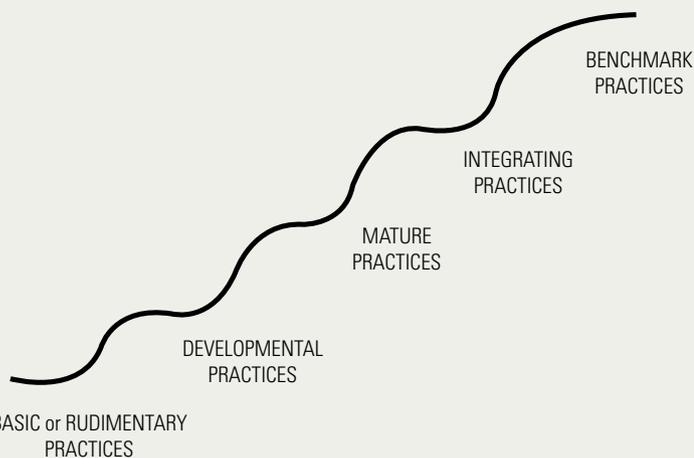
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Figure 4. SLMHC five-step Journey toward Excellence model for improving processes



SLMHC = Sioux Lookout Meno Ya Win Health Centre.

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Measuring Cross-Cultural Patient Safety: Identifying Barriers and Developing Performance Indicators

Roger Walker, Natalie St. Pierre-Hansen, Helen Cromarty, Len Kelly and Bryanne Minty

Figure 3. Cross-cultural patient safety risk factors and barriers

Medical literacy

The level of understanding of clinical terminology or concepts that may vary among different populations, especially where Native and other languages do not include medical or related terminology or concepts, or limited ability to access or navigate the health delivery system because of a lack of familiarity.

Linguistics

The potential for misunderstanding descriptions of the presenting symptoms, etc., and/or the prescribed course of diagnostic or therapeutic interventions by either the patient or provider. This may be due to language or dialect differences, terminology limitations in a language, slang, idiom, vernacular, or other factors. Non-verbal communications may also be critical factors.

Cultural differences

The potential for misunderstanding the cultural context of the presenting illness or injury or limits to successful implementation of a prescribed course of action resulting from different perspectives, world views, belief systems (including spiritual or religious beliefs), value sets, norms, customs, mores or other distinctive behaviour patterns.

Practice differences

When conventional medical services or practices differ from traditional practices specific to the culture(s) or population(s) in question.

Context or structure

Contextual or structural issues arise from the potential for misunderstanding or for mishap due to the lack of *provider* knowledge of the patient's (cultural) habitat(s), including physical or socio-economic setting, geographical context, other community-based issues such as lack of services or health status, etc. *Community* may mean the patient's cultural context.

Systemic

Systemic barriers occur when systems established to provide healthcare to mainstream populations exclude or fail to provide care to a specific population. As a result "things" in the two worlds (provider and patient) often work quite differently. This may be due to jurisdictional differences, overlaps in service mandates, gaps in service provision, differing approaches, territoriality, unilateral policy changes etc. It often relates to geography and mandate variations specific to different health service organizations.

Genetics

1. Understanding that the genetic makeup of a particular population (as defined by race, ethnicity etc.) may carry with it inherent health issues.
2. The failure to know of or take into account specific genetics issues in a particular population.

Racism/discrimination

Manifestations of bigotry, prejudice or intolerance that result in the differential provision of services as the result of ethnic or racial factors.

Power, history and politicization of health

The differential treatment of a population because of power imbalances, historical development (e.g., treaties) and the deployment of services, or political agendas that interfere with the equitable distribution of and access to services.

Table 1. Barriers to the provision of culturally competent care

Barriers Identified in International Literature			SLMHC Barriers								
Author	Domain	Factor	Medical Literacy	Linguistics	Cultural Differences	Practice Differences	Context or Structure	Systemic	Genetics	Racism/Discrimination	Power/History/Politics
Tripp-Reimer et al. (2001)	Barriers to care	<p>Practitioner barriers:</p> <ul style="list-style-type: none"> • Ethnocentrism <p>Care system barriers:</p> <ul style="list-style-type: none"> • Service availability • Accessibility (geographical, linguistic and financial factors) • Acceptability (patient comfort and satisfaction with providers and services) 		✓	✓	✓		✓		✓	
Regional Health Survey	Barriers to accessing health services faced by First Nations people (percentage of respondents who reported experiencing the barriers)	<p>Barriers related to First Nations–specific needs:</p> <ul style="list-style-type: none"> • Services not culturally appropriate (13.5%) • Inadequate care provided (16.9%) • Difficulty getting traditional care (13.4%) <p>Barriers related to geography and availability of services:</p> <ul style="list-style-type: none"> • Unavailability of health facility (10.8%) • Unavailability of service in participant’s area (18.5%) <p>Economic barriers:</p> <ul style="list-style-type: none"> • Childcare costs (7.1%) • Cost of care (13.2%) • Transportation costs (13.7%) <p>Systemic barriers:</p> <ul style="list-style-type: none"> • Unable to arrange transportation (14.5%) • Not approved for services under Non-Insured Health Benefits (NIHB) (16.1) • Not covered by NIHB (20%) • Waiting lists too long (33.2%) 				✓	✓	✓	✓		
Celik et al. (2007)	Barriers to the implementation of diversity in healthcare	<p>Lack of caregiver awareness and knowledge</p> <p>Poor information and communication</p> <p>Organizational constraints</p>	✓	✓		✓	✓	✓			
Alliance for Health Reform (2004)	Sources of racial/ ethnic disparities .	<p>Geography (geographical disparities in resource allocation)</p> <p>Not accepted for managed care plans</p> <p>Practitioner cost and time constraints</p> <p>Stereotyping</p> <p>Communication</p>		✓				✓	✓	✓	
Taylor (2005)	Barriers faced by healthcare providers	<p>Lack of cultural awareness</p> <p>Lack of cultural knowledge</p> <p>Lack of cultural competence skills</p> <p>Lack of organizational support</p> <p>Lack of time and resources (e.g., interpreters)</p> <p>Ethnocentrism and prejudice</p>					✓	✓		✓	✓

Table 1. Continued.

Barriers Identified in International Literature			SLMHC Barriers								
Author	Domain	Factor	Medical Literacy	Linguistics	Cultural Differences	Practice Differences	Context or Structure	Systemic	Genetics	Racism/Discrimination	Power/History/Politics
Betancourt et al. (2003)	Socio-cultural barriers to healthcare	Organizational barriers: <ul style="list-style-type: none"> • Institutional leadership • Healthcare workforce (diversity population of providers) Structural barriers: <ul style="list-style-type: none"> • Lack of services (e.g., interpreters) • Bureaucratic intake process • Inequity in referral to specialists • Lack of continuity of care Clinical barriers: <ul style="list-style-type: none"> • Cross-cultural interactions 		✓				✓ ✓		✓ ✓ ✓	✓
U.S. Department of Health and Human Services (2003)	Barriers to culturally competent care	Verbal communication barriers: <ul style="list-style-type: none"> • Lack of linguistic clarity • Limited or lack of health literacy or physician use of jargon unfamiliar to the patient Cultural barriers: <ul style="list-style-type: none"> • Different perceptions of illness 	✓	✓	✓						

SLMHC = Sioux Lookout Meno Ya Win Health Centre.

Table 2. Barriers identified in the literature

SLMHC Barriers	Number of Articles in which Barrier Is Identified
Systemic	6
Linguistics	5
Racism/discrimination	4
Practice differences	3
Context or structure	3
Medical literacy	2
Cultural differences	2
Power, history or politicization	1
Genetics	0

SLMHC = Sioux Lookout Meno Ya Win Health Centre.

Table 3. Outcomes-based performance indicators of cultural competence

Study	Indicators
Office of Minority Health (1999)	Linguistically and culturally factored consumer satisfaction surveys Health plan dropout rates
Tirado (1996)	Patient satisfaction survey: <ul style="list-style-type: none"> • Ability to communicate with doctor • Frequency of interpreter services given • Availability of services in primary language • Satisfaction with interpreter services • Ability to understand written communication • Pharmacist explanations given
Maternal and Child Health Bureau (2000)	Comparison of infant mortality rates by race
Centre for Mental Health Services (1998)	Decrease in misdiagnosis and inadequate treatment resulting from failure to communicate effectively across cultures Consumer and family satisfaction: inclusion of culturally specific activities and practices in daily living in treatment services Rates of symptom relapse and recidivism Rates of medication side effects, adverse incidents and use of latest pharmacological interventions Rates of adverse occurrences during treatment Satisfaction with communication styles and linguistically competent services
Lavizzo-Mourey and Mackenzie (2001)	Effectiveness of an outreach program Mammography rates Member satisfaction with language and cultural translations and support services
Abt. Associates (January 2000)	Satisfaction with cultural competence: <ul style="list-style-type: none"> • Availability of services in primary language • Respect for health beliefs and practices • Provider-patient congruence
New York State Office of Mental Health (2001)	Program retention rates Rates of service use Reason-specific no-show and dropout rates
Siegal et al. (2003)	No-shows/missed appointments Dropouts Consumer satisfaction
Puebla Fortier and Bishop (2003)	Adherence to medications and lifestyle changes Improved health status Lower undesirable healthcare use: <ul style="list-style-type: none"> • Emergency department visits • Hospitalization
Linkins et al. (2002)	Rate of service use relative to need Retention of clients/reduced attrition rates Reduction of broken appointments/no-shows Reduction of misdiagnoses and inadequate treatment plans Rates of appropriate management of selected chronic conditions Satisfaction with care Patient knowledge/understanding regarding prevention, diagnosis and treatment plan Agreement/compliance/adherence with treatment plan Medication compliance/reduction in misuse of medications Improved management of chronic conditions Increase in healthy behaviours and prevention practices, reduction in risky behaviours

Table 4. Percentage of international listserv respondents who reported experiencing or observing barriers to care

Barrier	Percentage of Participants Who Reported Frequency of Observed Barriers (n = 107)*					
	Never	Rarely	Occasionally	Frequently	Almost Always	"I don't understand what you mean"
Medical literacy	1.4	6.8	33.8	39.2	17.6	1.7
Linguistics	9.5	14.3	23.8	46.0	6.3	0
Cultural differences	8.2	16.4	29.5	37.7	8.2	0
Practice differences	11.7	20.0	38.3	28.3	0	1.7
Context or structure	7.0	17.5	28.1	35.1	5.3	7.0
Systemic	11.5	21.2	21.2	38.5	5.8	1.9
Genetics	24.5	32.1	15.1	17.0	1.9	9.4
Racism/discrimination	23.6	29.1	32.7	9.1	3.6	1.8
Power, history, politicization	34.0	18.9	24.5	15.1	5.7	1.9

*Shaded areas represent majority response rates.

Table 5. Percentage of local respondents (SLMHC staff) who reported experiencing or observing barriers to care

Barrier	Percentage of Participants who Reported Frequency of Observed Barriers (n = 66)*					
	Never	Rarely	Occasionally	Frequently	Almost Always	"I don't understand what you mean"
Medical literacy	12.7	14.5	38.2	27.3	3.6	3.6
Linguistics	14.0	16.3	39.5	30.2	0	0
Cultural differences	16.7	28.6	35.7	19.0	0	0
Practice differences	30.0	35.0	27.5	7.5	0	0
Context or structure	25.0	17.5	35.0	17.5	2.5	2.5
Systemic	20.0	17.5	27.5	27.5	5.0	2.5
Genetics	38.5	10.3	33.3	12.8	0	5.1
Racism/discrimination	34.2	31.6	13.2	18.4	2.6	0
Power, history, politicization	31.6	15.8	26.3	18.4	7.9	0

SLMHC = Sioux Lookout Meno Ya Win Health Centre.

*Shaded areas represent majority response rates.

Table 6. Examples of indicators of cross-cultural patient safety

Barrier	Potential SLMHC Performance Indicators		
	Magnitude	Input/Activity	Outcome
Medical literacy	Proportion of clients seeking assistance to understand clinical terminology or to navigate the system	Average interpreter time per client allocated to assist clients to understand clinical terminology or to navigate the system	Polarity and rate of change in reported incidents identifying medical literacy as a root cause
Linguistics	Proportion of clients receiving language interpretation assistance in clinical transactions	Average interpreter time per client allocated to assist clients or providers to communicate	Polarity and rate of change in reported diagnostic, treatment or compliance incidents resulting from failure to communicate
Cultural differences	Proportion of reported incidents with the root cause identified as "cultural difference"	Average interpreter time per client allocated to assist clients or providers to identify and understand cultural differences Proportion of staff completing cultural competency training	Polarity and rate of change in reported diagnostic, treatment or compliance incidents resulting from failure to communicate Proportion of clients accessing one or more elements of the SLMHC traditional healing, medicines, foods and patient supports program
Practice differences	Similar indicators will be developed and tested for these six factors.		
Context or structure			
Systemic			
Genetics			
Racism/discrimination			
Power/history/politicization			

SLMHC = Sioux Lookout Meno Ya Win Health Centre.

Translating Research into Practice: Developing cross-cultural First Nations palliative care

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INTRODUCTION

The gap between research and practice is an ever-present chasm in medicine, public health management, and policy (1-4). Knowledge translation is the slow process of turning research findings into practice (5). In this paper, we describe how a small rural hospital bridged this gap by designing a program of palliative care in which practices, policies, and even values are research-based. We focus on the design of a culturally safe and culturally appropriate First Nations palliative care program at the Sioux Lookout Meno Ya Win Health Centre.

We will describe three research initiatives and their influence on program development and service delivery: first, theoretical research examining concepts of cultural safety, which has led to the elaboration of a pan-organizational continuum of care in cross-cultural client safety; second, the Biimaadiziwin and Meno Ya Win project, which involved multiple consultation methodologies to guide the integration of traditional healing and medicines at the Sioux Lookout Meno Ya Win Health Centre; and third, a qualitative study examining the experience of bereaved First Nations family members, which is directing the development of service delivery and which involves respectful communication, enhanced interpreter services and patient support, elder and spiritual support, and the design of new facilities to provide users with an appropriate palliative care environment to meet extended family needs.

RESEARCH AND EVIDENCE-BASED PROGRAMMING

The general deficiency of evidence-based management and decision making in the field of health care management is attributed to the research-practice gap, or “discovery-delivery gap” (4). Furthermore, this gap has been recognized as a contributing factor in health disparities, as current public health research generally benefits the more

affluent and influential members of society (1, 3, 6).

There are several barriers to evidence-based management and organizational change (1, 4): a lack of influential research on practice and policy (4); insufficient dissemination of research findings; and little collaboration between researchers (4) and practitioners and decision makers (1). Fortunately, in rural hospitals some of these barriers are absent (7). The researchers are local and are often also the practitioners. The questions arise from local experience; the answers come from local participants. Hence, our setting assisted our learning about cross-cultural First Nations palliative care.

RESEARCH AND PALLIATIVE CARE PROGRAM DEVELOPMENT

Internationally, other centres have combined a focus on palliative care research and practice. McGrath and Holewa in 2006 undertook an interdisciplinary, community-based set of 72 interviews to understand the palliative care needs of Aboriginal patients in Australia’s Northern Territory (8). They concluded with a “living model” based on seven principles of cross-cultural palliative care: cultural safety, equity, autonomy, trust, humane non-judgmental care, seamless care, and an emphasis on living and respect. The practical spinoff of that community-based research was the development of workshops based on the model that could be held in various communities in order to help determine how local and regional barriers to care could be addressed. The living model arose from qualitative and quantitative research, and it provides opportunities for participatory action initiatives in both research and practice (8).

Another palliative care research initiative linking research to intervention was undertaken in northwestern Ontario. Researchers held 10 focus

groups in northern communities to gauge 78 community members' awareness of palliative care, to document the available resources, and to understand community values and beliefs (9). They came up with several recommendations; one was to provide culturally appropriate educational resources. The second phase of their research has involved designing and delivering workshops (9).

MENO YA WIN HEALTH CENTRE

The Sioux Lookout Meno Ya Win Health Centre (SLMHC) was mandated by the Ontario Ministry of Health and Long-Term Care in 2005 to serve as a Centre of Excellence providing culturally integrated health care. It has made positive strides in program development, which has helped to break down some of the barriers and strengthen the connection between research and practice. The SLMHC has employed various research methods to inform its culturally responsive model of care; a prime example is the ongoing development of its palliative care delivery, which has been guided by: a qualitative study; theoretical research on culturally safe models of care; patient surveys; an elders' council; and consultations with community members, community leaders, and a traditional healer. Furthermore, the dissemination of findings and researcher-practitioner collaboration has been facilitated by SLMHC's emerging organizational culture of research and by its multidisciplinary teams of researchers who are invested in the future of the organization and the community.

MENO YA WIN MODEL OF CARE

The Meno Ya Win Health Centre service area covers the local community and 23,000 First Nations patients from 28 northern First Nations communities. The majority of these communities are remote and accessible only by fixed-wing aircraft. The service population is 85 percent First

Nations, many of whom primarily speak one of three Anishiniimowin languages: Ojibway, Oji-Cree, and Swampy-Cree. Within these languages are 19 dialects. Most hospitalized First Nations patients are far from the support of family and community and find it very hard to navigate an unfamiliar health care system within an unfamiliar community and culture. SLMHC has developed a model of care that is culturally responsive and includes optimal patient support.

The hospital has a specific mandate among Ontario hospitals. It must provide a broad set of services that address the health and cultural needs of a largely First Nations population. "*Menoyawin*" is an Anishnabe term meaning wellness, health, well-being — a wholeness in the spiritual, mental, emotional, and physical makeup of a person. This concept, along with traditional teachings specific to the people of this area, underpin the Meno Ya Win model of care and the five components of the model for the Traditional Healing, Medicines, Foods and Supports (THMFS) program (10).

THREE RESEARCH INITIATIVES

The development of Meno Ya Win's model of care and palliative care services has been carefully planned and investigated. The following research guides this development: theoretical research on cultural safety and models of care (10); *Biimaadizwin and Meno Ya Win: A Study of Development of Traditional Approaches to Health Care at Sioux Lookout Meno Ya Win Health Centre* (11); and *Palliative Care of First Nations People: A Qualitative Study of Bereaved Family Members* (12).

Theoretical Research on Cultural Safety and Models of Care

The SLMHC defines cross-cultural patient safety as "the safe and successful delivery of health care

Figure 1 / Research Initiatives and Organizational Factors Shaping Practice

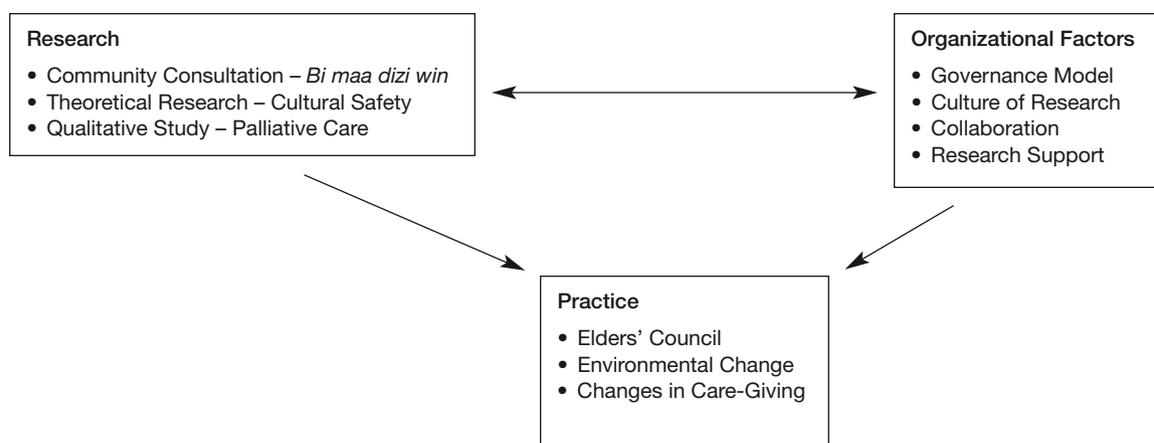
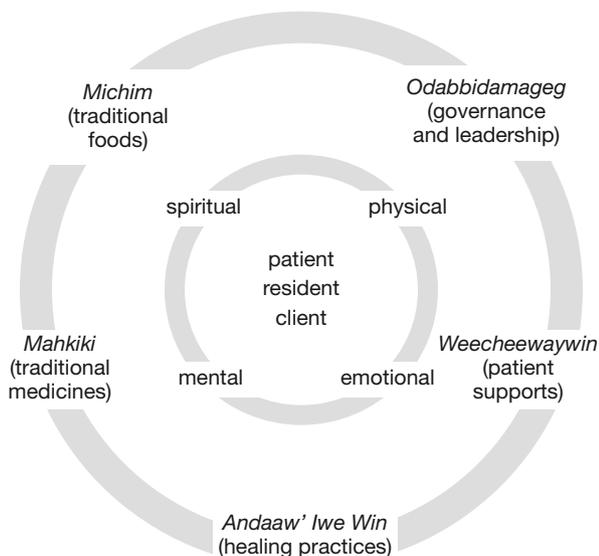


Figure 2 / Meno Ya Win Model of Care



services across the barriers to the understanding and identification of client needs” (13). Comprehensive theoretical research on cross-cultural care has guided the design of a model in which the perspectives and world views of the people represented are integrated into all facets of service provision. The SLMHC has developed a conceptual model to illustrate the desired transition into cultural congruence/integration; organizations and individuals progress toward a zone of cultural safety, a continuum in which patients exist in a safe and empowering environment of healing. In 2003, SLMHC began to develop an organization based on these values and concepts.

**Community Consultations:
Biimaadiziwin and Meno Ya Win**

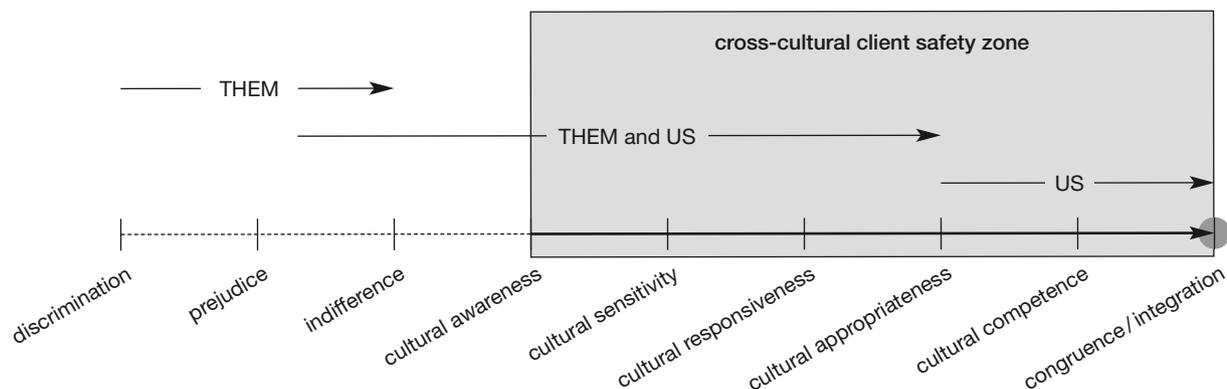
The objective of the Biimaadiziwin and Meno Ya Win project was to inform the integration of traditional healing and medicines at SLMHC by

exploring how integration should be carried out and by whom. “*Bii maa di zi win*” is an Anishnabe term that means “to live in a good way” and refers to teaching about how to live a life that is in balance. In doing so, it allows a person to reach a state of *menoyawin* (11).

The study used several research methodologies, which were employed by a predominantly First Nations research team, and the data were assessed by a First Nations-based program development team. Patient surveys, consultations with four of the communities and with 50 elders from different communities, and consultations with First Nations chiefs and leaders were carried out to gather the views of the communities. Additionally, site visits to 16 health care organizations in other jurisdictions across Canada were conducted. Further consultations were carried out with elders to member-check results prior to delivering the final recommendations.

Analysis of the elders’ consultations revealed five main areas where development was needed. The first was language: interpreters are required on a 24-hour basis; and transportation personnel have to be fluent in the appropriate languages. Second was education: Aboriginal youth should be encouraged to pursue health care careers. Third was comfort: traditional foods prepared in a traditional way are required. Fourth was escort services: escorts should be funded and given CPR and first aid training; policies need to be developed for them. Fifth was spirituality: spiritual healing and healers should be recognized and respected; traditional healing, Christian materials, and various combinations of practices should be made available. The consultations also led to the formation of an elders’ council made up of elders from the communities who were fluent in English and the Native language. This pan-organizational cultural evolution set the background for ongoing cross-cultural consultation.

Figure 3 / The Continuum Of Cross-Cultural Client Safety



First Nations Palliative Care Study

In 2007, a qualitative study using a phenomenological methodology was undertaken of the hospital-based end-of-life care experience of First Nations patients and their families (12). It was intended to inform the development of the SLMHC's palliative care program. This study was preceded by a 2001 qualitative study examining physician-Aboriginal patient communication (14); and in 2007, a manual on Aboriginal perinatal loss was developed for the region.

The bicultural and interdisciplinary research team developed a culturally appropriate set of semi-structured interview questions. In-depth audio-taped interviews were conducted with 10 participants whose family members had received palliative care as recently as several months, and up to several years, before the interview. All participants had lost a parent or a spouse. The transcribed interviews were then analyzed, triangulated, and member checked.

Three main themes arose from the analysis: communication, caregiving, and environment. The theme of communication was the most extensive, touching on communication with physicians, family members, and interpreters. The main findings within this theme include: respectful and direct physician communication is important; false hope is not appreciated; and intra-family communications and practices vary (some had conflict, others had a cultural tendency to avoid conflict in such situations, and others sought counsel from an elder).

In relation to the theme of caregiving, family members nearly always commented positively on the care the patient received. The main findings are: nurses are supportive, helpful, and friendly (with only the occasional exception); spiritual care is important, and there is a need for flexibility about diverse practices; flexibility is also needed when it comes to permitting family members time with their loved one after death and time to travel from the North.

The main findings linked to the theme of environment are: it is important to have extended family and community members present during the end-of-life stage; facilities are required to accommodate large groups in hospital; the practice of the nursing and kitchen staff of bringing refreshments wins participants' unanimous praise.

ORGANIZATIONAL FACTORS: A SHARED CULTURE OF RESEARCH

SLMHC has started to overcome many of the barriers that are commonly identified as contributing to the research-practice gap. First, the principles on which the hospital has founded its leadership

Figure 4 / Themes of First Nations End of Life Care



Source: Linkewich B, Cromarty H, St Pierre-Hansen N, et al. (12); reprinted with permission.

and governance are based on the integration of cultural values and beliefs into programming and, ultimately, practice standards and norms. In order for this integration to occur, it is crucial that the process of exploration and organizational reflection take place at all stages, from design to implementation. This process parallels, and strengthens, the discovery-delivery connection. Second, in the organizational research culture that SLMHC has developed, local practitioners drive the questions that are being asked. This leads to forward-thinking, practice/policy-relevant research and strengthens the collaborative relationship between researchers, decision makers, and care providers. The third point, dissemination, builds on the first and second points. With an organization devoted to providing research-based care and a group of practitioner-researchers, pathways for dissemination naturally exist and are promoted through local, regional, and national gatherings.

Initiatives providing funding and programming for rural communities are pivotal to the promotion of community-based research and the development of an organizational culture of research (15). SLMHC has benefited from having a driven, self-motivated team of primary care researchers with many years of local experience in palliative care. Team members have developed research methods that are culturally appropriate; they have been able to relate successfully to their research participants; and, due to their emersion in the project, their research results are trust-

worthy. These researchers also have an interest in seeing their hospital and community reach its potential as an integrated, culturally safe environment.

Additionally, the efforts of the researchers have been sustained by both personnel and financial support. A research intern has greatly assisted practitioners who are already involved in research and created an opportunity for new involvement. The internship was provided by the Northern Ontario School of Medicine in partnership with FedNor (Industry Canada's economic development initiative). Research funding has also been awarded through a College of Family Physicians of Canada D.M. Robb research grant and Lakehead University's Centre for Education and Research on Aging and Health. With these developments, the SLMHC is seeing the emergence of both the infrastructure and researcher interest to support locally driven and locally based research.

PROGRAM DEVELOPMENT

The previously mentioned research and organizational factors will continue to inform the development of all areas of care at SLMHC. The palliative care program is a prime example. There are on average 30 in-patient deaths at SLMHC per year. The hospital's new facilities will allow us to address all of the main points emerging from the research, including environment. In the meantime, programming development will benefit from, and incorporate, the information gleaned from the research.

SLMHC's new facilities will include larger patient rooms to accommodate extended family involvement in end-of-life care. A separate room will be built to allow family and community members to gather in an environment that is spacious and welcoming. This room will have a private entrance from the outside so that people will be free to come and go as they please. The design was based directly on the findings of the qualitative study of bereaved First Nations family members. The new SLMHC facility will integrate traditional healing, medicines, and support for First Nation patients. New facilities will include gathering and ceremonial spaces. In the ceremonial room, there will be opportunity to hold traditional healing ceremonies, including smudging, and traditional counselling and support. The THMFS program will continue to implement its components as a new facility is being built to meet its needs, such as special areas for preparing traditional foods and medicines. Support services, such as interpreters and elders-in-residence, will also grow and gradually become part of the SLMHC's

Weecheewaywin (patient support) program; interpreters will be trained as certified medical interpreters.

Respect for elders, their teachings, and their guidance is a fundamental value in First Nations communities. The recommendations of the Biimaadiziwin study have led to the formation of an eight-person elders' council to support board and management leadership. Extensive consultations with community elders have been highly influential in the development of SLMHC programming, strategic planning, communications, operations, and issue management. Elders also play a large part in providing patient support: they make regular visits to long-term-care residents and in-patients, including palliative care patients. The elders' council has shaped the development and implementation of several key programs and helped to manage several crucial diversity issues. The organization as a whole benefits from the normalization of elder involvement in a broad range of issues. Once a year, an elders' gathering that brings an elder from each of the Sioux Lookout Zone communities gives elders a chance to determine and/or evaluate the effectiveness of the council.

The Biimaadiziwin study highlighted the urgency of having interpreters available around the clock. Since then, interpreter availability has gone from 50 hours a month to more than 250 hours a month, and patient satisfaction has increased (10). The results of the Palliative Care of First Nations People study (12) emphasized the need for interpreters and other staff to have training in supporting palliative care patients and their families. The hospital's administrators have considered these results and will proceed to develop a training program for all staff. Broad dissemination of the results of that study will involve the presentation of the research participants' experiences with caregiver communication. Caregivers will then be able to reflect on their communication practices and ensure that they are respectful and direct and do not give false hope.

The conceptual research on cultural safety education and integration, along with the results from the Biimaadiziwin study, have led to the development of a two-day cultural orientation and conflict-resolution training program. All hospital staff participate in this training and are taught to question their cultural assumptions and to provide culturally appropriate care. Research has informed the development of the Weecheewaywin program. Elders-in-residence visit virtually every patient to determine if there is a need for support of any kind from the THMFS program.

EVALUATION

The process of exploring First Nations' experiences with palliative care confirmed the need for patient follow-up in order to continuously deliver care based on clients' needs. The palliative care program will continue this exploratory process by developing a telephone follow-up for bereaved families and ongoing consultation with the elders' council. This will help SLMHC deliver continuous, high-quality palliative care and make continuous improvements. It will also give family members the opportunity to express their concerns and ensure that they are heard.

CONCLUSION

Over the past several years, multiple research modalities have laid the groundwork for outlining the issues of cross-cultural care. Focused palliative care research has highlighted the importance of respectful communication, appropriate environment, and appropriate caregiving. The developing research culture of the organization will allow us to explore more palliative care issues, such as culturally appropriate approaches to organ donation.

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EDUCATION FOR HEALTH

ORIGINAL RESEARCH PAPER

Realistic Expectations: The Changing Role of Paraprofessional Health Workers in the First Nation Communities in Canada

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ABSTRACT

Context: First Nation communities in Canada rely on a mix of non-Indigenous professionals and large numbers of Indigenous paraprofessionals to deliver healthcare. Formerly allowed to perform controlled acts in emergencies, the direct care role of paraprofessionals is now restricted because of concerns about liability and accountability. As such, they are limited to health promotion and prevention activities.

Objectives: Focusing on the largest group of Indigenous health workers, viz. Community Health Representatives (CHRs), for illustration purposes, this paper (1) examines the evolving role of First Nation health workers, and (2) discusses the proposed introduction of competency-based standards for their education, certification and regulation.

Methods: The paper is informed by findings from open ended, semi-structured and focus group interviews, as well as qualitative survey data, derived from seven studies done in Ontario, Canada.

Outcomes: Paraprofessionals face conflicting and sometimes unrealistic expectations. Past practices have accustomed community members to hands-on care, however, professionals will no longer delegate tasks requiring clinical skills to them. Moreover, First



Nation leaders are concerned about liability for their paraprofessional employees' actions. The paper discusses issues related to paraprofessional competence, preparation for practice, and continuing health education. It then presents the National Indian and Inuit Community Health Representatives Organization's proposal to establish a scope of practice and set of competencies that can form the basis for national practice and training standards, accreditation and regulation.

Conclusions: In Canada or elsewhere, changing practice environments may require adjustments in the roles played by Indigenous health workers. The case of First Nation Community Health Representatives illustrates a strategy for role transformation.

Keywords: American native continental ancestry group; Canadian First Nations healthcare; paraprofessionals; Indigenous health workers; health human resources; lay health workers.

Context

Like other Canadians, members of First Nation communities rely on both professional and paraprofessional health workers for care. However, in their case the proportion of the latter group is much greater than it is for the general population. In the province of Ontario, for example, over 40 percent of all health providers working for a First Nation fall into the paraprofessional category (Minore *et al.*, 2008). This ratio reflects a number of factors. For many First Nations people, the chance of training as a health professional is impeded by inadequate early education, or geographic and funding barriers that restrict access to the training required (National Aboriginal Health Organization, 2003). As a result, the majority of professionals who work in these communities are not of First Nations ancestry and, in many cases, are reluctant to commit to work for a significant period of time in places where the health needs are high and the working conditions often difficult. Paraprofessionals tend to stay, providing a measure of stability and continuity. Moreover, because they are usually recruited from the communities, they are aware of local cultural beliefs and practices, as well as of the Indigenous languages and dialects used. While not always ideal, a staffing model that mixes professionals with substantial numbers of paraprofessionals has proven workable in such situations, which demand both clinical and cultural competence.

However, the roles played by First Nation paraprofessional health workers are in flux due to increasing uneasiness on the part of the workers and their supervisors about issues of liability and accountability. The outcome of comparing comments and observations from two interviews done by the authors in northern Ontario communities, illustrates the magnitude of the change occurring.

About fifteen years ago, the Community Health Representative (CHR) in one small, remote place talked about what happened for a couple of months every year when ice, forming in early winter and breaking-up again in springtime, prevented airplanes bringing visiting nurses from landing on a nearby lake. During these periods, she said: "I did nursing duties . . . emergency care, giving needles and suturing." She added, "I was not qualified . . . [but] was persuaded to do them." At the same time, she continued her usual tasks: "...collecting water samples, teaching prevention about AIDS and HIV . . . [and giving] fluoride rinses to school kids" (Kinch *et al.*, 1994). In interviews done twelve years later, it was reported that health program administrators in a larger community would not allow the CHR to do finger pricks for diabetes screening, even though the resident nurses were too busy to do them. As a result, there were no diabetes screening clinics held in the community for an entire year (Jacklin, 2007).

Paraprofessionals do not simply act in an extender role, performing tasks delegated by professionals (Mackenzie, 2006), but also apply their own unique knowledge, including cross-cultural awareness (Musser-Granski & Garrillo, 1997; Owen & English, 2005).



The nature of their work often requires extensive interaction with clients, so they are able to establish supportive relationships (Jack *et al.*, 2002), and advocate for (Ahmed *et al.*, 2006) or empower them (Schoenberg *et al.*, 2001), while “providing concrete services” (Walter & Petr, 2006, p. 468). A Cochrane review of 43 studies on lay health workers found they were effective in delivering specific preventive and health promotion programs (Lewin *et al.*, 2005).

Paraprofessionals are widely used in developing countries to facilitate access to care (Haq & Hafeez, 2009) or to respond to specific health risks (Swart *et al.*, 2008), as well as to reach populations within developed countries that are marginalized by poverty (Swider, 2002) or ethnicity (Walkup *et al.*, 2009), often related to particular diseases (Hoy *et al.*, 2005; Simmons *et al.*, 2008). However, practice environments change, requiring or allowing adjustments in the roles played (Witmer, 1995). With exceptions (Simon *et al.*, 2009), there are few documented instances of role revision such as that occurring in the First Nation communities of Canada.

Objectives

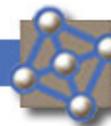
The healthcare system in Canada’s First Nation communities could not function without Indigenous health workers. Indeed, there has been a proliferation in the categories of specialized community health workers (e.g. Diabetes Workers), generally linked to funding for specific country-wide initiatives. This paper undertakes to:

1. examine the evolving role of First Nation health workers in Canada, taking into account their practice environments, educational issues and the factors promoting change; and
2. discuss a proposed national strategy for competency-based standards for their education, certification and regulation.

Methods

Although observations in this concept paper apply to all categories of Indigenous health workers in Canada, for purposes of illustration we focus on Community Health Representatives (CHRs). This is the first group created and likely the most numerous, although exact figures are not known (McCulla, 2004). Our paper is based on several studies conducted over a 14-year period in First Nation communities across Ontario, a province which is home to about 20 percent of the country’s Aboriginal population (Statistics Canada, 2008) and where the preparation and roles of Indigenous paraprofessionals reflect the national norm (Hammond, 2006). The following research informed this paper:

1. Kinch *et al.*, 1994: A study of factors affecting the retention of Indigenous health workers. Telephone interviews were done with 48 community health workers, of whom 30 were CHRs, by an Oji-Cree/English speaking interviewer. The questions were open-ended (e.g. “Since becoming a CHR, did your relationship with your community change? If so, how?”).
2. Boone *et al.*, 1997: A study of professional/paraprofessional interactions during crisis intervention situations. Based on in-depth unstructured interviews with all front-line workers, both professional and paraprofessional, who dealt with a series of suicide attempts in an isolated Cree community.
3. Minore & Boone, 2002; Minore *et al.*, 2004: A study of continuity in the delivery of care in three First Nation communities. Involved a systematic review of 135 clinical charts and in-person English/Oji-Cree interviews with 15 professionals and 15 paraprofessionals, asking open-ended questions about their roles.



4. Jacklin & Warry, 2005; Warry & Jacklin, 2004: Two evaluations of band-delivered health services on Manitoulin Island reserves. The research included focus groups with, respectively, 37 and 36 health centre staff, key informant interviews (4 and 29), participant observation, client exit surveys and analysis of hospital separation data and in-house statistics.
5. Jacklin, 2007; Jacklin & Kinoshameg, 2008; Jacklin, 2009: An investigation of factors influencing community health and healing at the Wikwemikong Unceded Indian Reserve, involving participant observation over a two-year period, in-depth interviews with 13 health centre staff and semi-structured interviews with 350 community members.
6. Minore *et al.*, 2008: An Ontario-wide health human resources survey, consisting of closed and open-ended questions, completed by health program staff for 101 of Ontario's 134 First Nations. The survey explored recruitment and retention of both professional and paraprofessional workers, especially those of First Nations heritage.

Findings

Practice environment: Because of their diversity – large and small, readily accessible and remote, adequately resourced and underserved – the sites in Ontario where the research was conducted encompass the range of conditions affecting health delivery in the majority of First Nation communities in Canada. The relative health of residents in all of them fails to match that generally enjoyed by Canadians, as is true in First Nations across the country (Young, 2003; Frohlich *et al.*, 2006). But this health status gap is narrowing (Romanow, 2002), in part because of the shift to Aboriginal governance (Health Canada, 2006).

Although the Canadian federal government is generally thought to be responsible for the health of individuals residing in First Nations communities, in fact, the majority of services are delivered by organizations operating under local authority. Since 1989, more than 80 percent of eligible communities have taken over management, either fully or to a significant extent, through a Transfer of Health Programs agreement. Beyond providing essential public health programs, they are free to plan and deliver services that address local needs and preferences.

First Nation paraprofessionals in practice: The Canadian Royal Commission on Aboriginal Peoples (Canada, 1996) concluded that the CHR program was a significant success story. Introduced by the federal government in 1962 to augment the health services available to First Nations and Inuit people, especially in places where access to routine care was restricted, CHRs quickly became an integral part of the healthcare system and, in some cases, the principal on-site providers.

From the outset, the CHR job description was vague, but intended to focus on health promotion and disease prevention along, in the early days, with some direct care of patients, including the delivery of babies. CHRs were only supposed to initiate clinical interventions when forced to manage an emergency. Doing so, however, became a routine practice, although never officially sanctioned. Narrowing the scope of practice to educational home visits and other prevention and promotion activities has caused consternation among community members, some of whom want paraprofessionals to continue offering hands-on treatment.

Because many nurses and doctors working in First Nation communities are there for comparatively brief stints – a few weeks or months – they often do not understand the roles of Indigenous health workers (Purden, 2005), or lack confidence in their training and skills (Boone *et al.*, 1997). As a result, these professionals fail to acknowledge paraprofessionals as colleagues with separate but equal knowledge who can make a valuable contribution to the team (DuBois *et al.*, 1991). Nurses, doctors and others with longer First Nations work histories recognize that sometimes paraprofessionals are their strongest link to community members.



First Nation paraprofessionals' preparation for practice: Of necessity, CHRs frequently work for a period of time without extensive preparation. The need to fill positions with responsible people simply outstrips the system's capacity to provide prior training. Most CHRs eventually do have formal instruction, but that can take many forms, from short certificate courses to two-year diplomas. The curricula tend to focus on generic skills: communications; counseling; case management; advocacy; program development; and delivery. Ideally, the course content is informed by the needs of communities in a program's catchment area, so issues of particular local relevance are addressed (Jacklin & Warry, 2005). For example, the curriculum for a course offered by the Oshki-Pimache-O-Win Education and Training Institute in Northwestern Ontario was developed with input from a First Nations advisory board and the organization mandated by the region's chiefs to represent their communities' health and educational interests to other levels of government.

There is a need for continuing health education for paraprofessionals, not only to update information and skills, but also to make them feel supported in their jobs. This same education can be used to help create career ladders. Some articulated education programs do exist, although none that are CHR-specific. For example, after one year in the First Nations Partnership Program in British Columbia, students are eligible for a certificate in Early Childhood Education; those who continue for a second year achieve a diploma in Child and Youth Care. Upon completing two more years of study in the University of Victoria-based program, they will receive a degree in Child and Youth Care. This "step on-step off" educational model accommodates changes in people's personal and work situations; progression from paraprofessional to professional levels may be interrupted, but the transitions are seamless (Ball & Pence, 2001).

Discussion

Factors promoting change in First Nation paraprofessionals' practice: The questions of liability that are challenging and redefining long existent paraprofessional roles come from two sources. On the one hand, "many nurses and physicians are second-guessing the roles of CHRs because of regulations and legislation" (McCulla, 2004, p. 44). Specifically, the legislation regulating health professionals only permits them to delegate controlled acts, such as giving sub-coetaneous injections to other professionals deemed competent to perform them. This concern exists, despite exemptions that allow unregulated individuals to perform such "acts of daily living" as giving insulin injections. On the other hand, First Nation Chiefs and Councilors, in their capacity as employers, are anxious about their liability for the actions of their health paraprofessional employees - an anxiety doubtlessly reinforced by their insurance carriers.

Professionals may be held accountable for breeches in the behavior of paraprofessionals working under their supervision, but they have little or no disciplinary authority. That rests primarily with the employers or, in other words, with community leaders. These leaders, in most cases, do not have backgrounds in health, so they are unfamiliar with acceptable procedures. In sum, professionals are concerned about answering to their own regulatory bodies, while employers face accountability for things that may seem ill-defined and indistinct to them.

A strategy for adjusting to change in First Nation paraprofessionals' practice: The ill-defined roles of paraprofessionals are being redefined, more by happenstance than plan, while they struggle to meet sometimes unrealistic and often conflicting expectations. The National Indian and Inuit Community Health Representatives Organization (NIICHO) has proposed a detailed strategy to rectify this situation. It would involve five steps: development of clear job descriptions; standardization of training; accreditation of educational programs; certification of graduates; and regulation of practitioners. These elements interlink with one another. Without agreed upon scopes of practice, it is difficult to establish a set of competencies that can form the basis for



educational curricula, as well as practice standards. Without such standards, it is hard to monitor people's practices in ways that are fair and justifiable.

As a start, NIICHRO led a multi-stage consultation with stakeholders to identify a core set of competencies. The result was a list of twenty-two that fall within seven domains: 1) Aboriginal and primary health care; 2) empowerment, community relations and cultural competence; 3) prevention, promotion and protection; 4) emergency care; 5) communications; 6) ethics, leadership and teamwork; and 7) administration (Hammond & Collins, 2007). Job descriptions for specific categories of workers must still be set, appropriate curricula developed and mechanisms established that would enable accreditation, certification and regulation. NIICHRO proposes that the latter three tasks could be done by provincial/territorial branches of a national association, since education and the regulation of health workers are subject to provincial or territorial jurisdiction in Canada. The approach mirrors the model in place for professionals; but practical and conceptual considerations will affect how – or if – it is implemented.

For instance, in practical terms, some individuals already in the CHR role, although they have considerable interpersonal skills and valuable local knowledge, may not have sufficient formal education to succeed in rigorous competency-based training or upgrading programs. However, in most cases, their experiential learning would likely justify their being “grand-parented” into the role, and thus continuing on the job.

Conceptually, the idea of national standards is at odds with the equally important notion that local autonomy must be upheld. Indeed, a structured, standard approach would take away much of the flexibility that allows paraprofessionals to respond to changing local circumstances, a hallmark of their success (Witmer *et al.*, 1995). Consequently, any system of accreditation or regulation that is established must explicitly recognize that First Nation communities have a right to not adopt or enforce the requirements locally. To help ensure that such decisions are fully informed continuous education is required. This should be directed toward community members as well as to the leaders, and emphasize the benefits for client safety that derive from standardization. As well, governance of the system should involve individuals who are representative of the population served.

Conclusion

Combining professionals' clinical knowledge with paraprofessionals' cultural and community awareness is the only workable means of delivering essential health services in most First Nation communities. However, because of uncertainty about the part they can and should play, and of concerns about liability and accountability, paraprofessionals are underutilized and somewhat marginalized within the care team. This situation is unacceptable, given the health needs of the people and the shortage of health human resources in most of their communities. The solution, in part, requires the determination of appropriate scopes of practice and expected competencies for paraprofessionals, on which standards for accredited educational programs and certification can be based.

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Achieving Cultural Integration in Health Services:

Design of Comprehensive Hospital Model for Traditional Healing, Medicines, Foods and Supports

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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 Anishinabe population living in 32 Northern Ontario communities spread over 385,000 sq. km. 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 Aboriginal population. We will outline our journey to date towards the design and early stages of implementation of our comprehensive *minoyawin*¹ model of care. This includes 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, and potentially transferable practices are identified.

KEYWORDS

Traditional healing and medicines, Aboriginal health, cross-cultural competency, transcultural care, integrative medicine, Anishinabe

INTRODUCTION

The Sioux Lookout Meno-Ya-Win Health Centre (SLMHC) has a specific mandate, among Ontario hospitals. It is to provide a broad set of services to a largely First Nations service population in a manner which addresses both health status and cultural needs. As SLMHC develops programs and services that respond to this mandate, it is expected that it will emerge as an Ontario center of excellence in the provision of culturally sensitive care.

Eighty-five per cent of our patients are predominantly Anishinabe people. Many of our patients use English primarily as a second language. These same patients live in a cultural context that results in Sioux Lookout, let alone Thunder Bay, Winnipeg or Toronto being experienced as “foreign” environments with major linguistic and cultural barriers encountered. The operations and settings of the health care system are complex, and equally “foreign.” This requires sensitive support and assistance for the system to be beneficially navigated, and for services provided to be fully effective.

Access to services is often a logistical nightmare for both patient and provider, e.g. the majority of northern patients access SLMHC by fixed wing air transportation. There is a need for special support mechanisms, some of which are the direct responsibility of the hospital. Non-Insured Health Benefit (NIHB) supports, including escorts, may be available to the point of entering the hospital for services. SLMHC is responsible beyond that point until the patient is returned to the NIHB-funded setting. This often includes patients and family who are traumatized by the logistics of getting to the service point, in addition to having to deal with the presenting health issue(s) and the “foreign” context in which they are met.

This article outlines a Traditional Healing, Medicines, Foods and Supports (THMFS) program developed by SLMHC to ensure that these services are provided in

response to this mandate, and on a basis that supports cross-cultural competency and safety requirements of the organization. The program development process and underlying research are also outlined. The program is in early stages of implementation, with complete adoption planned for 2010/2011, when our new facility is complete. The model of care arose from *Bi maa dizi win*, a 2005 multi-faceted research project involving consultations with Elders, community focus groups and visits to other successful Aboriginal programs.

The THMFS program is a new model for integrated First Nations hospital-based services, and will serve as a substantive prescription for progress in addressing the illness burden of Ontario’s most at risk population: the people living in our northern First Nations communities.

The program responds to all key aspects of a multi-dimensional cross-cultural patient safety analytical framework developed by SLMHC in 2005. It is congruent with the increased emphasis by the Canadian Council on Health Services Accreditation (CCHSA) and the Canadian Patient Safety Institute on formalizing patient safety programs.

LITERATURE REVIEW

Cultural Safety

Developing out of Leininger’s (1975) model of “trans-cultural nursing,” the concept of “cultural safety” was introduced by Ramsden (1993) in the nursing education context of New Zealand (Smye, 2002). Cultural safety is used as an analytical tool to understand the everyday social interaction between caregiver and client (Anderson, 2003). The concept which was originally used in the context of interactions between different racial or ethnic groups has been expanded by some to be applicable in any clinical interaction between individuals with different worldviews (NAHO, 2008). The concept of cultural safety is predicated on the understanding that a caregiver’s own culture, and assumptions that follow, impact the manner in which a clinical encounter is played out and therefore impacts the patient’s care. The burden of cultural adaptation that results when intercultural interactions occur, should be relieved from the patient whenever possible (Paasche-Orlow, 2004).

Cultural safety is integral to clinical safety: it is about minimizing risk and providing a safe healing environment (Bunker, 2001). Cultural safety educators aim to impart the understanding that past and present socio-political processes are intrinsically connected to contemporary health and social issues (Smye, 2002; Browne, 2002).

Knowledge of cultural differences is the first step. Caregivers need to also understand the ongoing impact of intergenerational trauma and continued injustices (NAHO, 2008). Skills gained from this understanding are transferable to many cultures. It helps to prevent oversimplification and stereotyping that may occur with earlier trends in cultural competency education that focused on the differences between cultures (Bischoff, 2003; NAHO, 2008). Cultural safety educators instead focus on the differences between how various cultures are treated (Paasche-Orlow, 2004). At the level of the individual, cultural competence focuses on patient-centered care which improves care regardless of nationality, culture, age, gender or religious beliefs (Anderson 2002; NAHO 2008).

A true understanding of the imbalances in a caregiver-patient dynamic requires that the caregiver engage in a process of self-reflection in which one's own culture and assumptions are recognized (NAHO, 2008; Papps, 1996). This attitude of "cultural humility" entails an enduring commitment to self-evaluation and self-critique (Bischoff, 2003). A culturally safe environment develops from an individual and institutional philosophy of empowerment, individuality and choice (Bunker, 2001). Patient empowerment arises from practices that increase access to information and increase individuals' decision making power (NAHO, 2008). The term "health literacy" refers to an individual's ability to use the health care system appropriately and maintain a healthy lifestyle, which is connected to health outcomes (Bischoff, 2003).

Assessing Cultural Safety and Cultural Competency

Migrant Friendly Hospitals, a initiative which aims to improve healthcare delivered to migrants and minorities in Europe, suggests approaching cultural safety as a measure of quality by including cultural issues in all quality monitoring (Bischoff, 2003). Bunker recommends that caregivers be assessed on both practical technical skills and on aspects of attitude and behaviour. Buetow (2004), in his discussion integrating Māori healing with western medicine, stresses the need to use both frameworks to define quality improvement. Since quality improvement develops out of the moral values embedded within an institution it should reflect the moral values of the people it represents. The result is a distinct, hybrid system of quality improvement specific to that institution (Buetow, 2004). The literature on interpreter/translator competencies has expanded to include defined competencies, articulation of standards of practice and accepted codes of ethics (Diversity Rx, 2003; American Medical Interpreters Translators Association,

2003; American Translators Association, 2004; International medical Interpreters Association, 2007). In the U.S.A., since 2001 federal funding to healthcare providers is premised on conformity to National Standards for Culturally and Linguistically Appropriate Services in Health Care (U.S. Department of Health and Human Services, Office of Minority Health, 2001). Assessing competency relative to these standards has generated many proponents and approaches (Salimbene, 2002; U.S. Department of Health Human Services, Health resources and Services Administration, 2002; Agency for Healthcare Research and Quality, 2003).

Traditional Healing Practices - Canadian Context

Canadian policy makers are increasingly recognizing traditional healing practices as valuable and appropriate. Despite landmark policy developments such as the 2007 introduction of *Eating Well with Canada's Food Guide - First Nations, Inuit and Métis* (Health Canada, 2007), or the exemption of Ontario's Aboriginal healers and midwives from Regulated Health Professions Act (Regulated Health Professionals Act, 1991), there still exist legal and policy challenges that remain undefined (WalDRAM, 2005).

The Ontario Aboriginal Healing and Wellness Strategy (AHWS) published guidelines for implementing traditional healing programs (AHWS, 2002). It recommends that each organization develop their own program guidelines that respect local healing practices. Through open and honest dialogue the following should be established:

- Appropriate and respectful ways of accessing a traditional healer (this is often from a process of community validation based on reputation of the healer).
- The appropriate offerings and/or payment for the healer (contacting the healer's home community may be helpful).
- Storage and handling of medicine.
- Protocols for dealing with inappropriate behaviour and practices.
- The roles and responsibilities of all people involved in the patients care.

Patient and Client Supports - Interpreter Services

One of the more urgent and immediate interventions to enhance cultural safety is with improved communication through interpreter services. Andrusis' study of patients needing interpreter services (n=4 161) found that 75 per cent of those who needed and received an interpreter

described the facility as “open” compared to 45 per cent of those who needed but did not use an interpreter (Andrulis, 2002). Kaufert (1999), O’Neil (1988) and Smylie (2001) describe the disadvantage of using family member interpreters as conflicting values may lead family members to alter the doctor’s message in order to tell the patient what they believe the patient should hear (Kaufert, 1999; O’Neil, 1988; Smylie, 2001).

The literature on interpreter/translator competencies has expanded to include defined competencies, articulation of standards of practice and accepted codes of ethics (Diversity Rx, 2003; American Medical Interpreters Translators Association, 2003; American Translators Association, 2004; International Medical Interpreters Association, 2007).

Patient and Client Supports - Cultural Translation

The role of the interpreter in many qualitative studies has been documented as a cultural broker or cultural translator (Kaufert, 1999; Smylie 2001; O’Neil, 1988). An examination of the role of the medical interpreters in two Winnipeg hospitals revealed that interpreters mediated potential conflicts, as well as connected patients with traditional healers. In this function they were acting as medical educators and medical advocates: unofficially, bridging the divide between western medicine and tradition healing systems (Kaufert, 1999; Smylie, 2001). The Whitehorse General Hospital builds on the concept of patient empowerment and advocacy by employing liaison workers (Aboriginal Nurse Association, 2005).

PROGRAM DEVELOPMENT

1. Program Design at *Meno Ya Win*

SLMHC was founded as a result of the Sioux Lookout Four Party Hospital Services Agreement which was signed in 1997 by Canada, Ontario, Nishnawbe-Aski Nation, and the Town of Sioux Lookout. The agreement underlines the need for culturally responsive programming in almost every section from the preamble through foundational philosophies and principles to operational and capital funding, planning, service definitions, and special requirements and exemptions.

SLMHC further documented the need for this program in several other documents including:

- *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 *Bi maa dizi win* and *Meno Ya Win* study on the proposed integration of traditional healing and medicine was conducted in 2004/2005. The project team of the SLMHC consisted of eight members, most of whom were Aboriginal and fluent in one of the native languages. The study emerged in the context of amalgamation between a provincial and federal hospital in Sioux Lookout; and a subsequent interest and commitment to utilizing traditional means in health care for First Nations people. The research questions how integration should be carried out and who should be involved. A variety of methods were used.

The views of First Nations community members were explored through: patient surveys; four separate community consultations with 50 Elders from different communities in the service area; and consultations with First Nations chiefs and political and spiritual leaders. The practices of other organizations that provide culturally appropriate care were explored by site visits to 16 organizations in other jurisdictions across Canada. The site visits included interviews with key informants and documentation of demographics, funding, protocols, governance, successes, and challenges.

Results were member-checked with further Elders’ consultations prior to recommendations and program proposals going to the SLMHC Board and government levels for review and approval.

The four main areas of importance that emerged from the consultations with Elders were: language, comfort, escorts and spirituality.

Language: Discussions around language identified that interpreters in all three Aboriginal languages should be available 24 hours, transportation personnel should be fluent in one of the languages, and the pursuit of health careers should be promoted to Aboriginal youth.

Comfort: Access to traditional foods, the serving of foods without spices, and the introduction of cultural activities into the hospital are factors relating to comfort.

Escorts: Respondents recommended that escorting should be a paid job involving training and certification in CPR and First Aid, and that escort policies be developed.

Spirituality: Respondents identified the need for spiritual healing to be respected and for traditional healers to be given the same recognition as a pastor. The ability to choose between diverse practices and the availability of both traditional healing and Christian materials should exist in the hospital.

Respondents also recommended the formation of an Elders Council made up of Elders from the communities who are fluent in English and the native language. The Elders Council would inform the development of the traditional medicine and healing program.

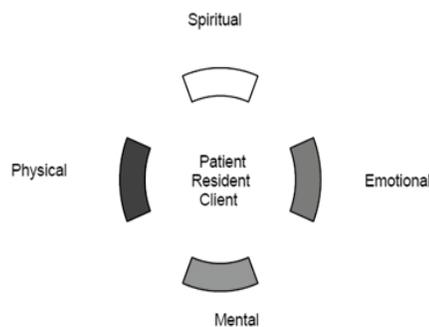
The study further documented that 90 per cent of our Anishinabe patients would use one or more components of the traditional healing, medicines, foods, and services (THMFS) program once available.

The above results from the *Bii maa di zi win* study have informed program development and implementation which is described below, including the now functioning Elders Council.

2. Program Context

The THMFS program was developed to be a core aspect of all SLMHC clinical services. This means that the program is being fully integrated as an element of virtually all clinical programs, not as a separate, stand-alone program. It conforms to the principles of *integrative medicine* and is based on teachings and practices unique to the Anishinabe people of our area. As it develops and matures, the THMFS program will provide a real set of choices: patients, residents, and clients and their caregivers will be able to choose to access the services available through the THMFS program as an adjunct or alternative to other conventional clinical services and supports. The program will become an equal partner to modern (or contemporary) approaches to healing.

Our very name, *Meno-Ya-Win*, is the Oji-Cree word that represents the English terms health, wellness and well-being. It denotes a wholeness of our physical, emotional, mental, and spiritual aspects. The *medicine wheel* is based in part on incorporating these aspects of our being into all healing processes. The THMFS program adds key programming that brings into play *Andaw' Iwe Win* (healing approaches and practices based on this wholeness) and not just *Kee ge win* (the healing of a wound or injury, or care-giving in this physical sense of healing).



The program is informed by and incorporates principles, approaches and practices based on these and other traditional *teachings*. The program is particularly respectful of the sense of *community* and *family* that underpin Anishinabe society.

The THMFS program is developing and operates in the political and social context of Aboriginal and northern health services:

- The importance of treaty rights to health and health services.
- The growing responsibility of First Nations through transfer agreements to provide their own health services.
- The developed continuum of services painstakingly built by the First Nations and the First Nations and Inuit Health Branch of Health Canada.
- The partnerships developed with stakeholder and provider organizations to ensure fewer gaps in service and better local responses to health needs and health status issues.
- The shift to bring services closer to home.
- Provincial policy initiatives determining program priorities and the health transformation agenda.

3. Program Objectives

The THMFS program is intended to:

- Provide a welcoming, supportive, familiar environment for patients, residents, and clients.
- Embed a culturally appropriate set of services and supports.
- Reduce patient, resident and client difficulties in accessing and using SLMHC services to best advantage.
- Provide healing practices, including ceremonies, specific to the Anishnabe context.
- Promote healing and healthy practices.

- Reduce required lengths and frequency of hospitalization and “expatriate” service requirements.
- Provide appropriate choices in healing approach, medications and foods.
- Build a solid foundation for benchmark performance.
- Ensure enhanced levels of organizational, work unit and individual cultural competency.
- Enhance cultural congruency² of the organization.
- Integrate cross-cultural patient safety issues and understanding into the organizational culture of safety and associated practices.

4. Cross-Cultural Patient Safety

The totality of the THMFS program is intended to respond to cross cultural patient safety issues. Our search for a standard of practice in this area took us well beyond the apparent focuses of the Canadian Patient Safety Institute and Canadian Council on Health Services Accreditation in raising patient safety into the limelight. The result of our efforts is the definition of a set of cultural factors which expand the analytical framework for all safety-related programming.

Cross cultural patient safety (CCPS) occurs through “culturally competent” practice and effective delivery of health care services across barriers to understanding; and by overcoming cultural obstacles to implementing prescribed remedial or supportive actions.

The primary frame of reference for CCPS has been the area of linguistic diversity but there are several other important cross-cultural risk factors.

4.1. **Linguistic barriers:** the potential for misunderstanding descriptions of presenting symptoms and history of the client and/or the prescribed course of diagnostic or therapeutic intervention. E.g. a traditional language may have no contemporary vocabulary hence no word or phrase that can be used to communicate an essential idea.

4.2. **Cultural barriers:** the potential for misunderstanding the cultural context of the presenting pathology and/or the ability to successfully implement a prescribed course of action in the face of contradictory world views, perspectives, value sets, norms and mores. E.g. even if the words are understood, compliance may not occur because of differences in custom with the mainstream, or provider population.

4.3. **Practice barriers:** conventional services or practices contrasted with traditional practices specific to the culture(s) in question. E.g. contraindications in the use of manufactured pharmaceuticals concurrent with traditional medicines.

4.4. **Context or structural barriers:** the potential for misunderstanding or mishap due to cultural habitats and (lack of) knowledge associated with them. E.g. the differences in community infrastructure and differences in accessing services and support in urban, rural or remote settings.

4.5. **Systemic barriers:** disconnects between mainstream systems and specific population providers including: territoriality, overlaps, gaps, policy differences, differing approaches, health status, etc. Examples often relate to access and availability.

4.6. **Genetics:** failure to know of or take into account inherent issues in a population. E.g. genetic predisposition to diabetes.

4.7. **Racism/discrimination:** manifestations of bigotry, prejudice or intolerance that result in the differential provision of services or care.

4.8. **Power, history and politicization of health:** spotlights individual issues which risk disrupting energy and resources from other priorities, often associated with ties to treaty rights to health, or racial discrimination as an underlying issue – relates to historical issues and grievances, failure to consult and/or power/control issues.

Failure to identify and respond to patient safety needs beyond medical errors, infection control and adverse events leaves our organizations and patients at very serious risk of harmful outcomes.

These issues must be addressed in order to meet the CCHSA ROPs related to creating a culture of safety and, particularly, to undertake any well-designed failure modes and effects analysis (FMEA) to prevent risks from actualizing in a multi-ethnic or cross-cultural setting. This entails most Canadian health services, whether Aboriginal serving or not, because of the growing diversity of our population.

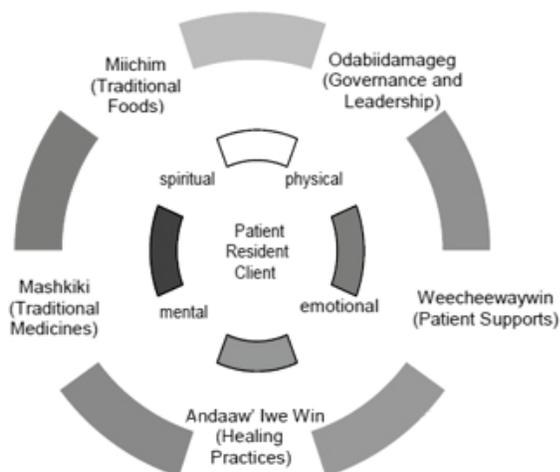
Ultimately, CCPS is at the desirable end of a continuum that moves from cultural awareness to cultural sensitivity, from sensitivity to responsiveness, responsiveness

to appropriateness, then cultural competence, and finally cultural safety.

In conclusion, CCPS encompasses a broader set of constructs than conventional patient safety theory and practice. It is rooted in difference and diversity, and is based on awareness, understanding, acceptance, respect, and empowerment of individuals, communities and populations within their own cultural context.

5. THMFS Program Components

The SLMHC Traditional Healing, Medicines, Foods and Supports (THMFS) program includes five core components that echo the foundational philosophy of the program.



Once developed to a point of maturity and fully integrated into our organization, these core components and their foundational philosophy will overlay all other SLMHC patient, resident and client programs and services.

They will provide SLMHC patients, residents and clients with an important range of personal options and the ability to exercise choices in the care that they receive. As each of the elements of these program components is normalized, they will potentially serve as benchmark practices for other First Nations serving hospitals and health centers in Ontario and elsewhere.

The program elements as developed to date are as follows:

1. *Odabiidamageg* (governance and leadership):

1.1 Board of Directors:

SLMHC is governed by a board of 15 directors appointed on a “proportional representation” basis: 2/3 Anishinabe, 1/3 non-native. The Board also includes two physician representatives and an Elder/healer.

Significant board characteristics are identified below:

- Board appointments are representational, and are not specifically “skill-based.” Appointments are made by the Board after consultation with First Nations or sponsoring organizations.
- The Board operates on a “blended model” versus a “governance model” or “management model” borrowing characteristics typical of both “Chief and Council” and conventional “hospital board” constructs.
- The Board operates successfully as an “integrated” board versus the nominal representation, liaison, consultative, advisory, constituency, caucus, or similar approaches tried by other organizations across Canada which have a mix of Aboriginal and non-native members (Semple, 2005).

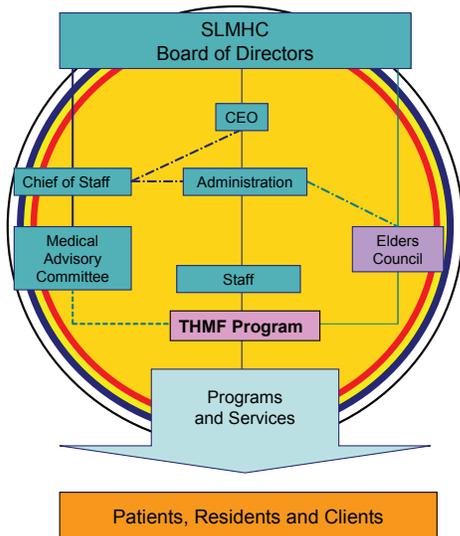
1.2 Elders Council:

SLMHC held four major Elders’ gatherings to support Board and Management leadership efforts between Fall 2003 and Summer 2007. Many visits were made to Elders in other contexts. An eight person Elders Council was formally established in October 2007.

- Respect for Elders, their teachings and their counsel is a fundamental value in our First Nations communities.
- Numerous traditional healing programs were visited during the planning of the THMFS program. Virtually all of them underscored the importance of Elders’ support and involvement to the successful development, implementation, management, and continuity of the programs. The means by which this is accomplished varies, but frequently was based on establishment of an Elders’ council connected to the organization or program.

- Community Elders have been extensively consulted in the development of this program and other key aspects of SLMHC planning, operations and issues management. Advice provided has proven fundamentally valuable. The Board, administration, program managers, staff, and providers benefit from the normalization of a continuing Elders' role and presence.
- The Elders Council is similar in many respects to a typical Medical Advisory Committee including regular involvement/representation at board meetings.
- The Elders Council will continue to advise on program development and management, communications and issues management, strategic planning, board processes, and other relevant issues.
- The Elders Council will be based on broad representation from our communities.
- Both Christian and traditional beliefs will be represented to reflect the needs and desires of our communities and our people.
- Current unscheduled Elders visits to SLMHC patients and residents are notably beneficial to the patients and residents.

The following organization chart shows the Elders Council relationship to the SLMHC board, administration and staff, and medical staff, etc.



1.3 Management and Leadership

The Senior Management Team includes a Special Advisor for First Nations Health, and an Advisor to the Board and CEO. Both of these positions function at the Vice President level and are integral to the management and leadership of the organization. The Communications and Community Development division of SLMHC also has strong First Nations leadership. This unit was given responsibility to oversee planning and development of the THMFS program. THMFS program implementation and on-going leadership and management will be the responsibility of the Health Services Division of SLMHC. This will facilitate integration of the THMFS program into all aspects of SLMHC.

- Awareness, understanding, sensitivity, acceptance, and responsiveness to the cultural diversity and legacies of our patients, residents and clients is imperative for everyone with management and leadership roles, and must be embedded in the psyche and psychology of the organization as a whole.
- Identification of and support for board, administration, program, and medical *champions* is essential.
- Increased opportunities for First Nations professional development, career and employment opportunities as part of the SLMHC management and leadership team are being mandated and aggressively pursued.

2. *Weecheewaywin* (patient, resident and client supports):

Basic patient supports for Anishinabe patients were developed by the predecessor organizations to SLMHC including a part-time, non-dedicated interpreter service and some translation of materials and common phrases. The interpreters were staff who had been hired into other roles and, based on their personal language skills, asked to assist with interpreting when required. Many issues had prevented this service from fully meeting identified needs: lack of timely availability, lack of medical terminology, lack of training as an interpreter, mismatches of interpreter and patient language base, role limited to basic linguistic interpretation, etc.

The new *Weecheewaywin* component is based on the following core elements:

2.1 Elders in Residence working in association with other providers, and who provide patient contact, support, education, and counseling as an integral element of the care plan. Two Elders are now fulfilling this role.

2.2 *Weecheewaywin* workers will build on an enhanced interpreter service, elements of the discharge planning function and patient navigator role. Available 24/7, the *Weecheewaywin* workers will assume a defined caseload and provide support to both patients, residents and clients, and to other members of the care team. They will ensure the required comfort, support, community interfaces, navigation, and non-clinical assistance are in place to minimize cross-cultural, institutional and health system barriers. They will specifically assure complete bi-directional cultural and linguistic interpretation to optimize care planning and delivery.

2.3 Translation of all core signage, client informational materials, notices (simultaneous with their English release) and other public materials will support the work of caregivers. Development and instruction in the use of a common lexicon will facilitate the work of interpreters/*Weecheewaywin* workers.

2.4 SLMHC will move beyond providing cultural awareness and training support for staff to a point where cultural diversity and fluency are embedded in the psyche of the organization and reflected in the behaviour of the staff.

2.5 Specific employment, education and staff supports will result in a balance in SLMHC staff that mirrors the First Nations/non-native make-up of the SLMHC service population with no discernible discrimination/ reverse discrimination.

2.6 We acknowledge the need for broad-based supports to ensure diagnostic and therapeutic understanding on the part of both provider and client and to ensure other significant needs of the client are identified.

3. *Andaw'Iwe Win* (healing practices):

Many of our patients, residents and other clients have indicated a desire for traditional healing practices to be available to support conventional SLMHC programs and services, or as an alternative to them. Many of these practices have been lost from common use in our communities. Our patients and many community leaders have expressed a desire for these services to be available for those who wish to access them. Experience in other settings demonstrates the value of providing the option of traditional healing approaches.

Andaw'Iwe Win 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. In addition to birth and palliative practices; smudging, healing circles and possibly other ceremonial practices will be introduced on-site prior to the construction of the new hospital (2010) with its additional ceremonial and support spaces. Sweat lodge ceremonies will be available for capable clients. Ultimately additional ceremonies will be available.³

Many ceremonies have an underlying spiritual character in addition to any physical, emotional or mental focus. We accept that the fundamental premise that individuals need to be whole (or healthy) in all aspects to be able to develop and maintain health in any one dimension. Consequently ceremonies supported by SLMHC will be an integral part of the care of individuals who seek that course of treatment/support.

A process of "certifying"⁴ healers will ensure that healers will be reviewed and "credentialed" to ensure appropriate qualifications and standards are in place.

4. *Mashkiki* (traditional medicines):

Traditional medicines have great curative properties and will be available to those who choose to use them. 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. The new facility (2010) will house both preparation and storage areas for a broad variety of medicines⁵. The site of the new facility was selected in part because of the prevalence of many of the medicines that will be used. Other medicines will be raised on site or acquired by healers as may be necessary. Specific

policies governing the use of traditional medicines will be developed. Consultation with Pharmacy and Therapeutics Committee of Medical staff, the Pharmacy Department, the Aboriginal Pharmacy Association of Canada, and others will be required before major enhancements are added.

5. *Miichim* (traditional foods):

Traditional foods⁶ have only been used on a very limited basis to date. Many of our clients are disadvantaged by the need to make a wholesale change in their eating practices and dietary content. A broad range of traditional foods is being added to the menu selections regularly available to patients and LTC residents. Preparation of these foods will require special handling in some instances. Regional variations and preferences in menu item, cooking style (fried, boiled, baked, roasted, dried, smoked, stewed, etc.) will be provided to the extent possible. Menu development and cooking instruction is being supported by Elders from several communities.

Special occasions will require additional traditional food items to be available.

6. Administrative Supports:

Secretarial and research support will be available to the program governance and leadership as required.

7. Program Supports:

The program is supported by a full-time THMFS Program Coordinator who oversees detailed program development, implementation, operations, and evaluation.

CONCLUSION

Achieving cultural integration institutionally is a challenge. Throughout the previous few years the Sioux Lookout Meno Ya Win Health Centre has proceeded broadly, yet with a focus, honouring both the journey and the destination.

The approach has arisen from research and broad community and Elder consultation. This model of care is intended to permeate throughout institutional programming. Patients will have choices to access traditional medicines and services. It is expected that this approach will address multiple access to care barriers, which are

intertwined with the twin legacies of “colonization” and “residential school,” and negatively impact the health of First Nations people. We continuously monitor health outcomes. In coming years, we may need to develop novel evaluation tools, which combine qualitative and quantitative methods, and provide more holistic outcome measures.

The THMFS Program at the Sioux Lookout Meno Ya Win Health Centre relies heavily on an understanding and philosophical foundation which is materially different than Euro-Canadian. This tradition may ultimately prove successful at addressing some of the root causes of the profound health status issues facing First Nations.

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END NOTES

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

2. Culturally congruent care is care that is beneficial and meaningful to the person being cared for, and fits within their needs and realities (Leininger, 1988).

3. SLMHC will ensure that birth, naming and dying practices, vigils, healing circles, smudging, singing and drumming, and other healing lodge ceremonies will be available as facilities permit. Sweat lodge ceremonies will be conducted from temporary facilities pending construction of a permanent sweat lodge facility close to the hospital. Some ceremonies need to be delivered over prolonged periods of time and in a specified location and may not be amenable to SLMHC-based support.

4. The Draft Guidelines for Traditional Healing Programs promulgated February 2002 by the Aboriginal Healing and Wellness Strategy will be followed.

5. In addition to herbal teas, wikenj, sage, tobacco, cedar, sweetgrass, etc. many other traditional medicines will added to those available on site.

6. Common foods will include herbal teas; bannock; a variety of fish; rabbit, moose, caribou, and other wild game; goose, duck and other water fowl; nogaiganny; wild rice; and other common foodstuffs will be available.



***Palliative Care in First Nations Communities:
Perspectives, Experiences and Educational
Needs of Medical Interpreters***

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1.0 - Acknowledgements

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2.0 - Executive Summary

The purpose of this project was to document current levels of awareness, understanding, and perceived access to palliative care among current and prospective First Nations medical interpreters based in Sioux Lookout, Ontario. The project also sought to document the interpreters' perceptions of community beliefs and values related to death and dying, the preferred place for receiving end-of-life care, and the service and educational needs. Lastly, this project provides reciprocal benefit to the interpreters and the clients they work with by providing palliative care education based on the identified needs of the interpreters.

Interpreters are an integral part of the provision of palliative and end-of-life care to First Nations people who access hospital care. First Nations people are dying of illnesses where they would benefit from the wholistic care that a palliative care approach offers; however, the end-of-life care needs of this population are not well understood and formalized programs on First Nations communities are virtually non-existent. There is also very little research on First Nations medical interpreters and the role that they play in the provision of culturally relevant and safe care. In order to address the palliative care needs of First Nations people, the needs of medical interpreters must be addressed.

This report includes a brief review of the existing literature about the health status of Aboriginal people in Canada, with a specific focus on older Aboriginal people and First Nations interpreters. It also presents the project findings based on the analysis of data gathered from 21 survey participants, and 20 focus group participants originating from at least 14 different First Nations communities in the Sioux Lookout Meno Ya Win Health Centre (SLMHC) catchment area in Northern Ontario. Survey and focus group participants represented the following groups: current medical interpreters employed at SLMHC, and medical interpreters enrolled in a college certificate program in Sioux Lookout, Ontario.

The findings are organized under four themes: awareness, understanding and perceived access to palliative care resources within First Nations communities; community values and beliefs related to death and dying and the preferred place for end-of-life care; service and educational needs of caregivers in First Nations communities; and the benefits of providing education targeted to the identified needs of the interpreters.

Awareness, Understanding and Perceived Access to Palliative Care Resources within First Nations Communities

Participants expressed a good understanding of palliative care. The majority of survey participants indicated that they would approach a family physician to obtain information on palliative care services. A majority of participants either personally cared for or knew of a family member who had provided care for someone who was dying. The majority of care was provided

outside of the home with some assistance from palliative care services. Participants estimated that 123 hours per week would be required to care for a dying loved one at home. About half indicated they could not devote the estimated amount of time given their current schedule.

Community Values and Beliefs Related to Death and Dying and the Preferred Place for End-of-Life Care

The majority of participants stated that talking about death and dying was acceptable in their community. Participants felt that traumatic death experiences overshadow the natural dying process, which resulted in less of an emphasis on end-of-life planning. A majority of participants believed that, if services were available and adequate, community members would choose to die at home. Participants also recognized that the health of their communities is undermined by addictions and the lack of medical services and that providing palliative care and a home death in the community seems out of the current realm of possibilities.

Service and Educational Needs of Community Caregivers in First Nations Communities

Focus group and survey participants detailed additional services or programs they felt are needed to improve the experience and care of people who are dying in their communities. Participants overwhelmingly saw a need for improved basic medical services in the communities. Additionally, participants spoke about the need for ongoing grief counselling and mental health services within the communities, and to support them in their own occupations. Finally, ongoing education and training was also a strong need for the interpreters and their communities.

The Benefits of Education Targeted to the Identified Needs of the Interpreters

The interpreters were provided twelve hours of palliative care education based on their needs identified in the initial survey. One of the benefits of the palliative education session according to participants was that it created a separation between natural expected palliative deaths, and unexpected and traumatic deaths. The sessions helped to clarify how to support expected death, and helped to create a vision for palliative care.

Recommendations

Based on the data, the report makes eight recommendations to begin to address the palliative care needs for the medical interpreters and First Nations people.

Recommendation 1:

Ensure that ongoing grief support and grief programming occurs for the interpreters.

Recommendation 2:

Provide ongoing opportunities for the interpreters to debrief in a group setting about their caregiving experiences.

Recommendation 3:

Hold palliative care staff development sessions facilitated by an experienced palliative care clinician for the interpreters every two months to apply knowledge gained from the palliative care education session held in November 2010.

Recommendation 4:

Include palliative care curriculum as part of the core training and educational curriculum for medical interpreters.

Recommendation 5:

Ensure other health professionals are educated on the roles of the medical interpreters.

Recommendation 6:

Continue to use the interpreters as cultural consultants for decision-making in the hospital.

Recommendation 7:

Ensure interpreters are integrated into the core health care team for both Aboriginal and non-Aboriginal clients.

Recommendation 8:

Work with community health teams and regional strategies to improve health care conditions in local First Nations communities.

3.0 - Literature Review

Canada's First Nations population is aging and the rates of chronic and terminal disease are increasing. First Nations people are dying of illnesses where they would benefit from the wholistic care that a palliative care approach offers; however, the end-of-life care needs of this population are not well understood and formalized palliative care programs on First Nations communities are rare. First Nations people, therefore have to access end-of-life care services in urban and regional hospitals outside of their communities. The removal from the communities creates many barriers, including language and cultural barriers, to quality care. The role of the medical interpreters is therefore vital to many individuals at the end-of-life.

Aboriginal people comprise approximately 3.8% of the Canadian population (Statistics Canada, 2008), and between 2001 and 2006 the population showed an increase of 20.1% (Statistics Canada, 2010). The Aboriginal population as a whole is young (Statistics Canada, 2010), and the population of registered Indians over the age of 55 is around 11.7%, compared to 25.3% of all Canadians (Statistics Canada, 2008). Average life expectancy is over 7 years less for registered Indians than it is for all Canadians (Indian and Northern Affairs, 2005).

Aboriginal people in Canada have higher risk factors for chronic disease than non-Aboriginal Canadians and show an increase in terminal disease and disability (Assembly of First Nations, 2007; Lix, Bruce, Sarkar, & Young, 2009; National Aboriginal Health Organization, 2002; Reading, 2009). In a self-reported study, rates of chronic disease and illnesses such as, heart disease, hypertension, arthritis/rheumatism, asthma and cancer were all reported as higher by First Nations than the general Canadian population (Assembly of First Nations, 2007; Health Canada, 2009). Diabetes rates are also at epidemic levels for Aboriginals in Canada, with nearly 20% being affected, and 88% reporting complications related to their diabetes (Assembly of First Nations, 2007; Health Canada, 2009). The health indicators clearly show a population at risk, and the numbers predict increasing care needs for Aboriginals in the coming years (Assembly of First Nations, 2005). Thus, the need for palliative care strategies to support Aboriginals at the end-of-life care is an undeniable need and social obligation.

In addition to geographical isolation, because of colonial impacts, socioeconomic isolation is a reality for First Nations communities. Medical services, equipment and supplies, and support workers are sparsely available in First Nations communities (Kelly & Minty, 2007; Parrack & Joseph, 2007). Access to medical care often requires either a flight or a long drive to neighbouring urban or rural hospitals (Prince & Kelley, 2010). Caregiver respite is often difficult to obtain, let alone formal medical care. Coupled with the absence of formal medical care, and supplies and equipment, First Nations communities also do not have adequate mental health services for families and caregivers to address lingering grief, anticipated grief and historical trauma (Hampton et al., 2010; Prince, Grinnell, & Kelley, 2010; Prince & Kelley, 2006). Regardless of this absence of formal care, Aboriginal people would prefer to receive palliative and end-of-life care in their communities (Prince, Grinnell, & Kelley, 2010; Prince & Kelley,

2006, Wilson et al., 2006), and from people they know (Durst & Bluechardt, 2001). However, the Canadian federal government responsible for funding First Nations health care does not consider palliative care funding in First Nations communities an essential element of health care for First Nations (Health Canada, 2010). Political jurisdictional issues further complicate these matters (Maritime Centre of Excellence for Women's Health, 1999).

It is no secret that hundreds of years of oppression and colonialism have damaged Aboriginal people and their communities' cultures and systems, some to a state of crisis. The reserve system and residential schooling had a devastating and lasting effect on traditional support systems in Aboriginal communities (Deiter, 1999; Jaine, 1995; Monture-Angus, 1999; Thomas-Prokop et al., 2004). Traditionally, Aboriginal communities have a high level of internal interdependence and support comes from this system of kinship and social relationships (Buchignani & Armstrong-Esther, 1999; Durst, 2006; Prince, Grinnell, & Kelley, 2010; Thomas-Prokop et al., 2004). The resilience of Aboriginal people is evident in the strong will to continue to provide care in a traditional community setting with the need for culturally appropriate care (Buchignani & Armstrong-Esther, 1999; Gahagan, Rehman, Loppie, Side, & MacLellan, 2004; NAHO, 2002; Prince & Kelley, 2006, Prince, Grinnell, & Kelley 2010; Thomas-Prokop et al., 2004). Death in the hospital setting is less preferable and care processes often fundamentally conflict with Aboriginal culture and worldviews (Hampton et al., 2010; Kaufert, 1999; Kaufert, Putsch, & Lavallee, 1999; Kelly & Minty, 2007; Prince, Grinnell, & Kelley, 2010). Although hospitals are beginning to work towards accommodating the wishes of Aboriginal people receiving end-of-life care (Kaufert & O'Neil, 1995; St Pierre-Hansen, Kelly, Linkewich, Cromarty, & Walker, 2010; Walker, 2009), the reality is that the community is still a preferable place for death. Despite this, most Aboriginal people will end up dying in the hospital, away from their communities.

It is clear from the literature that Aboriginal people in Canada are in a unique circumstance in relation to the provision of end-of-life care. Caregiving is most often informal, and limited formal services exist in First Nations communities to support people who want to die in their community. There is very little support for informal caregivers. Effects of colonialism and socioeconomic isolation have contributed to a lack of community care provided and the health status of Aboriginal people. Western medicine and worldviews often conflict with Aboriginal worldviews and systems of care, displaying a strong need for culturally appropriate and sensitive end-of-life care. As indicated by many authors and the lack of literature, much more research needs to occur in relation to the provision of end-of-life caregiving for First Nations.

Sioux Lookout Meno Ya Win Health Centre (SLMHC) Interpreter Program

The Sioux Lookout Meno Ya Win Health Centre is located in the Northwestern Ontario Municipality of Sioux Lookout. The Health Centre service area contains 23 000 First Nations residents with most coming from 28 remote northern First Nations communities. Concerning Aboriginal language, the Health Centre uses 3 distinct language families with about 19 separate dialects. Approximately 85% of individuals who access the hospital are First Nations and

language is an important priority as the majority of these individuals are fluent in their local Aboriginal language. Many of these individuals are unable to communicate in English (http://www.slmhc.on.ca/traditional_support_program/traditional_healing_support_program). Interpreters are therefore required on 24-hour basis (St Pierre-Hansen, Kelly, Linkewich, Cromarty, & Walker, 2010).

The Health Centre recognizes that language and culture are inextricably linked. Cross-cultural patient safety is a concern, as information from medical professionals must first pass through the language and cultural filters of the translators, patients and their families (Walker, 2009). Different understandings of the end-of-life process between the western medical model and the Aboriginal worldview can create disharmony during the dying process. The western model “treat[s] the death experience in a technical manner” whereas “traditional Aboriginal understandings of death depict death as a transition from Mother Earth” and as a process involving family and ceremony to make the transition (Hampton et al., 2010, p. 12). The medical interpreter program at Sioux Lookout Meno Ya Win Health Centre is therefore enhancing the role of the interpreters to include assisting with discharge planning, patient navigation and providing support to clients and members of the health care team (http://www.slmhc.on.ca/traditional_support_program/traditional_healing_support_program).

Although some First Nation people require the use of interpreters while receiving medical care, very few studies document their involvement in the provision of end-of-life care. One study by Kaufert, Putsch & Lavallee (1999) details the communications barriers that arise from the use of interpreters, and how interpretation affects the end-of-life care experience. Although medical interpreters are supposed to remain neutral in their transmission of a message between professional and patient, this often is not the case (Hsieh, 2006). Cross-cultural differences influence this experience, especially in relation to delivering “bad-news” (Kaufert, 1999). One example of this barrier comes from Walker (2009) when he writes, “an old man died in hospital – not unexpectedly...except to the family”, as the family had not understood the explanations from the doctor (p. 10). For circumstances like these, it is clear that more research into the area of interpretation and its relationship to end-of-life care for First Nations people is required.

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First Nations women's knowledge of menopause

Experiences and perspectives

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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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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 Blackfoot 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

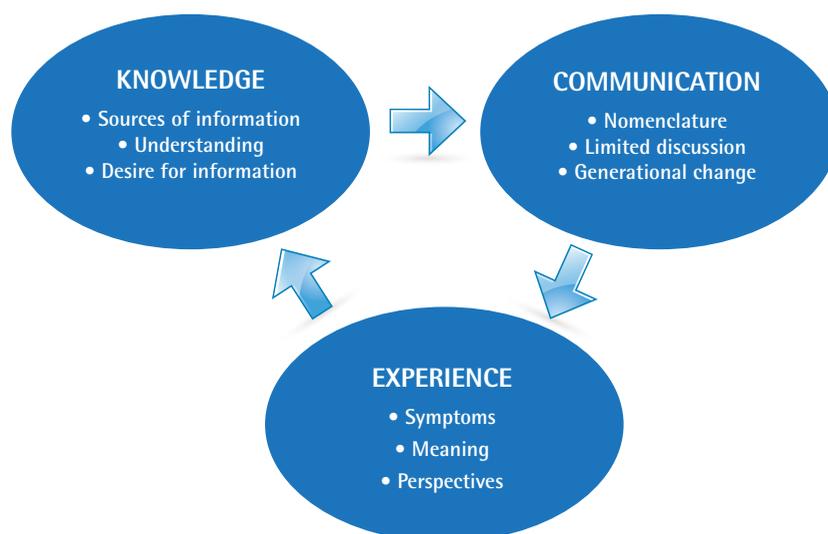
Most participants described menopause as something that was not discussed:

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." ❁

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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

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

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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

Competing Interests: None declared.

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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 comptaient 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, Sauteaux, 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)



Sioux Lookout Meno Ya Win Health Centre. Used with permission.

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

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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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Are women with psychosis receiving adequate cervical cancer screening?

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ABSTRACT

OBJECTIVE To investigate the rates of cervical cancer screening among female patients with psychosis compared with similar patients without psychosis, as an indicator of the quality of primary preventive health care.

DESIGN A retrospective cohort study using medical records between November 1, 2004, and November 1, 2007.

SETTING Two urban family medicine clinics associated with an academic hospital in Toronto, Ont.

PARTICIPANTS A random sample of female patients with and without psychosis between the ages of 20 and 69 years.

MAIN OUTCOME MEASURES Number of Papanicolaou tests in a 3-year period.

RESULTS Charts for 51 female patients with psychosis and 118 female patients without psychosis were reviewed. Of those women with psychosis, 62.7% were diagnosed with schizophrenia, 19.6% with bipolar disorder, 17.6% with schizoaffective disorder, and 29.4% with other psychotic disorders. Women in both groups were similar in age, rate of comorbidities, and number of full physical examinations. Women with psychosis were significantly more likely to smoke ($P < .0001$), to have more primary care appointments ($P = .035$), and to miss appointments ($P = .0002$) than women without psychosis. After adjustment for age, other psychiatric illnesses, number of physical examinations, number of missed appointments, and having a gynecologist, women with psychosis were significantly less likely to have had a Pap test in the previous 3 years compared with women without psychosis (47.1% vs 73.7%, respectively; odds ratio 0.19, 95% confidence interval 0.06 to 0.58).

CONCLUSION Women with psychosis are more than 5 times less likely to receive adequate Pap screening compared with the general population despite their increased rates of smoking and increased number of primary care visits.

EDITOR'S KEY POINTS

- The goal of this study was to assess the quality of primary care for women with severe mental illness; this was achieved through comparing rates of Papanicolaou screening among women with psychosis with the rates among women without psychosis. These female patients were from 2 urban family practice clinics affiliated with a teaching hospital serving an inner-city population in Toronto.
- Women with psychosis are less likely to receive adequate Pap screening.
- This study shows an important disparity in the provision of cervical cancer screening between women with and without psychosis. Further action is needed to increase cervical cancer screening among women who are diagnosed with mental illnesses.

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Research | Are women with psychosis receiving adequate cervical cancer screening?

Cervical cancer was once the leading cause of cancer death for women. However, mortality and morbidity of this disease have decreased substantially since the advent of widespread screening using Papanicolaou tests.¹ In Canada, age-standardized mortality rates from invasive cervical cancer decreased from 7.4 per 100 000 in 1969 to 2.4 per 100 000 in 1992. Cervical cancer incidence rates also decreased from 21.6 per 100 000 in 1969 to 10.4 per 100 000 in 1990.² From 1992 to 2001, there were further reductions in both incidence and mortality.³

The greatest risk factor for developing cervical cancer is infection with a high-risk human papillomavirus (HPV) type.¹ Another considerable risk factor is never having been screened or being underscreened.³ Factors such as smoking, low socioeconomic status, higher number of sexual partners, younger age at first sexual intercourse, and unsafe sexual behaviour of the woman's male partners also increase risk.⁴

Women with schizophrenia and psychosis might be at particularly high risk of cervical cancer: People with mental illnesses tend to be of lower socioeconomic status; 85% of people with schizophrenia smoke compared with 23% of the general population⁵; and people with schizophrenia have been found to have excess mortality compared with the general population, owing to differences in access to and use of health care services,⁶ as well as to decreased quality of treatment received within the health care system.⁵ Furthermore, women with schizophrenia and psychosis have a high lifetime incidence of sexual abuse (69%),⁷ which could confer a greater risk of cervical cancer owing to forced sexual activity. Women with mental illness have also been reported to have had more sexual partners in their lifetime than age- and race-matched controls.⁸

Results of a handful of US studies in this area have been inconsistent. One study examined the self-reported use of gynecological services including Pap screening and mammograms in older women with schizophrenia compared with women without schizophrenia. Women with schizophrenia reported significantly lower rates of Pap screening and mammography compared with controls (71% vs 96% for Pap screening, $P = .001$; 68% vs 98% for mammography, $P < .001$).⁹ Another study, which assessed Pap screening and other preventive care measures also through self-reporting among women with schizophrenia and schizoaffective disorder, found a very high overall rate of Pap screening with no difference between groups.¹⁰ However, both studies were limited by relying on self-reported data, convenience sampling, and a lack of age comparability between groups.

To our knowledge, no Canadian study has assessed whether women with schizophrenia and psychosis receive adequate screening for cervical cancer compared with women without psychosis. As Pap tests are an integral part of preventive medicine, rates are likely to

correlate with the general level of primary care that these women receive. The aim of this study was to investigate the quality of primary health care received by women with psychotic conditions at urban primary care centres compared with their counterparts by measuring adequacy of cervical cancer screening using retrospective chart review. Adequacy of cervical cancer screening was defined as having at least 1 Pap test in a 3-year time period.

METHODS

We conducted a retrospective cohort study using medical records at 2 urban family medicine clinics associated with St Michael's Hospital, a large teaching hospital that services the inner-city population of Toronto, Ont. All eligible women with psychosis (ie, cases) were identified using Ontario Health Insurance Plan physician billing codes for clinic visits, occurring between November 2006 and November 2007, associated with diagnoses of schizophrenia, bipolar disorder, schizoaffective disorder, or psychosis not yet determined. A random sample of women without any billing codes for psychosis (ie, noncases) were frequency-matched to cases according to 5-year age strata using a 2-to-1 ratio. The case or noncase status of each patient was confirmed through a diagnosis, or lack thereof, of a psychotic disorder (ie, schizophrenia, bipolar disorder, schizoaffective disorder, or psychosis not yet determined) documented on the chart. Inclusion criteria for all subjects were the following: women aged 20 to 69 years, at least 1 visit to the clinic between November 2006 and November 2007, and being a patient at the clinic for at least 4 years (determined by record of at least 3 visits between November 1, 2004, and November 1, 2007). Exclusion criteria consisted of record of hysterectomy at any time or a history of abnormal Pap test results prior to November 1, 2004.

The number of Pap tests performed between November 1, 2004, and November 1, 2007, was recorded, as well as where the Pap tests were performed (at the family medicine clinics vs another location) and who performed them (family physician vs gynecologist). The following information was also recorded during the study period: age; any psychiatric diagnosis; use of antipsychotic or mood-stabilizing drugs; comorbidities; smoking status; and number of clinical visits, missed appointments, and full physicals. One researcher (D.T.) reviewed all charts.

The traditional $P < .05$ level was used for all significance testing. Data analyses included descriptive statistics as well as unconditional logistic regression to identify independent determinants of cervical cancer screening. Variables that could be associated with cervical cancer screening and that would be available on chart review were determined by a priori judgment. For inclusion in the final multivariable model, variables were selected

using a backward selection procedure with a liberal *P* value of .30 and confirmed using a forward selection procedure. All statistical analyses were performed using SAS, version 9.1. Ethics approval was received from the Research Ethics Board at St Michael's Hospital.

RESULTS

There were 228 charts (ie, 69 female patients with psychosis and 159 female patients without psychosis) initially identified; of these, 59 charts were excluded (Figure 1). The final sample consisted of 51 female patients with psychotic conditions (ie, cases) and 118 female patients without such conditions (ie, noncases). Most of the women in the cases group (62.7%) had a diagnosis of schizophrenia (Table 1). Women in both groups were similar in terms of age, rates of comorbid medical illness and comorbid nonpsychotic psychiatric illness, and addictions to cocaine and opioids. Despite incomplete information in medical records on smoking status, the women in the cases group were significantly more likely to smoke than the women in the noncases group (51.0% of cases vs 20.3% of noncases, *P*<.0001).

Table 2 shows descriptive characteristics of the number of Pap tests completed and other clinical visit variables by case and noncase status. Women with psychosis had fewer Pap tests compared with women without psychotic conditions, with 47.1% versus 73.7% having had at least 1 Pap test in the 3-year study period, respectively. Of the 58 charts without recorded Pap tests, 6 of them

had reasons noted (ie, "declines," "refuses," "deferred," "not necessary," or "will do at gynecology clinic and send result"). Women with case and noncase status had a similar number of full physical examinations, with 33.3% versus 36.4% having had at least 1 full physical examination, respectively. Differences were seen in terms of the total number of clinical visits and number of missed appointments during the study period. Although more women with noncase status had gynecologists, more than 80% of Pap tests were completed by family physicians among women in both groups.

Table 3 presents results of multivariable logistic regression modeling. After adjustment for age, other psychiatric illnesses, number of physical examinations, number of missed appointments, and having a gynecologist, women with psychosis were significantly less likely to have had adequate screening compared with women without psychosis (odds ratio 0.19, 95% confidence interval 0.06 to 0.58). Younger age (*P*=.04), having a gynecologist (*P*=.03), and a higher number of full physical examinations (*P*<.0001) were also significantly associated with adequate cervical cancer screening in the final model.

DISCUSSION

The primary aim of this study was to assess the quality of primary care for women with severe, persistent mental illness. This was achieved through comparing rates of Pap screening among women with chronic psychotic illnesses with the rates among women without

Figure 1. Exclusion of ineligible charts from the 228 initially identified: Patients with psychosis (ie, cases) and patients without psychosis (ie, noncases).

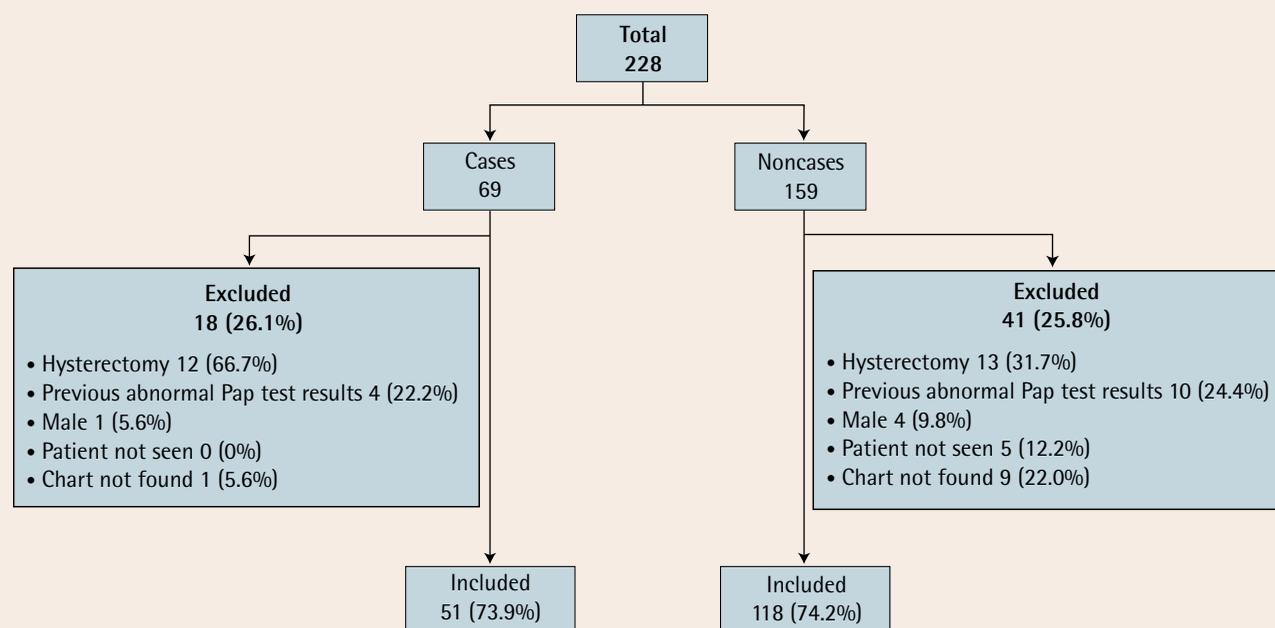


Table 1. Patient characteristics: Mean (SD) age was 47.8 (9.7) years for women with psychosis (ie, cases) and 47.0 (11.0) years for women without psychosis (ie, noncases) (P = .067).

VARIABLES	CASES (N = 51) N (%)	NONCASES (N = 118) N (%)	P VALUE*
Psychotic condition			
• Schizophrenia	32 (62.7)	0	
• Other psychotic disorder	15 (29.4)	0	
• Bipolar disorder	10 (19.6)	0	
• Schizoaffective disorder	9 (17.6)	0	
Other psychiatric comorbidity [†]	15 (29.4)	35 (29.7)	.97
Chronic comorbidity [‡]	31 (60.8)	78 (66.1)	.51
Opioid or cocaine addiction	3 (5.9)	5 (4.2)	.70
Smoking history			
• Current smoker	26 (51.0)	24 (20.3)	<.0001
• Not recorded	9 (17.6)	26 (22.0)	

NA—not applicable.

*P value for student *t* test, Pearson χ^2 test, or Fisher exact test comparing cases and noncases.

[†]Other nonpsychotic psychiatric comorbidities included the following: attention deficit hyperactivity disorder, anxiety, depression, eating disorder, mental retardation, obsessive compulsive disorder, panic disorder, personality disorder, and posttraumatic stress disorder.

[‡]Chronic comorbidities included the following: anemia, asthma, coronary artery disease, cancer, celiac disease, cholecystitis, chronic pain, chronic renal failure, Crohn disease, chronic obstructive pulmonary disease, cerebrovascular disease, diabetes, endometriosis, fibromyalgia, hepatitis C, HIV or AIDS, hypercholesteremia, hypertension, mitral valve prolapse, osteoarthritis, osteoporosis, pancreatitis, polycystic ovary syndrome, rheumatoid arthritis, seizure disorder, tardive dyskinesia, and thyroid disease.

such diagnoses at 2 primary care clinics that serve a large inner-city population in Toronto. We found that the screening rate for women without psychosis in this study (73.7%) was similar to a previously reported rate of 70.3% for Toronto.¹¹ Women with psychotic illnesses had a screening rate of 47.1%, and thus substantially lower odds of receiving appropriate cervical cancer screening (81% or 5.3 times lower odds). This finding is in keeping with previous research showing that people with schizophrenia are less likely to receive adequate primary health care.³ Previous studies relying on self-reported data among older women with and without psychosis in the United States have reported mixed results on rates of cervical cancer screening.^{9,10} To our knowledge, no previous study in Canada has examined Pap screening in this population.

In this study, the women in the 2 groups were similar in key respects, including age, rates of comorbid medical illness, nonpsychotic psychiatric illness, substance abuse, and total number of full physical examinations. There was a significant difference in smoking rates between

Table 2. Characteristics of Papanicolaou tests and clinical visits of women with psychosis (ie, cases) and women without psychosis (ie, noncases)

CHARACTERISTICS	CASES (N = 51), N (%)	NONCASES (N = 118), N (%)	P VALUE*
No. of Pap tests			.008
• 0	27 (52.9)	31 (26.3)	
• 1	14 (27.5)	47 (39.8)	
• 2	8 (15.7)	27 (22.9)	
• ≥ 3	2 (3.9)	13 (11.0)	
Pap test collected by [†]			.903
• family physician	20 (83.3)	74 (86.0)	
• gynecologist	2 (10.0)	7 (8.1)	
• both	2 (10.0)	5 (5.8)	
Has a gynecologist	4 (7.8)	23 (19.5)	.058
No. of full physical examinations			.198
• 0	25 (49.0)	42 (35.6)	
• 1	17 (33.3)	43 (36.4)	
• ≥ 2	9 (17.6)	33 (28.0)	
No. of clinical visits			.035
• 1-9	6 (11.8)	32 (27.1)	
• 10-14	13 (25.5)	35 (29.7)	
• ≥ 15	32 (62.7)	51 (43.2)	
No. of missed appointments			.0002
• 0	13 (25.5)	62 (52.5)	
• 1-2	15 (29.4)	36 (30.5)	
• ≥ 3	23 (45.1)	20 (16.9)	

*P value for Pearson χ^2 test comparing cases and noncases.

[†]In this category, n = 24 for the cases group; n = 86 for the noncases group.

Table 3. Variables associated with having at least 1 Papanicolaou test: Reported associations are adjusted for all other variables listed in the table.

VARIABLE	OR (95% CI)	P VALUE
Psychosis case	0.19 (0.06-0.58)	<.001
Age	0.95 (0.91-1.00)	.04
Other psychiatric illness	0.53 (0.18-1.56)	.25
Has gynecologist	4.99 (1.22-20.46)	.03
No. of full physical examinations	27.38 (9.54-78.54)	<.0001
No. of missed appointments		
• 0 (referent)	1.00	
• 1-2	2.52 (0.73-8.76)	.64
• ≥ 3	3.67 (1.09-2.37)	.14

CI—confidence interval, OR—odds ratio.

cases and noncases ($P < .0001$), in line with previous research indicating that people with schizophrenia are more likely to smoke.¹ Most of the women with case

status used antipsychotics or mood stabilizers; few women with noncase status used these medications. This finding is also expected, as women with psychosis have a clear indication for these medications. The difference in the use of health care services between the 2 groups, specifically both more appointments and missed appointments among the women in the cases group, is not surprising given the burden of illness and disorganization facing women with serious chronic mental illness.

One potential barrier to adequate screening for women with psychosis could be the high time demand for treating acute mental illness, which might supersede screening. Illness-related factors such as delusions and paranoia might adversely affect Pap test rates. Physician-related factors such as fear of being incorporated into a patient's delusions, fear of misunderstanding regarding an invasive procedure, and issues with patient hygiene might also account for some of the disparity in screening rates. Finally, patient-related factors such as understanding of the procedure and its risks and benefits might also be contributors to inadequate screening rates.

Limitations

This study has several limitations. Low screening rates have been associated with race, low income, low education, foreign language, and recent immigration.³ These potential confounders were not identifiable from medical records. However, the 2 family medicine sites were selected owing to their urban inner-city populations with high rates of patients with low socioeconomic status, recent immigration, and homelessness. Therefore, it might be reasonable to assume that these factors were similarly prevalent among both groups of women. Furthermore, the 2 clinics studied are closely connected and associated with the same large academic centre dedicated to providing inner-city care. The results might not be generalizable to family medicine clinics in other urban or rural settings or to clinics not specializing in inner-city primary care. Finally, because of the small number of women with psychosis, we were unable to conduct analyses stratified by psychotic condition.

Nonetheless, our finding that women with psychosis are being significantly underscreened for cervical cancer is an important one. Women with psychosis might be at greater risk of invasive cervical cancer owing to higher rates of smoking,¹ lifetime incidence of sexual assault,² and risky sexual behaviour associated with manic episodes; therefore, screening might be even more important in this group than in the general population.

Further directions for research would involve confirming these findings in other primary care settings. Collecting information on potential confounders such as race, immigration, income, and education would prove valuable. It might also be useful to compare rates of cervical cancer screening among women with psychotic illnesses with those among women with chronic

medical illnesses (eg, diabetes) to determine whether a chronic illness in general lowers screening rates rather than psychotic illness specifically.

Conclusion

This study adds to a limited body of research that examines patterns of use of primary care services among persons with severe mental illness and shows a serious disparity in the provision of cervical cancer screening to women with and without psychosis. In our setting, women with psychosis, who are likely at higher risk of cervical cancer, were 81% less likely to have adequate Pap screening compared with their otherwise similar counterparts. Considering that this study took place in a setting that specifically aims to provide primary care to people with severe mental illness, it is possible that other clinical settings might have even lower rates of cervical cancer screening for this population. Based on the unacceptably low rate of cervical cancer screening, one might infer that women with psychosis are receiving inadequate primary health care overall. Further action needs to be taken to increase cervical cancer screening in this population and to determine whether other primary health care measures are adequately provided to people with psychosis. 

Dr Tilbrook was a locum physician in the Department of Family and Community Medicine at St Michael's Hospital in Toronto, Ont, at the time of writing this paper. She is currently on locum in New Zealand. **Ms Polsky** is a research associate and **Dr Lofters** is a physician, both in the Department of Family and Community Medicine at St Michael's Hospital.

Contributors

Dr Tilbrook is the principal investigator for this study. She contributed to concept and design, all data abstraction, and data interpretation. She drafted the original manuscript and contributed to its revision and editing. **Ms Polsky** contributed to the research concept and design. She performed the regression analysis and contributed to manuscript revision. **Dr Lofters** was involved in the concept and design of the study. She made substantial contributions to data analysis and manuscript revision. All authors approved the final version of the manuscript.

Competing interests

None declared

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The occasional management of narcotic exposure in neonates

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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.^{12,15}

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 Lipsitz 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.³⁵ 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.³⁵ 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.^{8,44,45} 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.

Competing interests: None declared.

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Narcotic-exposed neonates in a First Nations population in northwestern Ontario

Incidence and implications

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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 ($P = .005$).

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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.*

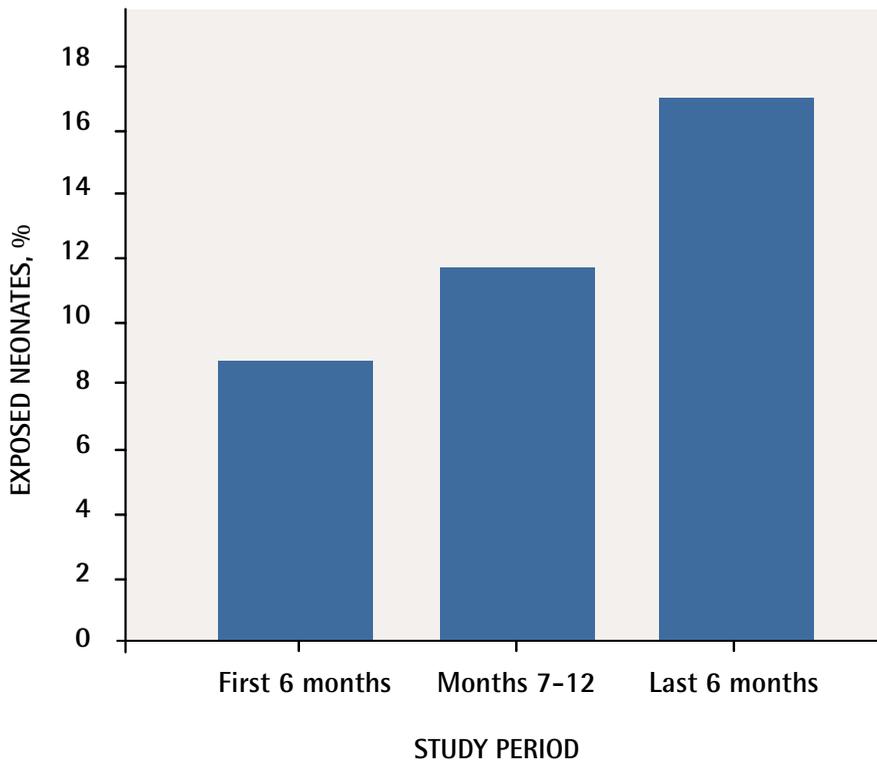
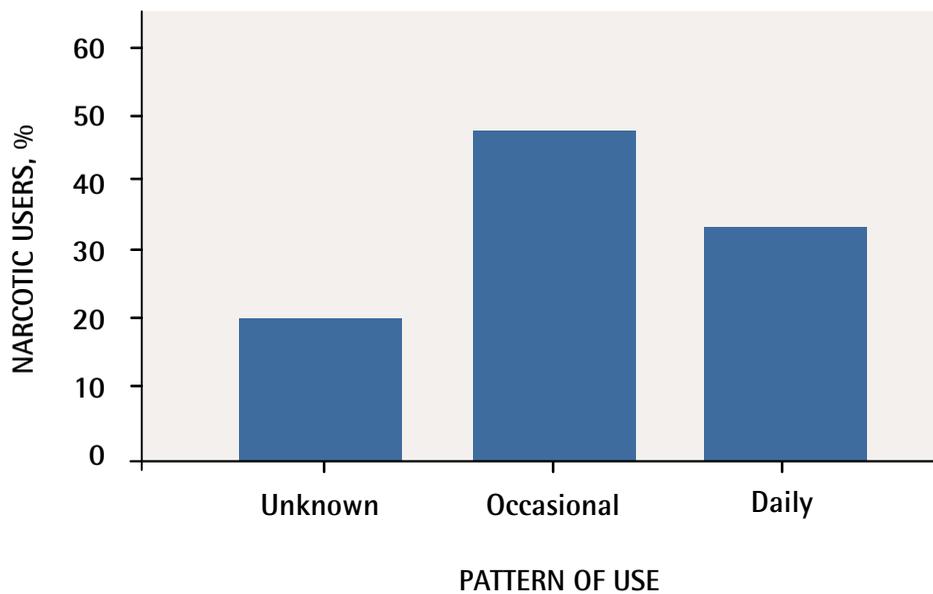


Figure 2. Patterns of narcotic use (n=61)



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)	P VALUE*
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.

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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

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Gallbladder disease in northwestern Ontario: the case for Canada's first rural ERCP program

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Introduction: The rate of cholecystectomy in northwestern Ontario is double the provincial rate. This paper explores the demographics of cholecystectomy and the role for rural endoscopic retrograde cholangiopancreatography (ERCP) services in the central part of this region.

Methods: We conducted a literature review of ERCP services and cholecystectomy rates, as well as a hospital chart review of patients who underwent laparoscopic cholecystectomies in Sioux Lookout, Ont. We contacted surgeons and gastroenterologists from referral centres in Winnipeg, Man., and Thunder Bay, Ont., for the charts of patients from our catchment area who underwent ERCP.

Results: Patients in our region who require urgent and emergent surgery are flown by fixed-wing aircraft to referral centres in Winnipeg and Thunder Bay for assessment and surgery. The rate of ERCP in our population is 150 in 100 000, which is threefold that of other populations, and our cholecystectomy rate is the highest in Ontario.

Conclusion: Substantial savings in transportation expenses would offset the development costs of an ERCP program and provide more integrated patient care. The volume of patients would support maintenance of competency. This rural area with a high rate of gallbladder disease would benefit from the development of a rural ERCP program.

Introduction : Le taux de cholécystectomie dans le nord-ouest de l'Ontario est deux fois plus élevé que celui de la province dans son ensemble. Cet article explore les caractéristiques démographiques de la cholécystectomie et le rôle des services ruraux de cholangiopancréatographie rétrograde endoscopique (CPRE) dans le centre de cette région.

Méthodes : Nous avons effectué une étude documentaire des services de CPRE et des taux de cholécystectomie, ainsi que des dossiers hospitaliers des personnes qui ont subi une cholécystectomie par laparoscopie à Sioux Lookout (Ont.). Nous avons communiqué avec des chirurgiens et des gastroentérologues de centres de référence à Winnipeg (Man.) et Thunder Bay (Ont.) pour obtenir les dossiers des patients de notre bassin qui ont subi une CPRE.

Résultats : Les patients de notre région qui ont besoin d'interventions chirurgicales d'urgence et d'extrême urgence sont transportés par avion à des centres de référence à Winnipeg et Thunder Bay pour évaluation et chirurgie. Le taux de CPRE dans notre population s'établit à 150:100 000, ce qui est trois fois plus élevé que celui d'autres populations, et notre taux de cholécystectomie est le plus élevé en Ontario.

Conclusion : Des réductions importantes des dépenses en frais de transport compenseraient les coûts d'établissement d'un programme de CPRE et fourniraient aux patients des soins mieux intégrés. Le volume des patients appuierait le maintien de la compétence. Cette région rurale qui a un taux élevé d'affections de la vésicule biliaire bénéficierait de l'établissement d'un programme rural de CPRE.

INTRODUCTION

This paper explores the demographics of cholecystectomy and the role for a rural endoscopic retrograde cholangiopancreatography (ERCP) service in northwestern Ontario. We hypothesized that it would be economically feasible to establish an ERCP program in our rural hospital based on geography, patient demographics, current and expected surgical volumes, and past referral patterns.

The rate of cholecystectomy in the Kenora–Rainy River District of northwestern Ontario is double the provincial rate.¹ A large part of the Kenora–Rainy River District is served by the Sioux Lookout Meno Ya Win Health Centre, which has a vast service area of 385 000 km² (roughly one-third of Ontario's land mass). The 30 000 population served by our catchment area is 82% First Nation,² a population known to have high rates of gallbladder disease.³

Urgent and emergent surgery involves an airplane medevac from a remote northern community to Sioux Lookout, Ont., for assessment and surgery. If more specialized surgery or anesthesia are required, the patient is flown 300 km to a referral centre in Thunder Bay, Ont., or Winnipeg, Man. We presently have a full complement of 2 general surgeons funded through the Northwestern Ontario Regional Surgical Network who perform laparoscopic cholecystectomies but not ERCPs.

METHODS

Literature review

To understand the feasibility of an ERCP service in our area, we undertook a literature search on MEDLINE and Embase, 1950–present, for cholangiopancreatography, endoscopic retrograde; incidence; practice guideline; and quality control. We searched for cholecystectomy rates in publications of the Institute for Clinical Evaluative Sciences.

Chart reviews

We reviewed the hospital charts of all patients who underwent laparoscopic cholecystectomies in Sioux Lookout in the 2-year period from April 2007 to April 2009. Referral tertiary care surgeons and gastroenterologists in Winnipeg and Thunder Bay were contacted for the charts of ERCP patients from our catchment area, who were identified by postal codes. Ethics approval was granted by the Meno Ya Win Research Review Committee.

RESULTS

Literature review

We reviewed a total of 439 abstracts and chose 25 articles based on relevance to our setting.

Provincial trends in cholecystectomies

Historically, laparoscopic cholecystectomies began in Sioux Lookout in 1992, with 100 performed annually, each with an intraoperative cholangiogram.

A 2005 analysis of the global increase in cholecystectomy surgery with the introduction of laparoscopic technique in the 1990s found a subsequent reduction in the rate of acute cholecystitis because of earlier surgical intervention.⁴

The regional rate of laparoscopic cholecystectomies in Sioux Lookout is now the highest in the province (Table 1^{5,6}). Since the introduction of laparoscopic cholecystectomies in the 1990s, times have changed again with the development of ERCP. Currently, any suggestion of stone in the duct or cholestatic increase in hepatic enzymes generally warrants an ERCP precholecystectomy, and intraoperative cholangiograms have become dramatically less common.

Trends in ERCP

Use of ERCP reached its peak in the United States in 1995, with a threefold increase from 1988.⁷ It has declined since then. Much of that decline is because of decreased use of ERCP for diagnostic purposes when safer options exist: endoscopic ultrasonography and magnetic resonance cholangiopancreatography (MRCP). Most ERCPs are now done for therapeutic indications.^{8,9} From 2002 to 2007, indications for the procedure changed dramatically. Stone retraction accounted for 94% of ERCPs in 2007 but only 38% in 2002.^{8,10}

Table 1. Characteristics of laparoscopic cholecystectomy in Ontario in 1990 and 1994

Characteristic	1990	1994
Length of stay, d ⁵	7.5	2.6
Conversion to open surgery, % ⁶	NA	5.3
Bile duct injury, % ⁶	NA	1.16
LC rate, Ontario ¹	311/100 000	339/100 000
LC rate, northwestern Ontario ¹	503/100 000	534/100 000

LC = laparoscopic cholecystectomy; NA = data not available.

Presently, the international rate of ERCPs pre-cholecystectomy is between 7% and 17%,^{9,11} and the annual US population rate is 50 in 100 000.⁷ Rates of post-ERCP pancreatitis vary internationally from 4% to 15%.^{12,13}

A 10-year prospective analysis of a rural ERCP program in West Australia¹² was the only program identified as rural. This series of 700 consecutive ERCPs in a catchment area serving a population of 26 000 over 10 years demonstrated a 94% success rate and 4% pancreatitis rate. Seventy-eight percent were done for therapeutic reasons, mostly stone retrieval.¹¹

Training in ERCP

ERCP is one of the “most technically demanding and highest risk procedures performed by endoscopists.”¹⁴ Training therefore requires the documented performance of a substantial volume (100¹⁵–200¹⁴) of successful (> 80% cannulations¹⁶) procedures for the training fellow. The present clinical training climate also favours therapeutic over diagnostic procedures.¹⁶ Training benchmarks for an experienced endoscopist for ERCPs are undocumented. Maintenance of competency is felt to require at least 50 procedures annually.^{16,17} The proposed competency threshold for sphincterotomies is 40–80 successful procedures.^{14,17}

A review of 199 625 inpatient ERCPs in the US from 1998 to 2001 demonstrated that 70% of inpatient ERCPs in the US are done in hospitals that perform fewer than 100 procedures annually, and the mean number of inpatient ERCPs is 48 per hospital per year.⁸ Numbers do not tell the whole story. Competence is widely agreed to rely on documented successful procedures and complication records of individual providers.¹⁸

First Nation patients and gallbladder disease

First Nation patients are known to have high rates of gallbladder disease in many constituencies in North America:⁵ Micmac in Nova Scotia,¹⁹ Ojibwa and Cree of Manitoba²⁰ and Ontario,⁵ Chippewa in Minnesota²¹ and Pima in Arizona.²² Genetic and environmental factors are involved. Traditionally, pregnancy, obesity and female sex are associated with gallbladder disease. Biochemical analyses of bile assays in First Nation patients in the 1970s noted “lithogenic bile.”^{23,24} Early and increased multiparity in many First Nation women accompanied by a Western diet high in calories and low in fibre also predispose First Nation people to risk for gallblad-

der disease.²⁴ Metabolic syndrome, a defined constellation of obesity, type 2 diabetes, hypertension and hypercholesterolemia may also play a role.⁵

A 1984 study in Manitoba that compared First Nation people to the general population found that First Nation women with gallbladder disease had a younger mean age (39.9 v. 52 yr).¹⁹ The latter age is consistent with other non-Aboriginal series that identify the mean age of women with gallbladder disease as 46–52 years.^{25–28} In 1989, a community-based research initiative in northwestern Ontario and northern Manitoba First Nation communities demonstrated a prevalence of all gallbladder disease of 18.5% in women aged 20–64 years.⁵ At that time, the mean age of women with gallbladder disease in Canada was 42.4 years. Interestingly, total cholesterol and low-density lipoprotein were lower in patients with gallbladder disease, compared with patients without gallbladder disease.⁵ There was also no association with obesity or diabetes in the 395 cases studied.⁵

Chart reviews

Cholecystectomy and ERCP in Sioux Lookout

From 2007 to 2009, 74 cholecystectomies were performed annually in Sioux Lookout. Because we have recently recruited our second surgeon to complete our complement, we expect this number will increase. In the first quarter of 2009 we had already performed more than 50 laparoscopic cholecystectomies, and we anticipate we will soon be performing more than 200 procedures annually. Of the patients who underwent cholecystectomy in the 2-year time frame, 14% required an ERCP ($n = 21$ interventions in 17 patients). Patient characteristics are shown in Tables 2 and 3.

ERCP in patients from our catchment area

A survey of our referral centres in Winnipeg and Thunder Bay found a 2-year total of 89 ERCPs performed

Table 2. Sex of 148 patients who underwent laparoscopic cholecystectomy in Sioux Lookout from 2007 to 2009, by age

Age, yr	Male	Female
< 18	1	8
18–44	15	90
45–64	16	13
≥ 65	4	1
Total	36 (25%)	112 (75%)

on patients from our catchment area, showing an annual rate of 150 in 100 000. This number included the 21 procedures mentioned above and patients who were referred to a tertiary care centre for both ERCP and cholecystectomy.

Patient transportation

Medical transportation of patients was important because the 148 patients who underwent cholecystectomies and ERCPs during this 2-year period required an average of 2.2 medevacs per patient. These medevacs are by airplane with air ambulance paramedics in attendance. The 17 ERCP patients alone had an average of 6 medical transportations, because their care was initiated in a northern community and progressed to Sioux Lookout for diagnosis and referral, at an average cost of \$3200 per flight (Dr. Jonathon Morgan, medical director, northern region, Ornge, Sioux Lookout; personal communication: 2010). They were then transferred to and from a tertiary care centre for ERCP and then for a postoperative observation period before their cholecystectomies were performed in Sioux Lookout, often with an intervening trip back to their home community.

DISCUSSION

The cholecystectomy patients in our catchment area were more numerous and younger than those in all other reported estimates.

The mean age of our female patients was 32 years. This is much younger than a similar population in northern Manitoba studied in 1984, which had a mean female age of 39.4 years.¹² Both of these findings contrast with the generally quoted mean female age of 46 to 52 years.^{12,25-28}

The largest demographic age group in our population profile is 10–14 years of age, with 35% of our population under age 15.² Because we have no reason to anticipate a decline in multiple parity, obesity

and type 2 diabetes, the incidence of gallbladder disease will likely remain high.

Other than being younger, our patients were similar to those studied in our region by Young and Roche³ in 1984. Our patients' average total cholesterol was 4.3 mmol/L, which was lower than the values Young and Roche found. This is consistent with Young and Roche's observation that total cholesterol values were inversely correlated with gallbladder disease. They also found high rates of hypertension and diabetes.³

Our patients travelled great distances for medical care. Because patients need to be transported to Sioux Lookout for assessment, diagnosis and triage, the provision of complete surgical care at that site would be optimal.

Transportation for ERCP services in our region is very expensive. Simply eliminating 5 of the 6 medevacs our 17 ERCP patients each incurred in the past 2 years could have saved more than \$272 000. The potential savings on 40–50 of the 89 ERCPs done on patients from our region would be greater.

Shorter lengths of stay in hospital, which are now spread between 2 hospitals (including a 3- to 5-day stay awaiting the tertiary care hospital's "ERCP day"), would also decrease global costs.

Global cost savings from each of the above would more than compensate for the training and equipment costs involved in having one of our surgeons learn ERCP skills.

The challenge of a rural ERCP program would be in surgical capacity. For a program to have sufficient volume for maintenance of ERCP competency, we would have to increase our laparoscopic cholecystectomy workload. With a full complement of 2 surgeons for our population of 30 000, we estimate an annual volume of 200 cholecystectomies.

An acceptable ERCP volume (45–50 annually) would be achieved by capturing most of our catchment area's cholecystectomy patients requiring ERCPs as well as referrals from nearby towns in the Northwestern Ontario Surgical Network that presently refer their ERCP patients longer distances to tertiary care centres.

Maintenance of competency would be feasible with an expected annual rate of 45–50 procedures. This compares favourably with the mean volume in US hospitals doing inpatient ERCPs.⁸ The only rural program cited in the literature maintained high-quality outcomes and at a higher average of 75 procedures per year.¹²

Training at high-volume tertiary care centres would be required for a rural surgeon to achieve the

Table 3. Patient profile for laparoscopic cholecystectomies performed in Sioux Lookout from 2007 to 2009

Characteristic	% of patients*
Mean age, yr	32.2
Female:male ratio	3:1
Type 2 diabetes	16
High blood pressure	18
Total cholesterol, mmol/L	4.3

*Unless otherwise stated.

required number of procedures and to fit well within the regional network and referral patterns. Additionally, annual updates in higher-volume centres may be required for skill and volume supplementation.

Gallbladder disease requiring ERCP intervention is higher in our region for unknown reasons. Our ERCP population rate of 150 in 100 000 is threefold higher than US inpatient rates and is only partially explained by the higher incidence of gallbladder disease.⁷

Although the rate of precholecystectomy ERCP in patients who received surgery in Sioux Lookout was normal at 14%, the total ERCP population rate is 3 times that seen in other populations. Our laparoscopic cholecystectomy numbers are supplemented by patients referred around us directly for ERCP in other centres. The high number of ERCPs includes some retrieval of retained stones from distant surgeries, but primarily comprises an increased incidence of choledocholithiasis in our region. We wonder if genetic, dietary or other mechanisms lead to gallstones entering the common bile ducts more commonly in our population. A local MRCP service might lower the number of suspected cases, but is not economically feasible.

Limitations

We were able to get accurate data from manual reviews of our own hospital charts. Data gathered electronically from other sites had less oversight. Identification of patients from our typical referral area was made difficult by the presence of a provincial border and recent changes in surgeon staffing levels. Nonetheless, every effort was made to underestimate rather than overestimate the relevant case burden of ERCP work for our program. Ideally, we would like to have had information on the ERCP findings done in the 3 tertiary centres by 4 providers, but those data were not readily available.

The data cited in the literature changed dramatically depending on the year of the surgeries because this field of surgery has been evolving rapidly. Many studies were therefore not used if they occurred before a shift in procedure adoption. Several studies referenced gallbladder disease and others pure rates of laparoscopic cholecystectomies, making comparisons difficult.

CONCLUSION

The patients in our catchment area who undergo cholecystectomy are young, widely distributed geo-

graphically and require expensive medical transportation for surgical consultations and procedures. These patients require an ERCP intervention at rates several times higher than other populations. From the perspective of both maintenance of surgical competence and best patient care, the volume of ERCPs done on patients in our catchment area of 30 000 justifies the establishment of a rural ERCP program.

Competing interests: None declared.

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CLINICAL IMAGES

Rectal bezoars in children

Bryanne Minty BSc, Len Kelly MD M Clin Sci

A previously well eight-year-old boy was brought to the emergency department with a three-day history of constipation. He had consumed three handfuls of flavoured unshelled sunflower seeds four days previously. His mother had unsuccessfully tried several sodium biphosphate and sodium phosphate enemas at home, as well as the use of bran to aid defecation. On examination, the patient's abdomen was soft and nontender with normal bowel sounds. A bolus of stool mixed with unshelled sunflower seeds was visible at the anus.

A radiograph of the abdomen showed stool extending from the descending colon down to the rectum, which contained a large mass (Figure 1). Oral phosphate soda and a mineral oil enema were ineffective. The patient was taken to the operating room for digital and instrumental extraction under general anesthesia. He was monitored in hospital for 24 hours and discharged when he was taking liquids and passing soft stool.

A bezoar is a solid mass formed in the gastrointestinal tract as a result of the consumption of indigestible or poorly digestible substances. Bezoars most commonly form in the stomach, but can occur in the small intestine and, rarely, in the colon or rectum. They are usually classified according to the material of which they are derived, for example, trichobezoars (hair), lactobezoars (milk curd), phytobezoars (plant fibre) and medication bezoars. The term originates from the Arabic term *badzehir*, meaning "antidote," a reference to historical medicinal use of these concretions found in animal gastrointestinal tracts in the treatment of human poisonings.¹

Although small rectal bezoars may pass spontaneously, options for the care of patients presenting to clinicians with symptomatic rectal bezoars include the use of enemas and extractions with conscious sedation or general anesthesia.^{2,3} Formation of bezoars from sunflower seeds may be more likely in children or preteens who are unable or unwilling to spit out the shells, particularly with flavoured shells.

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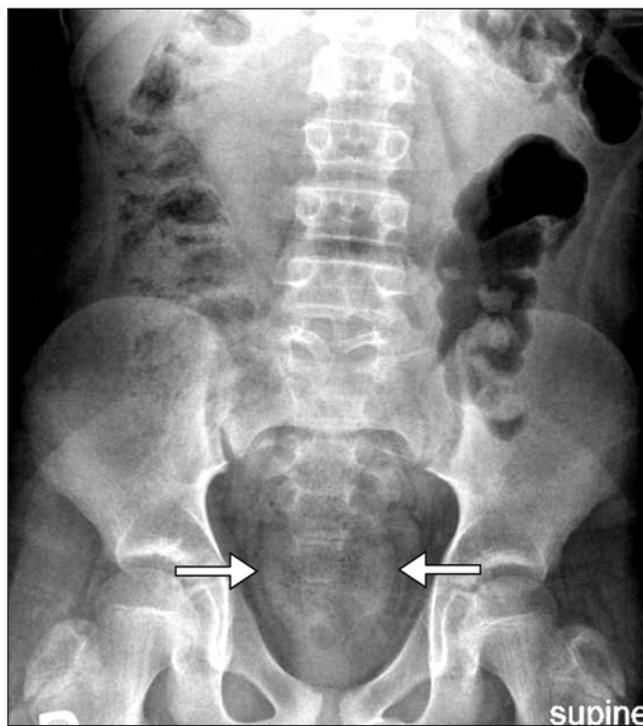


Figure 1: Abdominal radiograph showing a solid rectal bezoar (arrows) in a constipated eight-year-old boy following ingestion of flavoured unshelled sunflower seeds.

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The occasional injection for trochanteric bursitis

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Often a patient will arrive in the office stating that he or she has a sore hip. Because osteoarthritis of the hip is a common disorder, we may immediately order a radiograph of the hip. Before doing so, we should rule out trochanteric bursitis, which is easily diagnosed by a simple range of motion test and palpation of the hip and is treated in the office without the need for radiography.

HISTORY

Screening questions will usually sort out the location and source of the pain: “Is it sore when you are lying in bed?”; “Is it sore when you lie on that side?”

Trochanteric bursitis occurs about 4 inches lateral to the hip joint and hurts when the patient lies on it. Soreness occurs with climbing ladders or hills, running or using elliptical trainers. In distinction to osteoarthritis of the hip, trochanteric bursitis does not cause much soreness with walking. Also, osteoarthritis of the hip is not generally

painful with lying in bed. Confirm with the patient that no pathological flags are present (e.g., history of cancer, night pain, constant pain).

Sometimes there is an obvious precipitant (e.g., the patient went camping with the kids and slept on a rock, was doing a lot of uphill hiking or training, or sleeps on a poor mattress). Often the pain is longstanding and increasingly bothersome. It is more common in women (4:1) and affects between 15% and 20% of the population.¹

PHYSICAL EXAMINATION

The simplicity of the history is followed by an equally circumscribed examination. It is done with the patient sitting on the examination table. Swing the affected leg side to side (external and internal hip rotation) (Figs. 1 and 2). A painful limitation of internal rotation is an early sign of osteoarthritis of the hip.

Compare the range of movement with that of the other leg. If reasonable rotation exists, there is no osteoarthritis



Fig. 1. External rotation of the hip is generally normal and painless with bursitis.



Fig. 2. Internal rotation is usually limited and painful in osteoarthritis, but not in bursitis.

of the hip and no need for radiography.

Steady the patient with the other hand and press firmly with your thumb over the area of the trochanteric bursa. If the pain is recreated, you have the diagnosis and can offer the patient a simple, relatively painless injection (Fig. 3).

ANATOMY

Unlike the more commonly injected bursae of the shoulder and the knee, the trochanteric bursa is often not a discrete structure. This causes some authors to refer to pain in this area as “greater trochanteric pain syndrome,” a reference to the 5 or 6 bursae in that region.² Whereas some of these bursae are not universally present in autopsy studies, 2 commonly are (deep and superficial subgluteus maximus bursae) and are thought to be the location of the clinical pain^{3,4} (Fig. 4).



Fig. 3. Firm palpation over the greater trochanter reproduces the pain of bursitis. This is your confirmatory test.

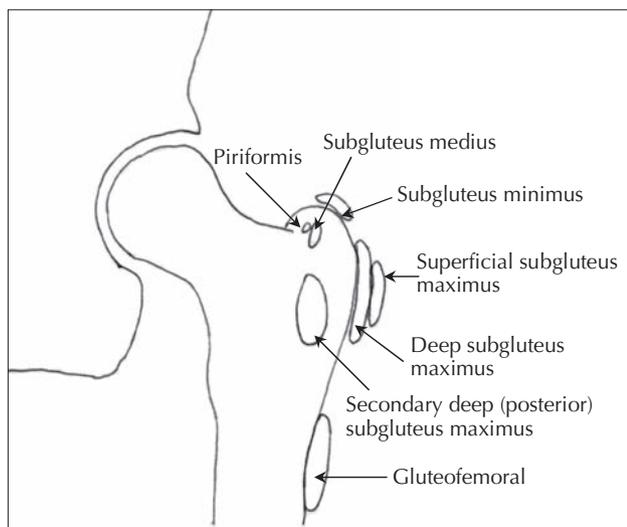


Fig. 4. The multiple bursae involved in trochanteric bursitis.

The trochanteric bursa decreases the friction around the insertion of the iliotibial band and hip abductor muscles into the greater trochanter. Repeated hip flexion (e.g., from climbing hills) and direct pressure (e.g., from lying on a poor mattress) lead to inflammation and pain in this area. Because the trochanteric bursa lacks a discrete anatomic structure, we use a large volume of steroid–lidocaine mixture spread over a larger area.

TREATMENT

1. Have the patient lie on his or her good side with a patch of skin exposed over the hip region (the patient need not completely undress).
2. Palpate with the palm of your hand to find the top of the “bony dome,” which is the greater trochanter of the femur (Fig. 5).
3. Localize the painful area with a finger press. When the affected area is found, the patient will easily let you know (Fig. 6).
4. You are looking for a tender area of soft tissue.



Fig. 5. With the patient lying on his or her good side, palpate the dome of the hip to find the highest point.



Fig. 6. Locate the highest point with a finger press. Move your finger around until you find the most tender spot.

- Mark the most tender spot with the needle protector to give you a bull's eye for your injection.
- Alcohol swab the skin. Use a 25-gauge, 1.5-inch needle to inject 5–10 mL of 1% lidocaine without epinephrine and 40 mg of methylprednisolone acetate or equivalent. The objective is to pepper an area about the size of a golf ball or larger.
 - Dive deeply with the needle. Inject 1–2 mL, bring the needle back to near the skin and rediver into the adjacent tissue (Fig. 7). Do this 2–3 times and you are done. If the needle comes out when you are repositioning it, no problem. If you hit bone, simply inject as you slowly back the needle out.

A review of trochanteric bursitis studies using cortisone injections documents 60%–100% efficacy.²



Fig. 7. Bury the needle at the most tender spot and deposit part of the mixture at or near the bone. Bring the needle back to the skin and reinject at a slightly different angle, trying to eventually infiltrate an area the size of a tennis ball.

AFTER CARE

Bandage. There is little else to do. Another injection can be done in a month if some of the pain remains. One injection may suffice, but sometimes 2 or 3 will be required. If the patient needs to replace his or her mattress, now is a good time. If the patient can avoid ladder and hill climbing for awhile, all the better.

CONCLUSION

This is a simple manoeuvre that will usually resolve the pain, which may have been longstanding if the patient believed he or she was simply getting old and had a worn-out hip. The injection is almost painless, and patients derive excellent symptom relief from this simple office procedure. There are a group of patients who will return after 1–2 years or sooner, and they are candidates for repeat injection. Trochanteric bursitis is common and is easily diagnosed and treated.

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Case Report

Invasive disease caused by *Haemophilus influenzae* type a in Northern Ontario First Nations communitiesLen Kelly,¹ Raymond S. W. Tsang,² Alanna Morgan,¹
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Seven epidemiologically unrelated cases of invasive *Haemophilus influenzae* type a (Hia) disease were identified in First Nations communities of Northwestern Ontario, Canada, in 2004–2008. In all cases, Hia was isolated from blood. The clinical presentation in most of the cases was moderately severe and all patients responded to antibiotic therapy. Laboratory analysis of Hia isolates from Northwestern Ontario indicated striking similarities in their phenotypic and genotypic characteristics. The findings are discussed in the context of current epidemiology of invasive Hia disease. Our data along with some published studies by others suggest an increased susceptibility to this infection among North American indigenous populations.

Introduction

Haemophilus influenzae is a Gram-negative coccobacillus which colonizes the nasopharynx of healthy individuals, but can also cause severe invasive diseases, such as meningitis, epiglottitis, septic arthritis and septicaemia (Peltola, 1993; Morris *et al.*, 2008). Most invasive infections are caused by encapsulated *H. influenzae*. Based on antigenic properties of their capsular polysaccharides, six (a, b, c, d, e, f) serotypes have been identified (Pittman, 1931). Before the late 1980s, *H. influenzae* type b (Hib), characterized by a polyribosyl ribitol phosphate capsule, was the most common cause of meningitis, epiglottitis and other invasive bacterial infections in children (Murphy, 2005). Introduction of Hib conjugate vaccines in the early 1990s dramatically decreased the incidence of invasive Hib disease among children in many industrialized countries (Peltola, 1993). In Canada, a rapid decline in Hib-associated morbidity and mortality has occurred since the conjugate Hib vaccine became part of the routine childhood immunization schedule in 1991 (Public Health Agency of Canada, 2006). Vaccination also significantly decreases the carriage rate of Hib in young children (Barbour, 1996). There is concern that following widespread vaccination against Hib, *H. influenzae* strains may

undergo capsule switching or replacement to fill the ecological niche previously occupied by Hib (Tsang, 2007). Indeed, the emergence of invasive non-type b *H. influenzae* disease has been reported in several countries (Heath *et al.*, 2001; Ribeiro *et al.*, 2003; Bajanca *et al.*, 2004; Degani *et al.*, 2008; Tsang *et al.*, 2007; Brown *et al.*, 2009). Interestingly, there are apparent geographical disparities in the prevalence of different types of *H. influenzae*, i.e. between Europe and America. The role of the genetic background as a predisposing factor to invasive disease caused by certain capsular types of *H. influenzae* remains unexplored, although some studies suggest an increased incidence of invasive *H. influenzae* type a (Hia) disease among indigenous people of North America (Millar *et al.*, 2005; McConnell *et al.*, 2007; Bruce *et al.*, 2008). We describe seven epidemiologically unrelated cases of invasive Hia disease that occurred in First Nations communities of Northwestern Ontario (Canada) during 2004–2008.

Case reports

Case 1

Patient 1 was a 15-month-old aboriginal male who presented with persistent fever, cough and irritability. He was diagnosed with chest X-ray-confirmed left-sided pneumonia and empyema (Fig. 1) and was treated with

Abbreviations: Hia, *Haemophilus influenzae* type a; Hib, *Haemophilus influenzae* type b; i.v., intravenous; ST, sequence type; WBC, white blood cell.

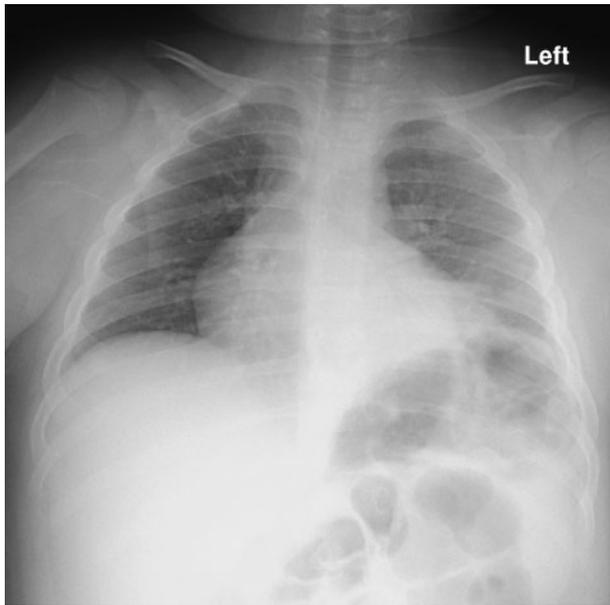


Fig. 1. Posteroanterior chest radiograph of the 15-month-old child in case 1 showing left-sided pneumonia and empyema.

intravenous (i.v.) cefuroxime for 3 days. He was transferred to a tertiary care paediatric hospital due to worsening symptoms, and treated with i.v. cefuroxime for a further 14 days and subsequently with oral amoxicillin for 1 month. Blood cultures grew Hia, sensitive to ampicillin. A follow-up chest X-ray at 21 months showed some residual atelectasis but had cleared at 22 months.

Case 2

Patient 2 was a 33-month-old previously well aboriginal male who presented with fever. An outpatient throat swab was positive for *Streptococcus pyogenes* and he was started on erythromycin. He presented 2 days later with a recurrent fever of 40 °C and subsequently developed a swollen, erythematous, painful right ankle. An X-ray from admission was normal. Blood cultures grew Hia, which was β -lactamase-negative and sensitive to ampicillin, chloramphenicol and cefotaxime. The patient was transferred to a tertiary care paediatric hospital and was diagnosed with possible osteomyelitis/septic arthritis of his right ankle. Blood cultures again grew Hia (β -lactamase-negative). His bone scan, X-ray and ankle ultrasound were normal. His erythrocyte sedimentation rate (ESR) was very elevated at 104 mm h⁻¹ (normal values=20–30) and white blood cell (WBC) count was $20.9 \times 10^9 \text{ l}^{-1}$ with 80% neutrophils. He was initially treated with i.v. cefuroxime for 10 days, and then he was discharged on oral amoxicillin for 25 days, for a total of 5 weeks of antibiotics for a presumed osteomyelitis or septic arthritis. Upon discharge, his ESR was 29 and a repeat ankle X-ray did not show any bone destruction. He fully recovered.

Case 3

Patient 3 was a 4-year-old aboriginal morbidly obese male with a BMI of 32 and a history of mild reactive airway disease who presented with severe abdominal pain and vomiting. He had an occasional cough for the preceding month and had been exposed to a cousin with pneumonia. His abdominal examination was benign, but a chest X-ray revealed a left lower lobe infiltrate. He was afebrile on admission, but the next morning developed a fever of 39.1 °C. His WBC count was elevated at $28.8 \times 10^9 \text{ l}^{-1}$ and blood cultures grew Hia. He was treated with i.v. cefuroxime and oral azithromycin. His WBC count had normalized by day 4. He was discharged on oral cefuroxime and fully recovered.

Case 4

Patient 4 was a 34-year-old aboriginal female who presented with cough, shortness of breath and fever of 38.9 °C. Underlying medical conditions and risk factors included type 2 diabetes mellitus, reactive airway disease, hypercholesterolaemia and smoking. Her WBC count was elevated at $19.6 \times 10^9 \text{ l}^{-1}$. A chest X-ray demonstrated a lingular and left lower lobe pneumonia and she was treated with i.v. ceftriaxone and doxycycline for 3 days. Blood cultures grew Hia, which was β -lactamase-negative and sensitive to ampicillin, chloramphenicol, ceftriaxone and meropenem. She was discharged on oral cefuroxime and recovered completely.

Case 5

Patient 5 was a 65-year-old aboriginal female who presented with a fever of 38.6 °C, nausea, vomiting and severe left elbow pain for 2 days. Her past medical history included tuberculous spondylitis at age 11, pulmonary and spinal tuberculosis at age 14 and Ménière's disease at age 42. She was being treated for congestive heart failure, chronic obstructive pulmonary disease, kyphoscoliosis and depression. She was diagnosed with upper respiratory illness and suspected elbow cellulitis. On admission, she had tachypnoea (respiratory rate=60) with a slightly elevated WBC count of $11.7 \times 10^9 \text{ l}^{-1}$ with 92% neutrophils. Her chest X-ray appeared grossly normal but was difficult to interpret due to the scoliosis. Elbow X-ray was normal. Elbow aspiration was unsuccessful, but blood cultures grew Hia, β -lactamase-negative, sensitive to ampicillin, chloramphenicol, ceftriaxone and meropenem. She was treated with levofloxacin for 4 days i.v. and 1 week orally. Her respiratory and joint symptoms resolved.

Case 6

Patient 6 was a 6.5-year-old aboriginal female who presented with tonsillitis, fever of 38.3 °C and appeared unwell. The previous year she had a surgical correction of her atrial septal defect. At admission, the WBC count was elevated ($18.2 \times 10^9 \text{ l}^{-1}$) and blood cultures were positive

for Hia. She was treated with clindamycin and ampicillin for 10 days and completely recovered. Her other medical conditions included iron deficiency anaemia, for which she took ferrous gluconate. She had completed the series of Hib conjugate vaccine according to the immunization schedule prior to her illness.

Case 7

Patient 7 was a 47-year-old aboriginal male who presented with tachypnoea (respiratory rate=40), haemoptysis and severe pleuritic chest pain. His past medical history included rheumatic fever at age 6, appendectomy at age 16 and abdominal hernia repair at age 22. Upon hospital admission, the patient had a dramatic chest X-ray with right middle and lower consolidations as well as a lingular infiltrate (Fig. 2). His WBC count was elevated at $25.6 \times 10^9 \text{ l}^{-1}$ and blood cultures were positive for Hia. Sputum smears for acid-fast bacilli, fungi and cytological abnormalities were negative. He was treated with i.v. cefuroxime and oral azithromycin. After 6 days of i.v. antibiotic therapy, he was feeling well and discharged home on oral amoxicillin.

Comment

We could confirm with certainty complete vaccination status in only one of the four paediatric cases (patient no.

6). However, the other children have likely been vaccinated due to the presence of a regional vaccination programme.

Methodology and laboratory results

Eight individual Hia isolates from Northwestern Ontario obtained during 2004–2008, including four isolates recovered from the seven cases described in this study, were analysed for their phenotypic and genotypic characteristics. The four isolates unrelated to the cases were included for comparison purposes and to examine the genetic diversity of invasive Hia isolates recovered from the Northwestern Ontario region. All isolates were from blood cultures performed in clinical laboratories in Sioux Lookout and Thunder Bay hospitals. The hospital charts were retrospectively reviewed for the demographical and clinical information. The study was approved by the Research Review Committee, Meno-Ya-Win Health Centre (Sioux Lookout, Ontario), and the Research Ethics Board of Thunder Bay Regional Health Sciences Centre.

Identification of *H. influenzae* was carried out using standard methods (Kilian, 2007) and confirmed by 16S rRNA gene sequencing (Lau *et al.*, 2004). Serotyping was accomplished using both a bacterial agglutination test and a PCR assay (Sill *et al.*, 2007a). Biotyping, multilocus sequence typing, PFGE and detection of the IS1016-*bexA* partial deletion were performed as previously described (Tsang *et al.*, 2006).

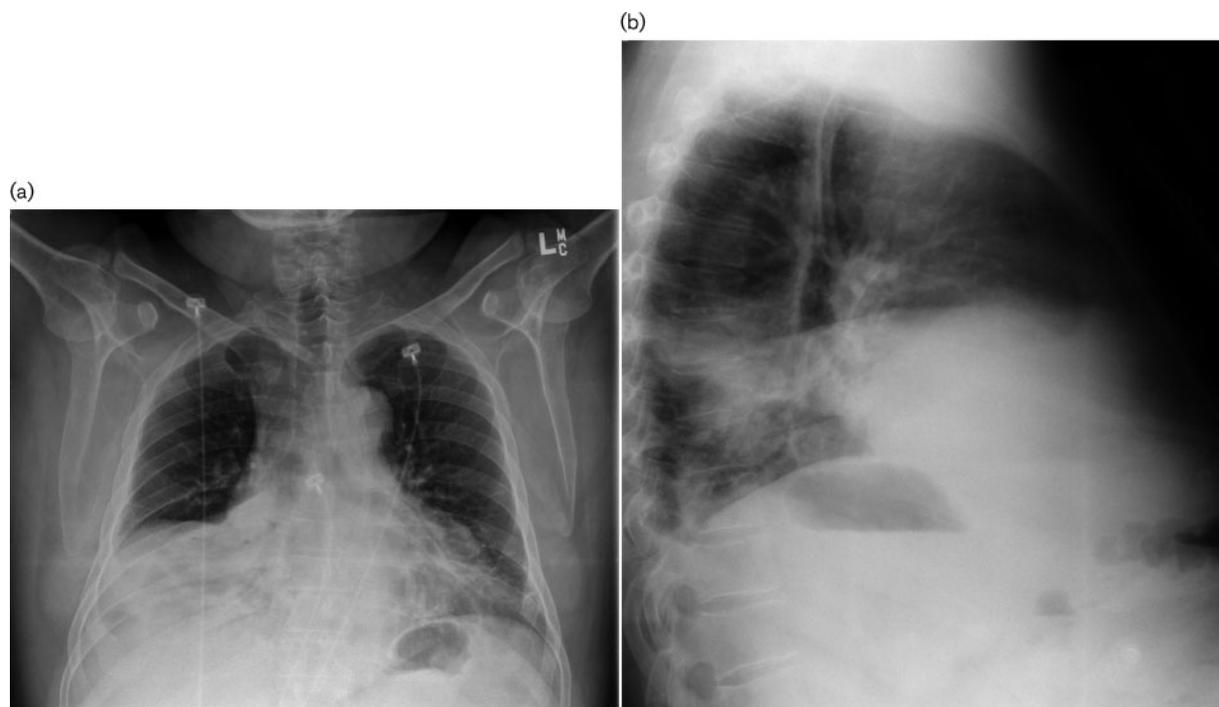


Fig. 2. (a) Posteroanterior chest radiograph of the 47-year-old patient in case 7 showing extensive consolidation in the right middle lobe and basal segments of the right lower lobe with some infiltrates in the lingula of the left lung. (b) Lateral chest radiograph of the same patient.

All eight isolates were positive for the capsular transport gene *bexA*, and confirmed to be serotype a by PCR. All eight isolates belonged to biotype II and to the clonal group of sequence type (ST)-23. Identical PFGE patterns (pattern a1) with *Sma*I enzyme were found in all eight isolates. None of the eight Hia isolates were found to contain the IS1016-*bexA* deletion in their capsule locus, *cap*. All eight isolates were also β -lactamase-negative and were susceptible to ampicillin, amoxicillin-clavulanic acid, cefaclor, ceftriaxone, chloramphenicol, sulfamethoxazole-trimethoprim, ciprofloxacin, moxifloxacin and clarithromycin.

Discussion

In the post-Hib vaccine era, non-type b *H. influenzae* (including other non-b serotypes and non-typable strains) causes most of the invasive *H. influenzae* disease, with the highest prevalence of disease due to non-typable *H. influenzae*. Among non-type b encapsulated *H. influenzae* causing invasive disease, serotype f is becoming the most prevalent in both North America and Europe (Dworkin *et al.*, 2007; Tsang *et al.*, 2007; Adam *et al.*, 2010; Ladhani *et al.*, 2010). In the province of Ontario, Canada, serotype a comprised a small percentage (2.1 %) of all the invasive *H. influenzae* isolates ($n=1455$) both before and after the introduction of the Hib conjugate vaccine (Adam *et al.*, 2010). In contrast, in Northwestern Ontario, 13 out of 31 (42 %) invasive *H. influenzae* isolates serotyped in 2002–2008 were Hia (Brown *et al.*, 2009). Of note, this region has a significant proportion of aboriginal people, i.e. 19.6 % of the population (Statistics Canada, 2006).

Previous studies found a high incidence of invasive Hia disease among North American aboriginal people, including Canadian First Nations (Hammit *et al.*, 2005; Millar *et al.*, 2005; McConnell *et al.*, 2007; Bruce *et al.*, 2008). According to Bruce *et al.* (2008), the incidence rate of invasive Hia disease in the North American Arctic was 2.9/100 000 for indigenous and 0.2/100 000 for non-indigenous people. The highest reported incidence rate of invasive Hia disease was among indigenous children <2 years of age, i.e. 52.6/100 000 (Bruce *et al.*, 2008). Although severe cases of invasive Hia disease have been reported in non-aboriginal populations (Adderson *et al.*, 2001; Kapogiannis *et al.*, 2005; de Pádua *et al.*, 2009), this disease is rare in the general population (ABC surveillance data quoted from Kapogiannis *et al.*, 2005; Adam *et al.*, 2010). In our study, we describe seven epidemiologically unrelated cases of invasive Hia disease in aboriginal individuals that have occurred over a period of 4 years in a region with population of 25 000, i.e. with a mean annual incidence rate of 7/100 000. The aboriginal population in the area is 82 % including 28 First Nations communities (Walker *et al.*, 2009).

The severity of some previously reported Hia disease cases, i.e. presenting as meningitis and septic arthritis, was reminiscent of the invasive disease caused by Hib (Adderson *et al.*, 2001; Kapogiannis *et al.*, 2005).

Multiple copies of the capsule locus as well as a partial deletion of the IS1016-*bexA* gene, which stabilizes the capsule locus causing an increase in the production of capsule polysaccharides, have been reported in both Hib and Hia as a mechanism for their enhanced virulence (Kroll *et al.*, 1993, 1994). However, not all Hia isolates from invasive disease have the IS1016-*bexA* partial deletion (Hammit *et al.*, 2005; Tsang *et al.*, 2006; Bruce *et al.*, 2008). According to Bruce *et al.* (2008), this mutation was absent from 28 Hia isolates from the North American Arctic, including those involved in fatal cases. Indeed, according to Leaves *et al.* (1995), Hia strains usually contain intact tandemly repeated copies of *cap*. It remains unknown whether any additional virulence factors, besides the capsule, may contribute to the virulence of Hia. In our study, clinical presentation of all the cases was moderately severe and all patients completely recovered although they required hospitalization and prolonged antibiotic therapy. The most common presentation was pneumonia (four out of seven cases); in two cases Hia disease involved joints. Of note, five out of the seven patients (aged 4–65 years) had significant underlying medical conditions, which may have contributed to reduced immunity, resulting in invasive Hia disease.

Although Hia has the potential to cause outbreaks, so far only one outbreak has been reported in the literature (Hammit *et al.*, 2005). Very few studies have examined Hia carriage rates, but in two studies performed in Alaska, rates of about 16–43 % were found among close contacts of a culture-confirmed Hia invasive disease case patient (Hammit *et al.*, 2005, 2006). The cases presented in our study appeared to be epidemiologically unrelated, as they occurred in isolated communities accessible to one another by air only, although all the Hia isolates from these cases showed remarkable phenotypic and genotypic similarities. This implies that Hia circulates in Northern Ontario, in particular, in First Nations communities, and may represent a significant risk for susceptible individuals, such as young children and adults with underlying co-morbidities contributing to decreased immunity, e.g. diabetes mellitus. Invasive Hia disease has also been reported to be common among the Navajo and White Mountain Apache American Indians, i.e. with an annual incidence rate of 20.2/100 000 for children under the age of 5 years (Millar *et al.*, 2005). In the Keewatin Region of Nunavut (northern Canada), the estimated incidence of invasive Hia disease was 418.7/100 000 for Inuit children under 5 years old (McConnell *et al.*, 2007). In four Canadian western provinces (British Columbia, Alberta, Saskatchewan and Manitoba), the rate of invasive Hia disease among aboriginal children under 5 years of age was 3.7/100 000 (McConnell *et al.*, 2007). Previous studies found that similar risk factors can predispose to invasive Hia as to Hib disease, i.e. young age, exposure to other children in child care centres and overcrowding (Adderson *et al.*, 2001).

We compared our findings to previously published reports describing invasive Hia disease and/or the bacteria isolated

from the cases (Table 1). Of the 10 studies, six provided DNA fingerprinting results (Adderson *et al.*, 2001; Ribeiro *et al.*, 2003; Millar *et al.*, 2005; Kapogiannis *et al.*, 2005; Hammitt *et al.*, 2005; Bruce *et al.*, 2008) and used the restriction enzyme *SmaI* for digestion of the Hia genomic DNA. In two of these studies (Hammitt *et al.*, 2005; Bruce *et al.*, 2008), an additional enzyme, *ApaI*, was also used, while in the study reported by Millar *et al.* (2005), the

restriction enzyme *BlaI* was also employed. While it was impossible to compare the DNA fingerprints reported in these six studies, more than one DNA fingerprinting pattern has been observed. However, the DNA fingerprinting in our study using multilocus sequence typing and PFGE analysis of Hia isolates from Manitoba and Northwestern Ontario suggested clonality of the Hia isolates collected from these two neighbouring regions in Canada.

Table 1. Review of case studies of invasive Hia infections and/or Hia bacteria

Reference	Nature of study	Study cases/isolates*
Rutherford & Wilfert (1984)	Report of two cases and review of literature (North Carolina, USA)	Female (2 years 5 months), fever and respiratory distress; pleural effusion yielded Hia Male (45 years), history of alcoholism, gastrointestinal bleeding; blood culture Hia-positive
Kroll <i>et al.</i> (1994)	Detection of <i>IS1016-bexA</i> deletion in the encapsulation (<i>cap</i>) locus of Hia (Africa)	Five Hia meningitis and pneumonia cases in Gambia were analysed; isolates from three cases showed the <i>IS1016-bexA</i> deletion
Adderson <i>et al.</i> (2001)	Described five cases of severe Hia invasive disease (Utah, USA)	White female (6 months); white female (1 year); female (7 months); male (13 months). All four cases with meningitis and bacteraemia and with Hia isolated from blood and CSF cultures. Male (4 years), with flash burn to the face, fever and lower lobe infiltration; endotracheal secretions yielded pure culture of Hia
Ribeiro <i>et al.</i> (2003)	Reported eightfold increase in Hia meningitis in Brazil after introduction of Hib immunization, characterized Hia cases and case isolates	Thirteen Hia case isolates were divided into two closely related PFGE groups, each with distinct biotype Severity and mortality of Hia meningitis cases were similar to those of non-type a cases including Hib
Hammitt <i>et al.</i> (2005)	Outbreak of invasive Hia disease among Alaska natives	Female (6 months), with history of respiratory illness, developed pneumonia and blood culture yielded Hia; 4 months later developed a separate episode of Hia meningitis Male (8 months), with pyelonephritis, developed fever and refusal to move left leg; joint fluid grew Hia, successfully treated with ceftriaxone; 3 months later fever and pain returned to his left leg and left arm; blood and joint fluid grew Hia Male (4 months), with history of neurodegenerative disease, developed bilateral pneumonia; blood cultures yielded Hia
Kapogiannis <i>et al.</i> (2005)	Reported two cases of invasive Hia disease with isolates showing <i>IS1016-bexA</i> deletion (ABC surveillance study, USA)	Male (14 months) of Middle Eastern descent, developed fever and swelling of right hand; blood culture grew Hia Male (30 months), African American, developed meningitis and septic arthritis; blood, CSF and synovial fluid yielded Hia
Millar <i>et al.</i> (2005)	Reported epidemiology of invasive Hia disease among Navajo and White Mountain Apache children in the USA	Seventy-six cases of invasive Hia disease were studied, median age of cases was 12 months; most Hia isolates were from blood, or blood and CSF; most common presentation was meningitis, followed by pneumonia; others presented as cellulitis and septic arthritis; unrelated Hia isolates were 90% similar when analysed by PFGE
Sill <i>et al.</i> (2007a)	Characterized four Hia isolates recovered from patients in Quebec, Canada	Four random isolates, three from blood (2-year-old female, 1-year-old male and 57-year-old female) and one from ear (10-month-old male) Three blood isolates belonged to unrelated clonal groups of ST-4, ST-23 and ST-62; ear isolate belonged to another clonal group of ST-403
Bruce <i>et al.</i> (2008)	Described epidemiology of Hia in North American Arctic	Forty-two Hia cases were identified among 132 cases with serotype information; 30 of the Hia cases occurred in children 2–5 years of age, 8 in adults aged 21–73 years; 35 of the 38 Hia cases with ethnicity data were aboriginal; the most common clinical presentations were meningitis and pneumonia, followed by septic arthritis
de Pádua <i>et al.</i> (2009)	Case report of Hia meningitis in Brazil	White female (5 months), CSF culture Hia-positive

*CSF, Cerebrospinal fluid.

In the present study, the eight isolates from Northwestern Ontario gave a DNA fingerprint identical to one of the three related fingerprint types found among Hia isolates recovered in Manitoba (Tsang *et al.*, 2006). In addition, the single ST of Northwestern Ontario Hia isolates is also the predominant ST found among Hia isolates in Manitoba. This is not surprising as the region of Northwestern Ontario is adjacent to the province of Manitoba, where many aboriginal communities are found. Similarity of the Hia isolates found in these two neighbouring provinces is further supported by our findings that invasive Hia isolates from Northwestern Ontario did not have the *IS1016-bexA* partial deletion. The lack of this mutation in the Hia *cap* locus may explain the apparently less virulent nature of the Hia disease observed in this series, i.e. lack of meningitis and mortality among the cases.

Despite the apparent similarity of invasive Hia isolates in Manitoba and Northwestern Ontario, other reports suggested some degree of Hia genetic diversity. In a study of four Hia isolates collected from patients in the province of Quebec, Canada (Sill *et al.*, 2007b), three distinct groups were identified: two groups were characterized by unrelated ST-4 and ST-62, and the third group consisted of two isolates of related STs (ST-23 and ST-403). Partial deletion of the *IS1016-bexA* gene was found in an isolate identified as ST-4 while this deletion was absent from the other three strains. In another study of Hia isolates recovered from meningitis patients in Salvador, Brazil, two clonal groups of Hia were identified, one represented by ST-4 with partial deletion of the *IS1016-bexA* gene while the other was represented by ST-23 without the partial deletion of the *cap* genes (Lima *et al.*, 2010).

In agreement with some previously published reports (Hammit *et al.*, 2005; Millar *et al.*, 2005; McConnell *et al.*, 2007; Bruce *et al.*, 2008), this study suggests that North American aboriginal people may have an increased susceptibility to Hia invasive disease. Importantly, before the introduction of Hib conjugate vaccines, some North American indigenous populations experienced the highest rates of invasive Hib disease worldwide (reviewed by Ulanova & Tsang, 2009). Whether genetic or environmental factors (or both) determine an increased susceptibility of aboriginal populations to invasive infections caused by encapsulated bacterial pathogens is uncertain and needs further study. Although the development of a new conjugate Hia vaccine appears feasible (Jin *et al.*, 2007), more research is warranted towards a better understanding of immunoepidemiology of invasive Hia disease. In particular, continuing surveillance of all non-type b *H. influenzae* invasive infections is needed to establish whether or not an increase in the incidence of invasive Hia occurs in the post-Hib vaccine era. Conjugated Hib vaccine is not effective against non-b serotypes or non-typable strains of *H. influenzae*. Therefore, as Hib disease is eliminated in the vaccinated populations, non-b serotypes or non-typable *H. influenzae* strains may replace Hib to become the major invasive

bacterial pathogens if they are of significant pathogenic potential. However, if such strains are considerably less virulent than Hib, they may only cause occasional disease in an opportunistic manner.

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Glycaemic control: do no harm

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Tight glycaemic control for type 2 diabetes (T2DM) has always been a tough sell. It is rarely achieved safely, owing to noncompliance and hypoglycaemic episodes, and there has been little evidence to support it. New studies now speak of its potential harm.

The initial United Kingdom Prospective Diabetes Study (UKPDS) in 1998 was widely interpreted as evidence for tight glycaemic control, then defined as a haemoglobin A1c value of 7.0%.¹ In fact, in this trial no reduction was demonstrated in serious clinical episodes, i.e. macrovascular events (stroke or myocardial infarction). The often quoted 22% relative risk reduction in microvascular events (renal, ophthalmic, foot) actually referred primarily to a decreased need for retinal photocoagulation. However, there was no effect on visual acuity or renal failure.¹

The one important item we learned from an arm of the UKPDS trial was that the use of metformin decreased mortality, independent of its hypoglycaemic effects.² Ten years later there is no other therapy that can claim such success.

Recently, several studies have added to our understanding of T2DM and the minimal microvascular benefits of tight glycaemic control, now defined as an A1c of 6.5% or lower.³⁻⁵ However, this is overshadowed by present concerns of increased mortality⁴ as hypoglycaemia continues to be an issue, with a two- to threefold increased incidence at lower A1c values.

The Normoglycaemia in Intensive Care Evaluation and Survival Using Glucose Algorithm Regulation (NICE-SUGAR) multicentre trial of 6 104 intensive care unit (ICU) patients demonstrated increased mortality in those whose sugar levels were kept between 4.5 and 6.0 mmol/l.³ Compared to patients kept “under 10”, tight glycaemic control led to an absolute increase in mortality of 2.6% [95% confidence interval (CI), 0.4–4.8].

A 2009 meta-analysis of 26 studies (including the previous one) involving 13 500 ICU patients concluded that intensive glycaemic control “conferred no overall mortality benefit among critically ill patients.”⁶ However, it did significantly increase the risk of hypoglycaemia (sixfold) even in these closely monitored patients.

How has tight glycaemic control affected ambulatory patients? In 2008, two studies looked at achieving an A1c of less than 6.5 mmol/l. The Action in Diabetes and Vascular disease: PreterAx and DiamicroN MR Controlled Evaluation (ADVANCE) trial introduced rosiglitazone, a thiazolidinedione.⁴ The Action to Control Cardiovascular Risk in Diabetes (ACCORD) study introduced gliclazide, a sulfonylurea.⁵ Both studies used agents that were added to other medications, including metformin and insulin.

The ADVANCE trial followed 11 000 patients over five years and demonstrated a “21% relative reduction in nephropathy.”⁴ It specifically found that the development of macroalbuminuria was lower in the intensively treated group, at 2.95 vs. 4.10% (95% CI, 0.57–0.85). Clinically there was no statistically significant increase in renal dialysis or renal deaths.⁴ This delay in worsening proteinuria was accompanied by a twofold increase in hypoglycaemic events, including some requiring hospitalisation. There was no beneficial effect on macrovascular events or death.⁴

The ACCORD study did find increased mortality with tight glycaemic control.⁵ It followed 10 000 patients for 3.5 years and terminated the trial as a result of higher death rates associated with lower A1c measurements (hazard ratio, 1.22; 95% CI, 1.01–1.46). Intensively controlled patients also had a threefold increase in hypoglycaemic events (16% vs. 5%), and one quarter of them gained more than 10 kg in weight.⁵

A recent commentary in the *Annals of Internal Medicine* suggests that “interventions that overwhelm patients’

capacity to cope clinically, psychologically and financially, need to change.”⁷ Its authors suggest that “A1c levels between 7.0 and 7.5% seem reasonable and feasible for many patients.”⁷

What about our elderly patients? The studies point out that the risk of hypoglycaemic events outweighs the changes in surrogate endpoints. Tight glycaemic control renders no statistically significant reduction in important clinical endpoints, including dialysis, stroke, myocardial infarction or death. Keeping hypoglycaemia at bay should be one of our primary concerns, as well as limiting the effects of hyperglycaemia. An A1c value of 7.0 or below is associated with a greater risk of falling.⁸ Diabetes guidelines in Nova Scotia, Canada for extended care residents in long-term facilities consider random blood glucose values of between 10.0 and 15.0 mmol/l as acceptable, and even higher unless there are reversible symptoms.⁹

The only proven strategy for reducing macrovascular events in T2DM patients is blood pressure control, often requiring three or more medications.¹⁰ A focus on exercise, diet and smoking cessation is far more important than glycaemic control, and this is confirmed by the literature.¹¹⁻¹³

A simple approach to T2DM therapy is to ensure aggressive blood pressure control. I introduce metformin gradually up to its maximal tolerated dose. If the A1c remains high, I add NPH insulin and increase that with no upper limit in a once-daily or twice-daily dosing. My hope is to achieve a fasting morning glucose level lower than 10.0 mmol/l. If A1c is below 7.0% and the patient is only on metformin, I have no concern, as this is often a patient who has taken lifestyle changes seriously. If, however, the patient is on a therapy that can cause hypoglycaemia (insulin or other oral agents associated with hypoglycaemia), I always reassess the therapy and usually back off. I never use two agents that can cause hypoglycaemia simultaneously. Older patients teach me that they are more interested in their quality of life and I accept an A1c between 7.0% and 8.0% or higher if that is the best we can do.

We have to remember that we are treating the whole patient, some who live far from medical care, some who drive commercial vehicles, many who have other social and medical challenges. How would a severe hypoglycaemic attack affect them? The decision is not what laboratory value we strive for, but how safely we get there. If we do not keep it simple, one of us, either the patient or the physician, will not be able to keep up. It is not surprising that primary care surveys identify that we achieve glycaemic guidelines less than 50% of the time.¹³ While this would seem to imply neglect or suboptimal care, is that in fact the case? Is it not maybe a reflection of the complex nature of what is primarily a lifestyle disease?

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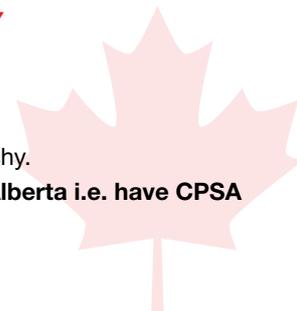
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An evaluation of the Acute Critical Events Simulation (ACES) course for family medicine residents

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Introduction: A 2-year residency must prepare family physicians to provide a broad range of services. In many settings, especially rural and remote practices, family physicians provide emergency and inpatient care and thus encounter critically ill patients. Evidence of the importance of early recognition and aggressive intervention in critical illness is growing. However, opportunities to safely practise critical care skills during residencies are limited.

Methods: The 2-day Acute Critical Events Simulation (ACES) course was offered to all family medicine residents at the University of Ottawa in 2009. The course included lectures, case discussions, hands-on task training and a half-day of high-fidelity simulation. Its aims were to enhance the abilities of residents in family medicine to recognize signs of critical illness, to teach competencies in the early resuscitation and care of such patients, and to increase residents' confidence to include inpatient and emergency care in their practices, or to practise in a rural or remote setting. A postcourse questionnaire, which included Likert-scale and open-ended questions, was distributed to all participants.

Results: Thirty-seven participants completed the survey. The ACES course was exceptionally well-received by participants, who reported increases in confidence and perceived competence, as well as intentions to change practice. The course appeared to increase participants' confidence to work in rural or remote areas and include inpatient or emergency medicine services in their practices.

Conclusion: The ACES course achieved its aims, and participants reported positive outcomes. This highly interactive, simulation-based program may help prepare residents for work in rural or remote communities with critically ill patients.

Introduction : Une résidence de deux ans doit préparer les médecins de famille à fournir un large éventail de services. Dans de nombreux contextes, en particulier dans les régions rurales et éloignées, les médecins de famille fournissent des soins d'urgence et des soins aux patients hospitalisés. Ils sont donc en contact avec des patients gravement malades. L'importance du dépistage précoce et du recours à des interventions énergiques en cas de maladies graves est de plus en plus évidente. Or, les possibilités de pratiquer en toute sécurité des techniques de soins critiques en résidence sont limitées.

Méthodes : On a offert à tous les résidents en médecine familiale à l'Université d'Ottawa en 2009 un cours de deux jours sur la simulation d'événements critiques en phase aiguë. Il comprenait une partie magistrale, des discussions de cas, une formation pratique et une demi-journée de simulation de haute fidélité. Les objectifs étaient de renforcer les capacités des résidents en médecine familiale à reconnaître les signes d'une maladie grave, de leur enseigner des compétences en réanimation précoce et prise en charge de ces patients, et d'accroître leur confiance en eux pour qu'ils puissent inclure dans leur pratique les soins aux patients hospitalisés et les soins d'urgence, en milieu rural ou éloigné. On a distribué un questionnaire à tous les participants après le cours. Il comportait des questions ouvertes et des questions cotées selon l'échelle de Likert.

Résultats : Trente-sept participants ont répondu au sondage. Le cours a été exceptionnellement bien accueilli par les participants, qui ont déclaré se sentir plus sûrs d'eux et plus compétents, et avoir l'intention de modifier leur pratique. Le cours semble avoir rendu les participants plus confiants pour le travail en région rurale ou éloignée et disposés à inclure des services de soins aux patients hospitalisés ou des services d'urgence dans leurs pratiques.

Conclusion : Le cours a atteint ses objectifs et, selon les participants, a donné des résultats positifs. Ce programme par simulation et très interactif peut aider à préparer les résidents à traiter des patients gravement malades dans les collectivités rurales ou éloignées.

INTRODUCTION

There exists a knowledge gap in most acute care settings. Typically, residents and family physicians are called on to provide initial assessment and management of critically ill patients, especially in rural or remote clinical settings.¹ In an effort to better equip residents, the Department of Family Medicine at the University of Ottawa partnered with CRI [Canadian Resuscitation Institute] Critical Care Education Network (now a unit of the Office of Professional Affairs, The Royal College of Physicians and Surgeons of Canada) to deliver the Acute Critical Events Simulation (ACES) course. The course was designed to teach the basic competencies required to deal with critically ill patients in any setting. The course meets an important recommendation of a 2003 discussion paper by The College of Family Physicians of Canada (CFPC)² that states the following:

The CFPC's accreditation standards should require all family medicine programs to provide family medicine residents with the opportunity to acquire the acute care skills needed for both rural and urban inpatient hospital care.

The discussion paper also suggests that the reluctance of family physicians to practise inpatient medicine may be owing to "a lack of self confidence in their professional abilities."

The goals of the course were to provide residents with the knowledge and skills to recognize the early signs and symptoms of critical illness; the competence necessary to deliver appropriate care in the early hours of critical illness, making optimal use of whatever resources may be available in their practice setting; and confidence in their ability to care for critically ill patients by meeting the above objectives. This, in turn, may have secondary benefits, such as improved recruitment, retention and overall professional satisfaction.

METHODS

Program

To the best of our knowledge, this is the only simulation-based course in Canada delivered to family medicine residents to be mandated by their department. Before delivery of the course, a brief focus group was held with representative residents in family medicine. Perceived needs with respect to education in critical care were discussed. Based on the results of the focus group and direction from M.K., an active educator in family medicine who works both with urban inpatients and in remote communities, the ACES course was modified in content and context to optimize relevance to residents in family medicine.

Four 2-day ACES courses, with up to 16 participants each, were delivered to residents during April and May 2009. CRI Critical Care Education Network assumed responsibility for course coordination, logistics and delivery. The department assisted the process by facilitating communication with the residents and arranging for time off from clinical placements.

The learning outcomes of the ACES course are to enable participants to understand the principles of effective crisis resource management, including leadership, communication, situational awareness, problem-solving and use of resources; recognize a critically ill patient by performing an initial assessment, initiate effective life-saving strategies for management and establish priorities for management in a patient with conflicting medical conditions; and assess and manage airway compromise, respiratory failure and shock.

Each course included the following modules:

- introduction to crisis resource management (lecture with video-based discussions);
- airway, breathing and circulation modules (all include a lecture, case discussions and hands-on training with equipment and manikins);

- neurologic and dysrhythmia modules (shorter modules including a lecture and case discussions);
- simulation (small-group sessions — maximum 4 participants — for 3.5 hours in team simulations with a computer-controlled lifelike manikin, dynamic vital signs monitor and real medical equipment, with video-based debriefing and feedback after each scenario).³

Participants received the course textbook in advance. The lecture on crisis resource management was the first module delivered. Participants were divided into streams and completed the other modules in variable order.

Instructors of these courses included 1 family physician, 5 critical care specialists and 3 critical care fellows. Teaching assistance was provided by critical care nurses and respiratory therapists from The Ottawa Hospital. The nurses were actors in the simulation scenarios, and the respiratory therapists helped to teach set-up of ventilators and troubleshooting.

Evaluation

These courses represent the first delivery of ACES to residents in family medicine. Postcourse questionnaires were distributed to all participants. Residents who did not attend both days of the course were excluded from the study. Questionnaires were delivered electronically, and 3 reminders were sent after the course. The survey included both Likert-scale (5-point) and open-ended questions.

We used quantitative methods to analyze the Likert-scale data, treating the responses as scale data. Means and 95% confidence intervals were reported. Intergroup comparisons of Likert-scale

data were done using independent-sample *t* tests and one-way analysis of variance, with significance set at $p < 0.05$. Comparisons of categorical data were performed using χ^2 tests, again with significance set at $p < 0.05$. For comparisons of groups based on anticipated practice location, participants were classified as having a preference for “tertiary/suburban,” “rural/remote” or “both.” Statistics were calculated using SPSS version 15.

Qualitative data were reviewed and coded by one of us (T.G.W.) using a thematic analysis, in which themes were progressively defined and modified (with data recategorized as necessary) as information was analyzed.

RESULTS

The ACES courses were delivered to 49 second-year residents in family medicine. Responses to questionnaires were received from 37 participants, resulting in a response rate of 76%. Table 1 summarizes respondents’ sex, anticipated practice location(s) and intent to include inpatient or emergency work in their practices. In this cohort, men were more likely to practise in tertiary or suburban settings, and women were more likely to practise in rural or remote settings (Table 2; $p = 0.006$). However, there was no association between sex and the choice to include inpatient or emergency care in one’s practice.

The postcourse questionnaires contained 4 items addressing the level of complexity of the course (Fig. 1), 12 items related to the curriculum, content and outcomes of the course (Fig. 2), and 14 items related to the teaching and learning methods used (Fig. 3).

All course modules (including simulation) were rated as appropriate or close to it, with airway and circulation rated as slightly too basic.

With respect to course content and outcomes, all participants agreed (78% strongly so) that the course was relevant to their anticipated job-related needs. Sixty-one percent disagreed with the statement, “There were not enough opportunities for me to solve patient cases.” Participants intending to

Table 1. Demographics of respondents and their anticipated practices (n = 37)

Survey question	Response	% of respondents
Sex*	Male	22
	Female	76
	No response	3
Anticipated practice setting(s)†	Tertiary or large urban	35
	Small urban or suburban	62
	Rural	70
	Remote	24
Intent to include in practice†	Inpatient care	51
	Emergency care	70
	Neither	16

*Total does not equal 100% because of rounding.

†Participants were permitted to select more than 1 response.

Table 2. Association between respondents’ sex and anticipated practice setting (n = 36*)

Practice setting	No. of respondents	
	Male	Female
Tertiary or suburban	6	5
Rural or remote	2	13
Both	0	10

*One respondent did not indicate their sex.

work in tertiary or suburban centres were less likely to disagree. Seventy-nine percent agreed (41% strongly so) their technical skills improved because of the course. All participants agreed (68% strongly so) the course increased their confidence to manage the treatment of critically ill patients. Participants believed their competence improved with respect to breathing problems (97%), circulation (95%) and airway problems (92%). Female participants were more likely to strongly agree that their competence in airway and breathing problems had improved. Ninety percent indicated they planned to change practice because of the course. Finally, 97% agreed (83% strongly so) they would recommend this course to their colleagues and future residents in family medicine.

With respect to educational methods, 70% found the book to be useful preparation for the course; participants who intended to practise in rural or remote areas and who intended to include emergency or inpatient care in their practices were more likely to agree. All respondents agreed the slides were clear and easy to follow and the presentations enhanced their learning. All respondents agreed the case studies were a useful learning tool, and 76% indicated there was enough time for discussion and feedback. Those who intended to practise in rural or remote areas were more likely to strongly agree. Eighty-six percent agreed the use of the technical skills models improved their abilities. Ninety-two percent agreed there was enough time with the models; those who intended to include emergency or inpatient care in their practices were more likely to agree. Eighty-nine percent indicated the simulator recreated life-like crises, and 94% agreed the simulations reinforced the concepts taught in the course modules. Ninety-seven percent felt they gained skills in crisis resource management from the simulator, and 97% agreed they received useful feedback after the simu-

lations. Only 6% found the simulations too stressful, and 95% indicated the simulations increased their confidence to manage critical situations.

Participants were asked 5 open-ended questions. Four questions were for purposes of quality improvement, addressing content or materials that could be altered or added. Eighteen respondents indicated they would like more simulations. The only prevalent theme for content to remove was, "nothing."

One question investigated whether the course had an impact on participants' confidence and attitudes toward rural practice. Nineteen respondents (51%) commented that the course increased their confidence to care for critically ill patients; 8 (22%) indicated it increased their confidence to work in a rural location; and 4 (11%) indicated it increased their comfort to include inpatient or emergency care in their practices. For example, one respondent wrote that the course "greatly increased my confidence to work in rural or remote areas with fewer resources." Another indicated, "Yes, I do feel more confident to work in emergency because I feel that in worst-case scenarios I have some tools at my disposal." Only 5 respondents (14%) indicated the course had little impact on their confidence or attitude; 4 of these respondents stated it was because they already worked or planned to work in rural areas or in the emergency department.

DISCUSSION

Skills in resuscitation are an important component of medical practice in rural and remote areas, where family physicians are responsible for the recognition and initial stabilization of critically ill patients.⁴ Previous studies of training in advanced cardiac life support (ACLS) in rural communities have demonstrated improvements in patient care and outcomes.^{5,6} Complementary to ACLS, the ACES

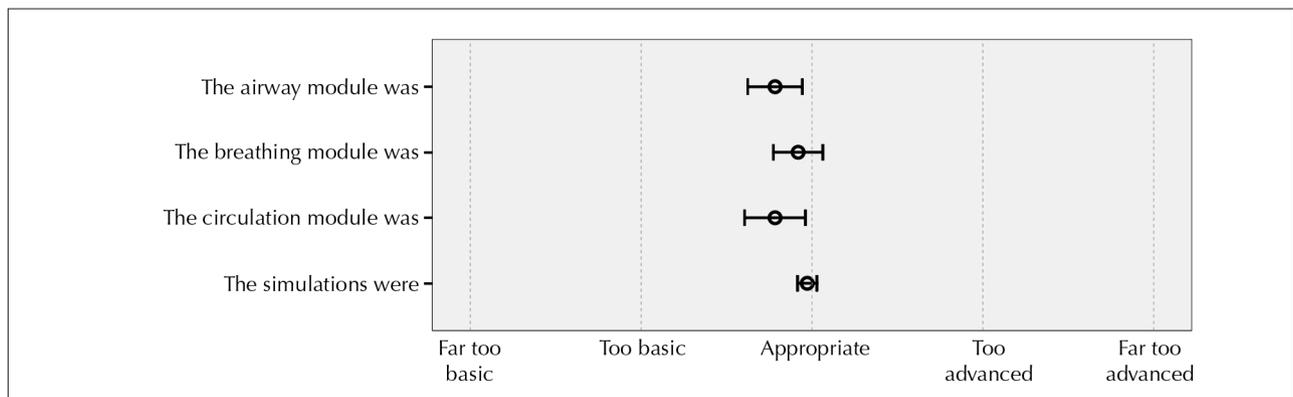


Fig. 1. Mean responses regarding participants' perceptions of the level of complexity of the course. Error bars represent the 95% confidence interval.

course aims to enable practitioners to provide resuscitation for the undifferentiated pre-arrest critically ill patient. This questionnaire-based ACES evaluation targeted levels 1 (satisfaction) and 3 (competence, confidence, intent to change practice) of Kirkpatrick and Kirkpatrick's model of program evaluation,⁷ with information based on participant perceptions. The 76% response rate is acceptable for analysis.

Overall, the ACES course was very well-received by the participants. Likert-scale scores were exceptionally positive, which suggests the

course is particularly appreciated by family physicians at this stage of their training. All respondents agreed the course was relevant to their anticipated job-related needs, and 97% would recommend the course to future residents.

Among course participants, some intended to practise in a rural or remote setting (largest group), some in a tertiary or suburban setting and some in both. Interestingly, female participants were more inclined to practise in rural or remote settings, although the current trend appears to be that about equal numbers of men and women enter rural practice.⁸

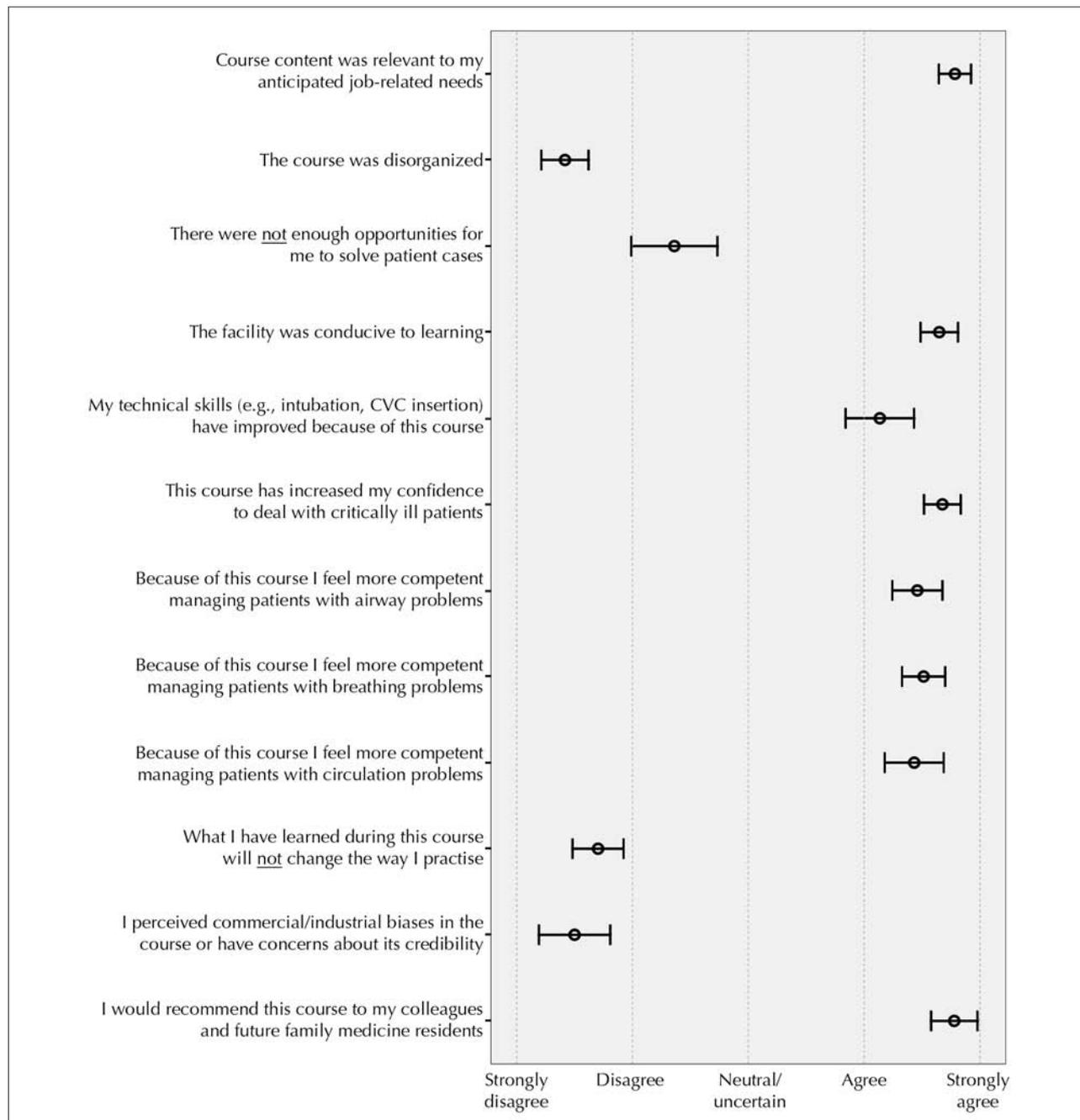


Fig. 2. Mean responses to Likert-scale items related to curriculum, content and outcomes. Error bars represent the 95% confidence intervals. CVC = central venous catheter.

The level of difficulty of the modules was considered appropriate by the vast majority of participants. Some found the airway and circulation modules too basic. These modules may benefit from addition of more advanced material. The relevance, organization, format and impartiality of the course were all rated favourably.

Responses to items addressing outcomes of the course were tremendously encouraging. Seventy-nine percent of respondents felt their technical skills had improved because of the course. A range of 92% to 97% believed their competence in airway,

breathing and circulation management had improved. All respondents agreed their confidence had improved, and 90% indicated they would change some aspect of their practices. These findings are particularly encouraging, because intention to change practice has been shown to predict actual changes in behaviour.^{9,10}

With respect to course content, the only significant theme that emerged regarding what should be removed from the course was “nothing,” indicating all current course content should remain. If there were room to add content, a few themes were



Fig. 3. Mean responses to Likert-scale items related to teaching and learning methods used in the course. Error bars represent the 95% confidence intervals. ACES = Acute Critical Events Simulation.

prevalent: more on medications (which could be accomplished with a pocket reference card), pediatrics and mechanical ventilation. However, none of these recommendations were given by more than 14% of respondents.

A prevalent comment for course improvement was to offer more simulations. Although possible, increasing the number of scenarios for each participant would have a substantial impact on the course's length and cost, given the logistics, equipment requirements, personnel and cost involved in running simulations.

The course was designed such that the modules are not a prerequisite to the simulations; feedback focuses on crisis resource management more than medical decisions specific to the cases. Although skills in crisis resource management are generic,¹¹ problem-solving skills are not,¹² so it may be beneficial to offer the simulation module last, as some respondents suggested. However, the course and simulations were rated favourably even by those who entered the simulation sessions before completing all other modules.

Participants were asked explicitly about the impact of the course on their confidence. Encouragingly, 84% of respondents indicated their confidence had increased, either with respect to critically ill patients generally, rural practice or inclusion of emergency or inpatient care in their practices. This sentiment was echoed in responses to the open-ended question about confidence. It was a primary goal of this program to augment trainees' confidence to practise in a rural or remote setting including emergency or inpatient care. Results from the questionnaire suggest this goal was achieved.

Limitations

The results of this evaluation are limited by the method, data source and sample size. A questionnaire was used to collect data from as many participants as possible, although the depth of qualitative information to be gained was limited. Furthermore, results pertaining to competence and intent to change are based on respondents' self-perceptions, not testing or performance observation. The small sample size reflects the cohort to whom this course was delivered and limits the generalizability of results. Finally, women outnumbered men in this sample; it is not clear if and how this may have affected findings. Although this study was an encouraging first step in evaluating the course, further research is required to determine whether com-

petence is objectively increased or changes in practice are indeed implemented.

CONCLUSION

The ACES course was adapted for and delivered to second-year residents in family medicine at the University of Ottawa to enhance their competence in identifying and resuscitating critically ill patients, and to increase their confidence to work in rural or remote areas and to include inpatient or emergency care in their practices. The course was rated as relevant by all participants, who indicated perceived increases in competence, increased confidence and intentions to change aspects of their practices.

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Primary care outreach in Markham, Ont

James Taylor MDCM

Historically, Canadian family physicians have operated out of their own clinics, providing excellent primary care to patients who come through the front doors. More recently, health care delivery has moved away from older models of paternalistic, physician-centred care and toward patient-centred care. At the same time, there are ongoing efforts to maximize efficiency in our resource-limited health care system. One approach that could be integral to the future of health care delivery in Canada is primary care outreach.

Health for All is a new family medicine teaching unit in Markham, Ont, affiliated with the University of Toronto in Ontario. In addition to delivering and teaching excellent primary care, the new team is committed to global equity and social justice. When the team is up and running with a full complement of residents, the unit will serve 10 000 patients, and the aim is to proactively seek out patients who would otherwise have difficulty navigating the health care system. In September 2010, as part of my Fellowship in Global Health and Vulnerable Populations at the University of Toronto, I set out to help Health for All identify the underserved populations in Markham and the barriers to accessing primary care that existed.

During a 1-month period, I met with representatives of community groups in Markham, senior administrators at the Markham Stouffville Hospital and the Town of Markham, and leading public health experts and primary care advocates in Toronto. Given that up to 75% of the population in areas of Markham are immigrants (and up to 65% speak neither French nor English at home), I expected that these would be the people who had difficulty accessing primary care, and that ultimately they would welcome a presentation on how to access primary care services.¹ The reality was quite different.

Underserved

In 2001, the National Centers of Excellence in Women's Health identified axes of oppression for women in accessing primary care in the United States: age, sexual orientation, socioeconomic status, gender, race, and ethnicity.² After my community visits and interviews, I added people with disabilities and stigmatized populations to my list.

Contrary to my preconception that people would not have family doctors, the impression I got from discussions with medical experts and community leaders was that most people in Ontario who want family doctors have them. In fact, 90% of Ontarians reported having regular medical doctors, 95% of Ontarians with chronic conditions reported having regular medical doctors, and few reported experiencing serious barriers to accessing primary care.³

This is not to say that barriers to access do not exist. The *healthy immigrant effect* is a well-documented phenomenon in which new immigrants, on average, arrive in better health than native Canadians and, over time, their health declines until it converges with that of the Canadian-born population.⁴ In fact, the 2001 Canadian Community Health Survey found greater use of general practitioners by visible minorities, yet considerably lower use of cancer screening tests such as prostate-specific antigen testing, mammograms, and Papanicolaou smears.⁵ The only group I encountered who did not have equal access to family doctors was the homeless and underhoused; for example 75% of clients of a Markham identification clinic had family doctors compared with 95% of the general population.⁶ Other underserved groups identified included the lesbian, gay, bisexual, and transgendered community; patients with palliative diagnoses who had been discharged from specialist care in Toronto; and young, pregnant teenagers not living at home. With a longer time frame for the project, many other underserved groups in Markham almost certainly would have been identified.

A variety of barriers to access emerged, which I grouped together under language, cultural, informational, cost, and transportation categories. These categories were not mutually exclusive.

Language barriers manifest in patient inability to convey health concerns in English, patient inability to interpret medical directions, and physician inability to comprehend health concerns.⁷ A considerable barrier that I have witnessed time and again training in Montreal, Que, northern Ontario, and Toronto is the inadequacy and unacceptability of interpreter services. Patients are generally expected to convey their health concerns through family members, often grandchildren. While specific immigrant or refugee health centres have evolved in Ontario with ethnocultural-specific staff support workers and interpreter services, there remains room for improvement in this area.⁸

Informational barriers can exist to navigating the health care system, as well as to educating patients about health-related issues and recognition of the need for care. For example, in China hospitals provide primary care. New immigrants often assume that the same is true here and have no concept of what family doctors are or the services they provide. In addition to language and cultural informational barriers, illiteracy and cognitive impairment are pervasive barriers to dissemination of health information.

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Among those older than 16 years of age, 42% of Canadians and Ontarians, and 48% of Torontonians, have literacy levels below that required to cope in a modern society.⁹

While Canada is widely revered for its universal health care system, cost remains an important barrier to accessing primary care. Many providers are unfamiliar with the Interim Federal Health Program for new refugees, who then face substantial costs that should be covered by the program.⁴ In Toronto, 18% of homeless people have never had health insurance and 31% do not have health insurance cards.¹⁰ Even with the Ontario Health Insurance Plan, many people cannot afford medications, equipment, eyeglasses, and dental care. Some of these patients get labeled as noncompliant, further compounding their access issues. Geographic access to family physicians can be poor and public transit can be costly and difficult to navigate, particularly for elderly and infirm patients. Of course, the discussion of cost would not be complete without addressing the issue of physician knowledge of the social determinants of health, and their lack of awareness of patients' income levels, housing status, and personal circumstances.

While evidence suggests—and community leaders in Markham agree—that immigrants have access to family doctors, ethnocultural barriers can influence the acceptance of preventive care, screening, and treatment. New immigrants tend to integrate in a functional way, but only go to see doctors when they are suffering. It takes generations to change behaviour when it comes to regular check-ups, antenatal care, diet, exercise, smoking, and stress management. Also, the illness experience differs considerably among cultures, and patients might describe their symptoms in terms of the Taoist concepts of *yin* and *yang*, or believe that hostile spirits or curses are the root cause of their illnesses. Provider awareness of these cultural differences is essential to caring for these patients adequately.¹¹

Overcoming

While a multitude of barriers to accessing primary care in Markham were identified, it was abundantly clear that there is great potential for the new family medicine teaching unit to actively address these barriers. The seeds for community partnerships have been sown; a vision retreat hosted by the Health for All team was well attended by many community leaders, patients, and hospital and municipal administrators who were interviewed for this project. The desire for community-based services expressed by many of these groups was supported by the findings of the 2003 nurse–community health advocate study, where barriers to access were reduced substantially by providing assistance with transportation, accompaniment to secure health services, interpretation and translation of health information, advocacy, information about local resources, and education about health and self-care.¹²

One success story in primary care outreach comes from the family medicine teaching unit at St Michael's Hospital

in Toronto, where family medicine residents spend 6 weeks at Seaton House practising with marginalized populations in shelters. This experience plants the seeds of social justice in family medicine trainees and aligns with the CanMEDS–Family Medicine role of health advocate.

A local success in Markham involved a community-based group that provided services in various community settings including Sikh temples, mosques, and churches. In partnership with the Markham Stouffville Hospital, a diabetes screening and education program was carried out and was a resounding success in the eyes of both the providers and the patients. Unfortunately, the resources did not exist to carry the program forward, leaving community members frustrated. This model for bridging the gap between mainstream programs and difficult-to-reach populations should be considered for future primary care initiatives while being mindful of the need for sustainability.

Health for All has initiated a process of proactively identifying barriers to accessing primary care in the community and reaching out to community groups, the Town of Markham, and other health care professionals to build partnerships and identify opportunities to connect with and care for underserved populations. While there are many challenges to this approach—not the least of which is the identification of new resources and the potential realignment of existing resources—the Health for All team is well positioned to take a leadership role, in partnership with the community, in establishing primary care outreach in Markham. 

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Competing interests

None declared

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Religion in primary care

Let's talk about it

John Guilfoyle MBBCh BAO FCFP Natalie St Pierre-Hansen

Religion continues to be an important element in the lives of many of our patients, despite an increase in atheism, and even antitheism, in academic and popular press.¹ A 2008 Harris-Decima poll found that 72% of Canadians believed in God.² Interest in the integration of spirituality, religion, and medicine is increasing: there are more than 1600 published studies on the relationship between religion and mental and physical health.^{3,4}

The broad concept of spirituality fits well with family medicine's perception of holistic care. But for many of our patients, spirituality means religion. Although often used interchangeably, religion and spirituality are different. They can inform each other but are separate. Religions create, at times, very distinct identities, behaviour, and expectations. This is quite distinct from the more amorphous, less delineated, more nebulous notion of spirituality. In many social scenarios, religion divides people and we often shy away from discussing it. But how relevant is religion in the care and healing of our patients? Are physicians more comfortable with the concept of spirituality and less so with religion? Can it be a dimension in the patient-physician interaction, and how is it best addressed?

Throughout human history man has sought a transcendent explanation of his existence. The varied stories of the world's great faiths give eloquent testimony of this across the expanse of time and the divide of culture. Religion attempts to answer that eternal question: What is the purpose of existence? The answer seems to be 2-fold. The first is the relationship of man with the divine, with what many call God. This relationship extends beyond the limits of our corporeal reality to the spiritual realm with its notions of infinite and eternal. The second purpose of existence focuses on our relationship with others. The emphasis is to become useful and productive members of society, thus contributing to our personal well-being and that of others.

Religion and health

Religion's contribution to health and well-being is controversial. History reveals how religion has directly contributed to wars, suffering, and destruction. Yet whatever the devastation laid at the feet of religion, it has easily been exceeded by that of man-made creeds. The

horrors, particularly in the past 100 years, of fascism, imperialism, communism, socialism, capitalism, and racism come readily to mind. Still, this is hardly a ringing endorsement for the positive contribution of religion to the health of the human family.¹

Despite this rather gloomy analysis, accounts abound of religion helping people live lives that are rich with meaning and significance. It influences individuals and groups to come to the assistance of others. The Christian concepts of *agape* and *caritas*, and their fellows, such as *zakat* in Islam and similar concepts in all the great religions, speak to a preoccupation with assisting in the well-being of others. This has given rise to endeavours, particularly in education and health care, that have benefited countless millions.

If we take the position that religion can contribute positively to the human condition, it might be helpful to understand how this is achieved.

It is not clear what elements of religion are essential. Are the intrinsic elements of one's relationship with God most important? Are the extrinsic elements of religious practices and relationship with community more important? Social cohesion might lessen conflict and promote health. Altruism, philanthropy, and caring for others might be key elements, almost paradoxically, in caring for oneself. Perhaps the interplay between the highly personal and private relationship with God becomes fully evolved only when it is expressed tangibly in helping others and contributing in a meaningful way to society.

Most studies on this topic use religious attendance as a measure for extrinsic religiosity.⁵ Studies examining intrinsic elements are harder to evaluate (and less common) than those evaluating religious commitment, as they lack consensus on the term *spirituality* and struggle to measure an intangible concept.⁶

A literature review found that 80% of the relevant studies showed a positive association between religious commitment (using various measures of religious involvement) and health status, with 15% showing neutral associations and 5% showing negative associations.⁷ Studies on religious commitment and mental health showed very similar percentages (83% positive, 14% neutral, and 3% negative).⁸ Religiosity was also associated with longer life expectancy.⁶ One American

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study in 1998 (n=232) examined the relationship between religious attendance and recovery from heart surgery. Six months after surgery, 11% of the nonreligious patients had died while none of the 37 “deeply religious” patients had died.⁹

Others are more critical of the data. Sloan and colleagues’ 1999 analysis finds methodologic issues to be abundant in the existing studies, including failure to control for multiple comparisons and for confounding variables and covariates. They conclude that the evidence is “weak and inconsistent.”⁴ In a 2010 Gallup poll (n=550 000) that controlled for a number of demographic and geographic variables,¹⁰ people who considered themselves very religious had only slightly higher physical health index scores than those who were not religious (78.0 vs 76.6).¹⁰

Despite flaws in most studies, some do control for confounding variables and suggest that the relationship between religious attendance or observance and health status is causative.¹¹ Religious attendance requires getting to services and might simply be associated with mobility, a marker of health. Matthews and colleagues highlight studies that suggest an inverse relationship between attendance and disability.⁶ They examine the suggestion that religious attendance simply leads to health-promoting behaviour. Yet, when controlling for such behaviour, the positive effects of religion remained.⁶

Spiritual discussions with patients

How do we approach our patients who are religious? Is religion merely another cultural variable or a marker for other factors that better explain variability in disease and health? Is it enough for physicians to know of varied cultural elements of the many religions—a form of cultural competence? How do we assess and help those who do not belong to a defined religion, yet for whom the spiritual dimension of health is important?

The percentage of patients who want to be asked about their spiritual beliefs ranges greatly (4% to 80%) depending on the setting¹² and severity of their illnesses.¹³⁻¹⁵ A 2003 American multicentre survey (n=456) showed that one-third of primary care patients wished to be asked about religious beliefs during routine visits, but not at the expense of discussing their medical concerns.¹²

A 2002 American random-digit-dial telephone survey (n=1052) found that while 69% would want spiritual discussions if seriously ill, only 3% would want those discussions with physicians.⁵ Ambulatory care patients (n=177) expressed a higher desire to discuss spirituality with physicians: 66% said that religious inquiry would increase their trust in the physician and almost 50% indicated religious beliefs would influence their medical decisions.¹³

There are no known Canadian studies examining physicians’ perspectives on religious discussion in their

practices. What is clear from the American data is that even when physicians strongly believe that religion or spirituality has an influence on health,^{16,17} they rarely discuss religion with their patients.¹⁸⁻²¹ The reasons include lack of time, lack of training in taking spiritual histories, concerns about projecting personal beliefs, difficulty identifying receptive patients, physician upbringing, culture, and their own lack of spirituality.^{20,21}

Sloan and colleagues acknowledge positive and negative effects of religious-oriented dialogue. They identify several ethical issues around the involvement of religion as adjunctive medical treatment and argue that it might be an abuse of physicians’ power and authority if they appear to be imposing their beliefs upon patients. They suggest the possibility that religious discussion might actually do harm, as linking religion with health might reinforce self-blame and the idea that illness is due to insufficient faith.⁴ Rumbold also suggests that spiritual care might be counterproductive, as spirituality enhances autonomy, which could be eroded by a doctor’s involvement.²² He suggests that “the experts will have taken over this aspect of life as well.”²²

Successful interventions in this area require a high degree of personal and spiritual maturity.²³ This requires the physician to reflect on his or her approach to religion and on a spiritual dimension of health. Increased attention to this in preclinical training seems logical so that the ethical dimensions are explored in tandem with other relevant cultural domains.

Spiritual assessment should “seek to elicit the thoughts, memories and experiences that give coherence to a person’s life.”²² It need not be an intrusive or invasive process. It opens another chapter in the story of the life of a patient. It might help us understand how and why patients approach their lives, and give us a richer understanding of how individual patients interpret the challenges they face. It might assist the therapeutic alliance in useful and unexpected ways. The very act of acknowledging a spiritual dimension in health allows the patient to know that we are sensitive to needs, aspiration, and concerns in this arena.

There is a danger here. If we blunder into the spiritual or religious journey of another with judgmental, insensitive, and unhelpful comments and analyses, we will do more harm than good. Another caveat, *physician know thyself*, rings particularly true in this arena. We will be called upon to examine our own worldview with respect to religion and our inherent biases.

A better understanding of how religion can affect our health has important implications for training, for practice, and for research. If we take the position that religion can contribute to the well-being of the individual and, by extension, society, family physicians might find it useful to understand and encourage its heuristic effect. This challenges us to research this area further,

particularly in Canada. It adds another dimension to the physician-patient relationship and asks us to look at the communities we serve with a new lens.

Religion is an important aspect in the lives of so many in our world. Perhaps we can help it to be both helpful and healthful. 

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Competing interests

None declared

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Epidural steroid injections for low back pain in rural practice: a 5-year retrospective study

See related articles on pages 119, 145 and 148.

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Introduction: Epidural steroid injections (ESIs) are a safe and accessible therapy for chronic low back pain, one of the most common and challenging chronic conditions seen in primary care. However, the indications for and effectiveness of ESI remain controversial. In rural settings with limited public transportation infrastructure, such a mobility-limiting condition can have even more negative effects on quality of life and function. Furthermore, diagnostic and specialist services are often limited. A paucity of safe, effective and accessible treatments leads to heavy reliance on oral analgesics, especially opioids, which have well-known complications.

Methods: We reviewed the use of ESI for the 2 most common types of chronic low back pain in those with neurologic symptoms: lumbar disc herniation (LDH) and lumbar spinal stenosis (LSS). We did a retrospective chart review of all patients who underwent ESI between Jan. 1, 2005, and Feb. 25, 2010, at our rural hospital in northwestern Ontario.

Results: During the study period, 123 ESIs were administered to 65 patients. After the first injection, 40 patients (62%) reported improvement, 10 (15%) reported worsening or no change, and 15 (23%) had no follow-up documented.

Conclusion: Some patients with neurologic compromise from LDH or LSS have improvement in symptoms after ESI. A prospective study is underway to more rigorously assess the effectiveness of this treatment.

Introduction : Les injections épidurales de corticostéroïdes (IEC) constituent un traitement sécuritaire et accessible de la lombalgie chronique, une des affections chroniques les plus courantes et complexes en médecine de premier recours. Les indications et l'efficacité des IEC ne font cependant pas consensus. En milieu rural, où les infrastructures de transport public sont limitées, une maladie qui affecte autant la mobilité peut avoir des effets encore plus négatifs sur la qualité de vie et le fonctionnement. En outre, les services diagnostiques spécialisés sont souvent restreints dans ces régions. Le manque de traitements sécuritaires, efficaces et accessibles entraîne une importante dépendance aux analgésiques oraux, particulièrement aux opiacés, dont les complications sont bien connues.

Méthodes : Nous avons passé en revue l'utilisation des IEC pour les 2 plus courants types de lombalgie chez des sujets qui en présentent des signes neurologiques : la hernie discale lombaire (HDL) et la sténose spinale lombaire (SSL). Nous avons examiné de manière rétrospective les dossiers de tous les patients qui ont reçu des IEC entre le 1^{er} janvier 2005 et le 25 février 2010 dans notre hôpital rural du Nord-Ouest de l'Ontario.

Résultats : Durant la période de l'étude, 123 IEC ont été administrées à 65 patients. Après la première injection, 40 patients (62 %) ont signalé une amélioration de leur état, l'état de 10 patients (15 %) s'est aggravé ou est resté stationnaire et pour 15 sujets (23 %), nous n'avons pas obtenu de données de suivi.

Conclusion : Certains patients qui éprouvent des difficultés neurologiques en raison d'une HDL ou d'une SSL voient leurs symptômes s'améliorer après des IEC. Une étude prospective est en cours pour évaluer plus rigoureusement l'efficacité de ce traitement.

INTRODUCTION

Low back pain is among the most common presenting symptoms in primary care.^{1,2} Whereas the vast majority of patients presenting with back pain have an excellent prognosis for both pain relief and functional recovery, the smaller number of chronic cases that require prolonged follow-up constitute a disproportionate number of clinic visits. In a rural setting, these patients typically travel long distances for advanced imaging and orthopedic referral.

Detailed pathophysiologic models and classification systems are in stark contrast to the great uncertainty faced by primary care clinicians and specialists in specific cases: an estimated 85% of cases cannot be given a precise diagnosis.^{3,4} The uncertainties arise from both the complexity of the disease entity itself, and from the limitations of our tools and models.

Chronic back pain often interacts with a host of other medical and psychological impairments, with each condition exacerbating the others and complicating management. In one survey, 20% of patients with lumbar spinal stenosis (LSS) reported symptoms of depression and 25% reported being "generally dissatisfied with life."^{5,6}

Frequently used terms such as "sprain," "strain," and "degeneration" have no widely accepted histologic or anatomic definition and are effectively synonymous with "idiopathic."⁷ The association between clinical and imaging findings on the one hand and patient distress and disability on the other is generally poor. Physical findings, although clear-cut in many acute cases, become increasingly ambiguous in more chronic ones. Inappropriate use of imaging is widespread and well-documented.⁸⁻¹⁰ The functional relevance of "abnormal" findings is often unclear. Potentially significant findings such as bulging or herniated discs turn out to be very common, even among asymptomatic adults,¹¹⁻¹⁴ and are often incidental, even in symptomatic patients. Such findings can lead to overdiagnosis, increased anxiety, and unnecessary and potentially harmful treatments.⁷ These uncertainties manifest as wide variations in diagnostic workup and treatment.⁴

At initial presentation, the first concern is ruling

out rare (1%–3%)⁷ but potentially life- and limb-threatening causes of back and lower extremity pain: cauda equina syndrome, tumour, epidural abscess, spinal osteomyelitis and aortic aneurysm.¹⁵ Fortunately, although these conditions do have their own diagnostic challenges, the key to accurate diagnosis remains an index of suspicion and thorough evaluation, which may involve emergency, long-distance transport for rural patients.

Of the remaining, so-called mechanical, cases, about 70% are short-lived, often labelled as "sprain" or "strain," and another 10% are due to nonspecific degenerative changes in discs and facet joints.⁷ Lumbar spinal stenosis and lumbar disc herniation (LDH) each account for 3%–4% of cases at initial presentation,¹⁵ but can portend a more chronic course and hence constitute a much larger portion of prevalent disease. Whereas 90% of patients presenting with nonspecific back pain within 3 days of onset recover within 2 weeks,¹⁶ those patients with LSS are likely to experience persistent or worsening pain, despite little progression in neurologic dysfunction. Two follow-up LSS studies (which included 32 and 47 patients, respectively) suggested that 50%–75% of patients with this diagnosis experience either persistent or worsening symptoms.^{17,18} In distinction, LDH has a more favourable natural history, with most patients showing significant clinical improvement within the first 6 weeks.¹⁹ A magnetic resonance imaging follow-up study has suggested that the herniation itself resolves at least partially in two-thirds of cases.²⁰

As with other conditions of subacute and chronic pain, there has been little progress in developing safe, accessible and reliably effective therapies. In a rural setting with limited public transportation infrastructure and large distances, the mobility limitations imposed by back pain can have even greater consequences for quality of life and function. In addition, diagnostic and therapeutic facilities are less accessible in such areas. Frequently, opioid analgesics become the only option for symptomatic treatment, with their limited effectiveness and long-term medical and social complications.²¹

Epidural steroid injections (ESIs) represent a fairly economical, accessible and safe alternative in

the rural setting. Their effectiveness, however, has been controversial since their introduction in 1953.²² Most ESI research to date focuses on LDH, often excluding patients with LSS.

In this paper, we briefly review the literature on ESI for low back pain related to LSS and LDH, and present 5 years of clinical experience in a rural hospital. We have included both LDH and LSS patients in our study. To our knowledge, this is the first study to be undertaken in a rural setting using general practitioner–anesthetists undertaking classic epidural technique without advanced imaging. This is currently the only widely available delivery model for ESI in the rural setting.

LOW BACK PAIN, LDH AND LSS

Lumbar disc herniation results from degenerative tears in the annulus fibrosus of the intervertebral discs, leading to herniation of nucleus pulposus into the spinal canal, or neural foramina.²³

Lumbar spinal stenosis is the gradual narrowing of the spinal canal, or the lateral recesses and neural foramina, leading to radicular or chordal neurologic dysfunction. It can arise congenitally²⁴ (primary disease) or, far more commonly, secondary to hypertrophic degenerative changes, degenerative disc disease or less common conditions.²⁵ The most frequent sites of clinically significant stenosis are the lumbar followed by the cervical spine.

In both cases, the resulting mechanical stress and tissue injury can trigger a complex of still poorly understood neurologic, inflammatory, microcirculatory, immune and endocrine changes. Compression can lead to local inflammation; sensitization of surrounding tissue and changes in the excitatory state of nerves;²⁶ impairment of arterial supply and venous return, leading to ischemia and further inflammation;^{27,28} autonomic dysregulation and further impairment of circulation;²⁷ and exacerbation of pain.

The classic manifestation of LSS is neurogenic claudication: a constellation of uni- or bilateral weakness, dull pain and fatigue involving the legs and lower back, worsening with activity and backward extension (e.g., walking downhill, looking up) and improving with rest and forward flexion (e.g., walking uphill, pushing a cart).²⁹ It is typically accompanied by sensory abnormalities, such as numbness and paresthesia.⁷ Consistent with a slow degenerative etiology, patients usually present with a history of months to years of gradually increasing symptoms.

Unlike most cases of LSS, the source of mechanical stress in LDH tends to arise more suddenly and

regress in most cases.^{19,20} However, despite differences in initial etiology, chronic cases of LDH likely involve the same pathophysiologic processes as LSS, with stenosis being caused by the herniated disc and the associated inflammatory and degenerative changes.

MANAGEMENT

Nonsurgical treatment

In addition to treatment for medical and psychiatric comorbidities, conservative management for low back pain consists of activity modification (to reduce spinal extension), conditioning exercise, stretching, physiotherapy, meditation and relaxation techniques, and transcutaneous electrical nerve stimulation.³⁰ Trials of conservative management regimens typically use multimodal strategies and report some improvement in up to 70% of cases.^{31–33}

Oral analgesics, usually nonsteroidal anti-inflammatory drugs (NSAIDs) and opioids, are used frequently but with limited effectiveness. There is no clear evidence for the benefit of one class over another, and both have potentially substantial side effects with prolonged use. NSAIDs are associated with renal impairment and gastrointestinal bleeding and, in the case of cyclooxygenase-2 inhibitors, potentially elevated cardiovascular risk.³⁴ The high incidence of diabetes and diabetic renal compromise in many rural populations, such as in our own catchment area in northern Ontario, limits the use of NSAIDs. Opioids, on the other hand, are associated with tolerance, potential abuse and dose-related risk of death.²¹ One recent study suggests that the use and dose of opioids for nonmalignant pain in socioeconomically disadvantaged patients has substantially increased in the province of Ontario,²¹ leading to increased mortality.

Surgery

For LDH without symptoms of cauda equina syndrome or foot drop, conservative management is recommended for at least 1 month, as only 10% of patients have sufficient pain after 6 weeks to consider surgery.⁷ Lumbar discectomy is the most common surgical treatment for refractory pain from LDH and has been documented to offer improved pain relief for up to 4 years.⁷

Lumbar spinal stenosis has a much higher rate of surgical intervention and has become the most frequent indication for spinal surgery in adults older than 65 years.^{35–37} Lumbar laminectomy for LSS is better supported by outcome evidence than the more complex instrumented fusion procedures.^{35,38}

In general, the effectiveness of surgery for chronic back pain remains controversial, and there is no consensus on specific indications. The general trend in outcomes is a transient improvement in pain scores in the first 1–5 years, with perhaps subtle improvement in disability and functional outcomes in the first 1–2 years. The longest follow-up data on LSS comes from the Maine Lumbar Spine Study,^{39–41} which followed a cohort of 148 patients for 10 years. Patients who received surgical treatment had more severe symptoms and worse functional status at baseline, and better outcomes at 4-year evaluation than the patients who received nonsurgical treatment.

Epidural steroid injections

Epidural steroid injections are a safe and widely available alternative treatment. Three techniques are commonly used: interlaminar (“classic”), transforaminal and caudal. The transforaminal approach requires fluoroscopic guidance, which is not commonly available in many rural centres. Both the caudal and transforaminal techniques require specific skills, whereas most rural anesthesia providers are proficient at interlaminar epidural injections, commonly used in obstetrics.

Overall, the evidence regarding the effectiveness of ESI over placebo is vast, yet inconclusive. The latest Cochrane review on the subject found a lack of evidence, not only for epidural steroids but also for other injection therapies for subacute or chronic low back pain.⁴² Some studies have reported a range of benefits, from reducing symptoms to delaying or reducing the rates of surgery,^{43–45} whereas others have found no benefit.⁴⁶ Difficulties in diagnosing the exact cause of chronic low back pain make classification of patients and identification of clinically relevant subgroups difficult. It may be that certain etiologies of low back pain are more responsive to epidural steroids than others. In addition, comparison of the techniques used in the positive versus negative trials suggests that the choice of steroid may be important, with nearly all studies using methylprednisolone having negative findings and most studies using other steroids finding some benefit.⁴⁵ Thus far, our centre has been using only methylprednisolone for ESIs.

METHODS

Data collection and analysis

Charts for all patients who underwent an ESI between Jan. 1, 2005, and Feb. 25, 2010, were

reviewed by one of the authors (L.M.). Demographic data, presenting symptoms, diagnosis, imaging results, comorbidities, dates and number of ESIs were coded. The patients had been referred by their family physicians to 2 local general practitioner–anesthetists. We were primarily interested in patients’ diagnosis at the time of injection and their response to treatment.

Outcome at follow-up was documented as “improved,” “no difference/worse” or “no follow-up,” as recorded in the chart. This represented physicians’ overall impression based on the patient’s reports of symptom severity, as well as physical findings. There was substantial variation in the type and detail of follow-up data available, as this was a retrospective chart review.

Data were collected in Excel and imported into IBM SPSS software (version 19.0 for Windows). Data were initially analyzed descriptively, with frequencies and percentages for categorical data and means and standard deviations for continuous data. The characteristics of those who saw improvement, saw no improvement or were lost to follow-up after the initial injection were compared using Pearson χ^2 tests for categorical data, and one-way analysis of variance for continuous data.

Research ethics approval was obtained from the Sioux Lookout Meno Ya Win Research Review Committee.

Method of injection

Before the injection, the physician discussed the risks and procedure with each patient. All patients sat in lumbar flexion on an operating table. The iliac crest was used as a reference point for the L3–4 interspace. From there, the level of injection was identified based on imaging results and patient anatomy. Using sterile technique, after subcutaneous lidocaine injection, the epidural space was identified using loss-of-resistance to air with a 17-gauge Tuohy needle, and 80 mg of methylprednisolone in 5 mL of 0.9% saline was injected. All patients received advice on postinjection management and instructions to follow up with their family physicians.

Previous back surgery, such as spinal fusion, laminectomy or discectomy, often alters access to the epidural space. As a result, in some cases the injection was given 1 level above or below the affected site.

RESULTS

During the 5-year study period, 123 ESIs were administered to 65 patients. Characteristics of the

patients are provided in Table 1. Given the small sample and our aim of identifying factors for future investigation, we highlight all findings with $p < 0.15$. Slightly more than half of all patients were female, one-third self-identified as Aboriginal and the aver-

age age at first injection was 55 years.

The most common comorbidities were hypertension (52%), osteoarthritis (49%), psychosocial conditions (37%) and type 2 diabetes (32%). The most commonly documented initial symptoms were back

Table 1. Characteristics of patients, by outcome after first epidural steroid injection

Characteristic	No. (%) of patients*†				p value‡
	Total, n = 65	No improvement, n = 10	Improvement, n = 40	Lost to follow-up, n = 15	
Age, yr, mean (SD)	54.8 (18.5)	48.6 (20.9)	56.2 (17.4)	55.1 (19.9)	0.51
Sex					0.70
Male	27 (42)	3 (11)	17 (63)	7 (26)	
Female	38 (58)	7 (18)	23 (61)	8 (21)	
Aboriginal (self-identified)	24 (37)	4 (17)	16 (67)	4 (17)	0.64
Location					0.26
Sioux Lookout, Ont.	42 (65)	5 (12)	24 (57)	13 (31)	
Northern community	15 (23)	4 (27)	10 (67)	1 (7)	
Other/unknown	8 (12)	1 (13)	6 (75)	1 (13)	
Radiographic diagnosis					
Lumbar spinal stenosis	33 (51)	4 (12)	22 (67)	7 (21)	0.65
Lumbar disc herniation	52 (80)	9 (17)	30 (58)	13 (25)	0.44
Spondylolisthesis	16 (25)	3 (19)	10 (63)	3 (19)	0.85
Back pain NYD	5 (8)	1 (20)	2 (40)	2 (40)	0.58
Symptoms					
Leg pain	54 (83)	8 (15)	35 (65)	11 (20)	0.44
Leg weakness	31 (48)	8 (26)	17 (55)	6 (19)	0.08
Leg numbness	33 (51)	8 (24)	19 (58)	6 (18)	0.11
Positive "shopping cart" test	8 (12)	2 (25)	6 (75)	0 (0)	0.23
Bowel or bladder incontinence§	9 (14)	3 (33)	4 (44)	2 (22)	0.26
Limited exercise tolerance	36 (55)	6 (17)	22 (61)	8 (22)	0.95
Abnormal deep tendon reflexes	25 (39)	5 (20)	15 (60)	5 (20)	0.60
Back surgery	15 (23)	4 (27)	9 (60)	2 (13)	0.29
Analgesic use					
Narcotics	37 (57)	7 (19)	23 (62)	7 (19)	0.51
NSAIDs	42 (65)	5 (12)	26 (62)	11 (26)	0.49
Other analgesics	28 (43)	4 (14)	17 (61)	7 (25)	0.94
Physiotherapy					0.37
No physiotherapy	31 (48)	3 (10)	21 (68)	7 (23)	
Education/exercise	16 (25)	2 (13)	10 (63)	4 (25)	
Physiotherapy	16 (25)	5 (31)	7 (44)	4 (25)	
Comorbidities					
Type 2 diabetes	21 (32)	2 (10)	15 (71)	4 (19)	0.49
Osteoarthritis	32 (49)	4 (13)	20 (63)	8 (25)	0.78
Rheumatoid arthritis	3 (5)	1 (33)	1 (33)	1 (33)	0.51
Peripheral vascular disease	6 (9)	0 (0)	5 (83)	1 (17)	0.46
Psychosocial (anxiety, depression, stress)	24 (37)	5 (21)	13 (54)	6 (25)	0.61
Hypertension	34 (52)	3 (9)	25 (74)	6 (18)	0.08
Coronary artery disease	12 (19)	1 (8)	7 (58)	4 (33)	0.57
Cerebrovascular disease	6 (9)	0 (0)	3 (50)	3 (50)	0.21
Scoliosis	11 (17)	2 (18)	5 (46)	4 (37)	0.52

Note: Findings with p values < 0.15 are highlighted in bold.

NSAID = nonsteroidal anti-inflammatory drug; NYD = not yet diagnosed; SD = standard deviation.

*Unless stated otherwise.

†For the full sample, percentages are out of 65; for the 3 outcome groups, percentages are by row. Percentages do not always total 100 because of rounding.

‡Tests of significance are based on the t test (age) and the χ^2 test (all others, Pearson or Fisher Exact test as appropriate).

§All cases of bowel and bladder incontinence were chronic. None of the patients in this series presented with cauda equina syndrome.

pain (all), leg pain (83%), limited exercise tolerance (55%), leg numbness (51%) and leg weakness (48%). Sixty-one of the patients had computed tomography or magnetic resonance imaging; of these, 80% had disc herniation or bulging in at least 1 level, 51% had LSS and 25% spondylolisthesis. Only 1 patient had no abnormalities on imaging. There were no cases of acute cauda equina syndrome in the group.

Outcomes of ESI

Of the 65 patients who received a first injection, 33

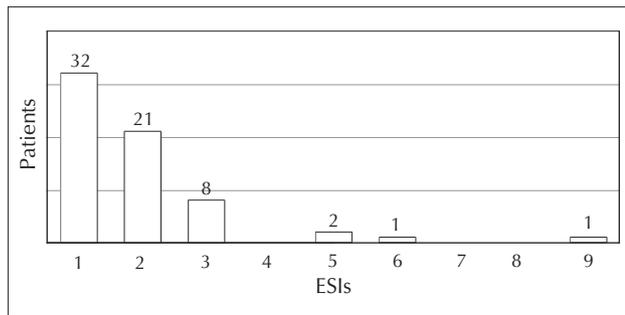


Fig. 1. Number of epidural steroid injections (ESIs) per patient (total 123 ESIs in 65 patients).

(50%) had subsequent injections, with 12 (18%) having 3 or more (Fig. 1). The interval between injections ranged from 9 days to 4 years, with a median of 109 days (Fig. 2).

After the first injection, 40 (62%) reported improvement, 10 (15%) reported worsening or no change and 15 (23%) had no follow-up documented. Of the patients who had multiple injections, 58%–67% reported improvement. The outcome data for the 123 ESIs are presented in Figure 3. Patients whose symptoms improved with their first ESI were somewhat more likely to receive future injections ($p = 0.17$).

Comparison of groups

Factors associated with improvement ($n = 40$), no improvement ($n = 10$), or loss to follow-up ($n = 15$) are presented in Table 1. Those with no improvement tended to be somewhat younger than those who did improve or were lost to follow-up (49 years of age compared with 56 and 55 years, respectively), but this association was not significant ($p = 0.51$).

Two symptoms showed a potentially significant

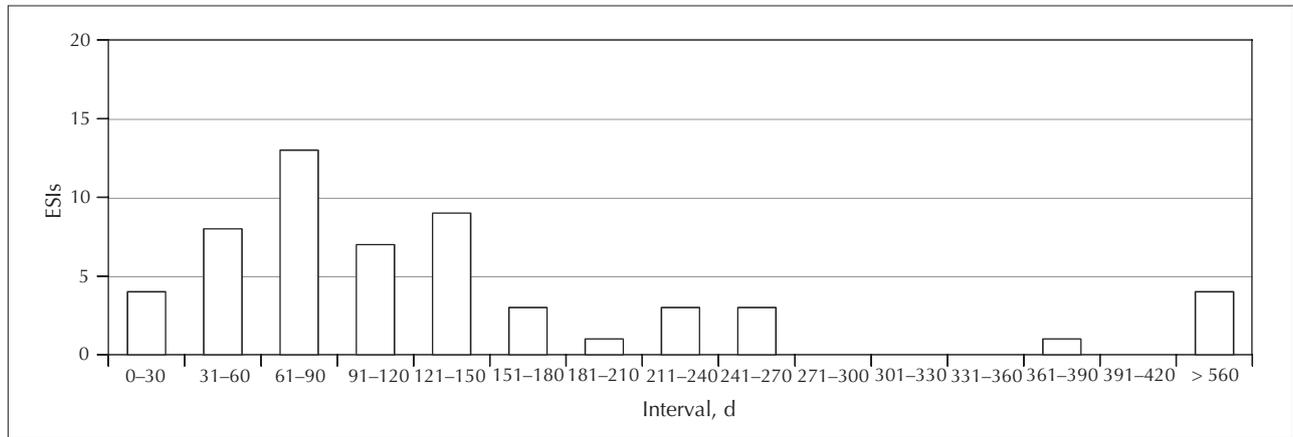


Fig. 2. Interval between procedures in patients who had more than 1 epidural steroid injection (ESI; 59 ESIs in 33 patients).

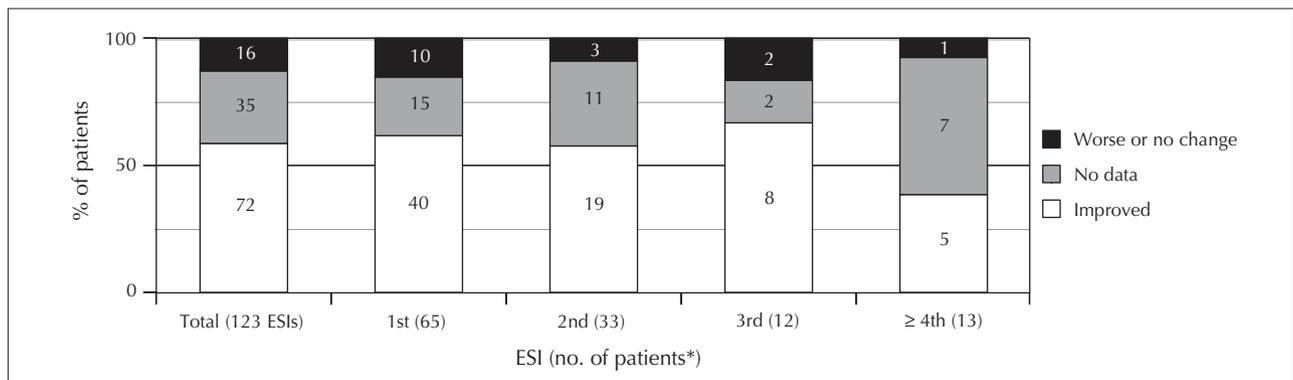


Fig. 3. Outcome in epidural steroid injections (ESIs), by total ESIs performed and by number performed in patients. *Unless stated otherwise.

association with a negative outcome: leg weakness ($\rho = 0.08$) and leg numbness ($\rho = 0.11$). Both are suggestive of neurologic dysfunction. Hypertension was the only comorbidity potentially associated with injection outcome ($\rho = 0.08$), with the improved group having a higher proportion of patients with hypertension. More than half of those whose symptoms improved did so despite having no access to physiotherapy. There were no apparent associations between diagnosis and ESI outcome, or between analgesic use and ESI outcome. More patients with LSS had improved symptoms than those with LDH, although many patients had both LSS and LDH (Table 1).

Surgery

Fifteen of 65 patients had documented back surgery. Six patients had undergone back surgery before the study period and 10 had surgery during the study period (1 patient had both). Three patients underwent 2 surgeries. The type of surgery was not documented for 2 of the 15 patients. Of the remaining 13 patients, 2 underwent spinal fusion, and 11 had 1 or 2 laminectomy/discectomy procedures.

One patient had undergone 2 previous surgeries and received 9 ESIs during the period under review. Excluding this patient, the number of injections for patients who underwent surgery (either before or after) ranged from 1 to 6 with an average of 1.8, similar to the overall average.

DISCUSSION

Inferences from these data regarding the effectiveness of ESI are limited by the retrospective nature of the study, the incompleteness and potential inconsistency of follow-up data, and the real-world complexities of copathology and diagnostic uncertainty.

Although the sample is small, and therefore underpowered, the data do suggest that symptoms of leg weakness and numbness may be associated with poorer outcomes. Among those with follow-up data, 80% had documented improvement. We cannot say whether this is an improvement over the natural history of the disease.

Epidural steroid injections can be a useful therapy for a common and symptomatic condition, in settings where other options are limited. Whereas fluoroscopically guided techniques are a common standard in the literature, our study highlights that commonly used obstetric anesthesia techniques available in many rural areas can provide positive results. As such, the pre-

cise indications and effectiveness of epidural steroids in rural areas deserves more rigorous study.

CONCLUSION

We have documented that some patients with neurologic compromise, from either LSS or LDH, seem to have improvement of symptoms after an ESI, but the retrospective nature of our study does not allow us to draw any clear causal links. This requires larger, prospective pools of clinical data, as well as improved understanding of the pathophysiologic mechanisms of chronic back pain and the potential points of therapeutic intervention. We have already begun a multicentred prospective rural study of the effectiveness of ESIs.

Competing interests: None declared.

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The occasional epidural steroid injection

See related articles on pages 119, 127 and 145

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This article has been peer
reviewed.

This description of an epidural steroid injection accompanies a related research article in this issue.¹

Epidural steroid injection for back pain is a procedure that a general practitioner–anesthetist, experienced in epidural anesthesia administration, may want to consider for treating back pain in appropriately selected patients. The procedure differs from a standard epidural (typically given in healthy, young pregnant women) in that the patient population typically has moderate to severe lumbar osteoarthritis, making the procedure technically more difficult.

Patients with lumbar spinal stenosis (in which neurogenic claudication is

relieved by forward flexion) and patients with lumbar disc herniation (which includes reproducible sciatica) could be considered candidates. The present supporting evidence for this procedure is weak, but it is sometimes suggested by orthopedic specialists when conservative or surgical options are limited.

PATIENT SELECTION

It might be wise to initially avoid selecting patients who have had back surgery, as the procedure is most challenging in these patients, and indwelling hardware always increases the risk of infection.

We evaluate the patient for interspinous ligament and quadratus lumborum trigger points, which can be treated effectively with tissue injections of lidocaine and do not need epidural steroids.²

THE PROCEDURE

As in any other epidural injection, the patient must be instructed to notify the physician if any paresthesia is experienced during needle advancement. If this occurs, the physician must realign the needle and change angles. No injection or advancement should be done until the needle is repositioned and any paresthesia is resolved. See Figures 1–6 for step-by-step instructions on performing the procedure.

AFTERCARE

Be cautious with mobilizing the patient afterward as some people are prone to



Fig. 1. The equipment is a standard epidural tray set-up (containing 17-gauge Tuohy loss-of-resistance needle, sterile preparation and lidocaine in a 25-gauge 1.5-inch needle), with no need for the catheter component or securing adhesives.



Fig. 2. We have the patient seated with lumbar spine in flexion. Using the iliac crest as a marker, we generally consider this to be L4-5 level.



Fig. 4. With the use of the Tuohy needle (with obturator) along the same tract, the epidural space is identified by using loss-of-resistance technique with a glass syringe or specific epidural loss-of-resistance syringe (included in disposable epidural kits). Loss of resistance at a more superficial depth than the actual epidural space may occur in patients with long-standing osteoarthritis (and variable bony architecture). If you feel this is occurring, try injecting 1–2 mL normal saline. If you regain resistance, you are in soft tissue and not yet at the epidural space.



Fig. 3. We infiltrate the skin and subcutaneous tissue with lidocaine to the depth, by feel, of the interspinous ligament. The transiliac-crest level may actually identify the L3-4 level more often (77% of cases)³ than the L4-5 level, even though the line radiographically correlates well with the L4-5 level.² Palpation and radiographic assessment may therefore differ in what levels are being identified, and identification of levels is affected by interobserver variability.⁴ We identify the space where most symptoms arise clinically or radiographically. If a fusion or graft exists at that level, we generally go 1 level above and try to avoid surgical scars.



Fig. 5. Continue to safely advance the needle to find the epidural space with loss of resistance.

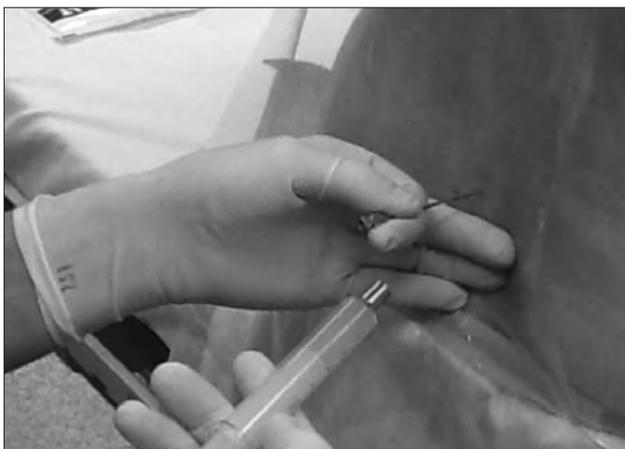


Fig. 6. Once the needle is correctly positioned, inject 80 mg methylprednisolone diluted to a total 5 mL solution with normal saline. Remove needle and apply a bandage.



fainting after procedures involving needles.

If the injection is effective, we typically see benefits within a few days and seldom encounter a "steroid flare." The relief of symptoms may last for months or longer. If the injection is initially effective and pain subsequently recurs, we consider a repeat injection at 3 months. We typically do not repeat injections that failed to relieve symptoms.

Competing interests: None declared.

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Health in Action

Where There Is No Paramedic: The Sachigo Lake Wilderness Emergency Response Education Initiative

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Introduction

Indigenous people face poor health outcomes in comparison with the Canadian population [1,2]. In remote indigenous communities, the health impacts of historical and systemic disadvantage are compounded by geographic isolation and limited access to services. This presents a critical challenge in managing time-sensitive medical emergencies in very remote settings. In the absence of local paramedical services, the management of health emergencies depends on the capacity of laypeople. These communities in Canada mirror a global phenomenon: not only do rural and low-income populations worldwide face a disproportionate burden of disease, they also face systemic barriers to accessing timely care [3,4].

Here we report on the Sachigo Lake Wilderness Emergency Response Education Initiative (SLWEREI), a collaboration between physicians, first aid educators, researchers, and a remote indigenous community to develop and deliver a life supporting first aid (LSFA) program in northern Canada. This program integrates community-based participatory research (CBPR) methods with LSFA training, and advances a potentially scalable model for LSFA education and research programs in remote and underserved communities.

Background

Aboriginal Health in Canada

Indigenous populations in Canada—including First Nations, Inuit, and Métis peoples—are over-represented among populations with the poorest health in Canada, with markedly elevated rates of diabetes, hypertension, obesity, addiction, infectious disease, and suicide [1,2,5]. Life expectancy

at birth for First Nations people in 2000 was 8.1 years less for men and 5.5 years less for women in comparison with the Canadian population [5]. The lifetime risk of severe trauma among First Nations populations is nearly four times the Canadian average, and accounts for one-third of deaths [6,7].

According to the Assembly of First Nations, an application of the United Nations Human Development Index to living conditions in many First Nations communities would place them 63rd worldwide—“or amongst Third World conditions” [8]. For decades, researchers have identified the severe inadequacy of effective health infrastructure in these settings, including the lack of potable water and safe housing [2]. Political leadership and researchers have called for improved health services through an emphasis on capacity building, cultural continuity, and self-determination [9–11].

Life Supporting First Aid Training

In many remote communities without formal paramedical services, laypeople and bystanders provide all on-site emergency

care. First aid training programs have been shown to provide skills to engage in health promotion and address critical health emergencies [12,13]. The Red Cross identifies first aid among essential health promotion interventions [14]. The World Health Organization asserts, “Even in settings with limited resources, many lives may be saved and disabilities prevented by teaching motivated people what to do at the scene.” [3]

LSFA training may confer public health benefits to populations with elevated rates of cardiac arrest and trauma [12,15]. Cardiopulmonary resuscitation (CPR) performed by bystanders in urban settings may reduce sudden cardiac arrest mortality by as much as 22% [16,17]. Basic pre-hospital services may reduce trauma mortality by 15%–20% [18,19]. There is no strong evidence to support a singular educational or clinical approach to first aid in low-resource environments [20]. Compelling studies have demonstrated benefits arising from LSFA programs in remote and underserved settings (Box 1).

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Competing Interests: AO, DV and SS have worked for Wilderness Medical Associates International, a wilderness medicine education organization. MW is director of Wilderness Medical Associates International. This organization was not involved in the research submitted as part of this manuscript but does provide medical training to laypersons in remote/wilderness contexts. All other authors have declared that no competing interests exist.

Abbreviations: CBPR, community-based participatory research; LSFA, life supporting first aid; SLWEREI, Sachigo Lake Wilderness Emergency Response Education Initiative

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† AO and DV are joint senior authors on this work.

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The Health in Action section is a forum for individuals or organizations to highlight their innovative approaches to a particular health problem.

Summary Points

- In many northern indigenous communities in Canada, systemic health disparities are compounded by extreme geographic isolation and limited access to emergency services.
- In these settings, the initial management of health emergencies depends on the capacity of laypeople. Few studies have explored the effects of first aid training in these settings.
- This paper reports on a collaboration to develop, deliver, and study a community-based first response training program in a remote indigenous community.
- A focus on geographically and culturally relevant content, pedagogy, and evaluative methods may transform first response training into an important local capacity-building, public health and health promotion intervention.
- This project advances a model for first response education programs in isolated and resource-poor settings, and offers socio-cultural insights into the role of first response programs in these settings.

The Project

The Community and Setting

Sachigo Lake First Nation (population 400) is a remote community in northern Canada (Figure 1). Similar to more than a hundred communities across Canada, Sachigo Lake is accessible only by air or seasonal ice roads. Full-time nurses and community health workers staff the local nursing station, funded by the Canadian government. A family physician visits the community for 2–3 days per month. Hospital care is provided hundreds of kilometres away, with transport times seldom less than 4 hours. Community members hunt, fish, and trap on their traditional lands, often travelling hours or days by motorboat, all-terrain vehicle, or snowmobile.

The Collaboration

SLWEREI is a collaboration between Sachigo Lake First Nation, university researchers, and low-resource medicine educators. Our team involved three phy-

sicians and a paramedic experienced with low-resource medicine education, a researcher trained in CBPR, and community health leaders in Sachigo Lake.

CBPR transforms research into a vehicle for community engagement, and is an effective approach to the challenges of conducting research with marginalized populations [21]. CBPR can “enhance understanding of a given phenomenon and the social and cultural dynamics of the community, and integrate the knowledge gained with action to improve the health and well-being of community members.” [22]. CBPR may redress inequities and establish trust between communities and researchers [23,24].

Our project methodology integrated community partners in every phase of development, delivery, and evaluation of the initiative. We developed a research agreement that emphasized equitable and reciprocal partnerships; sensitivity to Sachigo Lake community priorities; integration of programmatic and evaluative

components; a flexible and responsive agenda; and the creation of a project representing learning opportunities for everyone involved. Community partners identified the program’s effects on community resilience as a priority for evaluation. A successful program was described by community partners as one that created community satisfaction and engagement, and that enhanced the sense that emergencies could be managed appropriately. Community partners favoured participant observation and focus groups as the data collection methods.

The project team met with community stakeholders involved in governance and health care to discuss existing emergency systems, critical incidents, community perceptions about emergencies, and local training. Recent incidents had included motor vehicle and aircraft crashes, chainsaw and construction injuries, inhalational injuries, a near drowning, burns and frostbite, diabetic emergencies, myocardial infarction and strokes, suicide attempts, and aggressive behaviour. Community members articulated an interest in learning to adapt best practices in pre-hospital emergency care to the local context, rather than emphasizing skills that required new technologies or infrastructure.

The Course and Data Collection

In November 2010, researchers and course instructors travelled to Sachigo Lake First Nation and coordinated an intensive 5-day LSFA training program, based on a curriculum and pedagogical approach designed specifically for the community. The community research partner selected the adult participants from various community roles, including community health workers, Canadian Rangers, school staff, maintenance and sanitation workers, local government, and general store employees. There were 20 course participants (5% of the community population, 13 men and seven women), including three community research partners.

The curriculum focused on the immediate management and transportation of patients with critical health problems (Figure 2). The course included classroom teaching and discussions, small group skill-building exercises, and simulated emergency scenarios, but varied from conventional first aid programs by including opportunities for debrief, open question-and-answer sessions, and discussion about local challenges and experiences related to the medical problems being discussed.

Our course also integrated research, group reflection, and program evaluation.

Box 1. LSFA in Remote and Underserved Settings.

Ghana: Tiska et al. report on a first aid course for truck drivers in a low-resource setting with elevated rates of motor-vehicle trauma. The course emphasized airway management and external hemorrhage control, and improved the pre-hospital provision of first aid [25].

Cambodia and Northern Iraq: Husum et al. report on a 5-year prospective study to test a model for rural, low-income trauma services. More than 5,000 laypeople and paramedics were trained. Trauma mortality was reduced from 40% to 14.9%. Husum et al. conclude that training programs in isolated, low-resource settings can have significant mortality benefit, even with severely injured patients [26,27].

Uganda: Jayaraman et al. report on a program to provide over 300 police officers, taxi drivers, and community leaders with a 1-day first aid course. Six months following the course, 97% of participants had used at least one skill learned in the course, and there was evidence of knowledge retention [28].



Figure 1. Map of Ontario showing Sachigo Lake First Nation. (Image: Department of Natural Resources Canada. All rights reserved). doi:10.1371/journal.pmed.1001322.g001

The course began with a plain-language informed consent presentation and discussion. Eight focus groups, with four to five participants each, as well as a sharing circle with all participants ($n=20$) were integrated into the course. A semi-structured interview guide was used during focus groups. Community participants chose not to have focus groups recorded. A researcher took detailed notes during focus groups, interviews, and participant observation. Themes emerging from focus groups were discussed and validated with three members of the group who were selected by the community research partner. Daily feedback from the researcher to course instructors permitted course curriculum and pedagogy to be redirected and

refined on the basis of participant concerns on a day-to-day basis.

Results

A number of themes emerging from this research have implications for LSFA programs in remote and underserved communities.

First, conventional first aid courses, their clinical content, and pedagogical assumptions may not meet the needs of remote communities. Some community members who had participated in conventional or standardized first aid training articulated dissatisfaction with courses conducted outside their cultural and geographic context. For example, where

conventional first aid courses make the implicit assumption that first responders will likely provide care to strangers, Sachigo Lake community members have personal or familial experience with resuscitations, and expect to provide care to family and friends. One course participant remarked, “I had to splint up my daughter’s arm last week. They [children] are rough with each other nowadays.” Another member of the group added that “from what I’ve seen from my own experience the kids are always putting stuff in their mouth. I’ve seen one kid choke already... I want to know what to do in that situation.” A course tailored to specific medical and cultural needs focused on providing first aid to family and friends, a

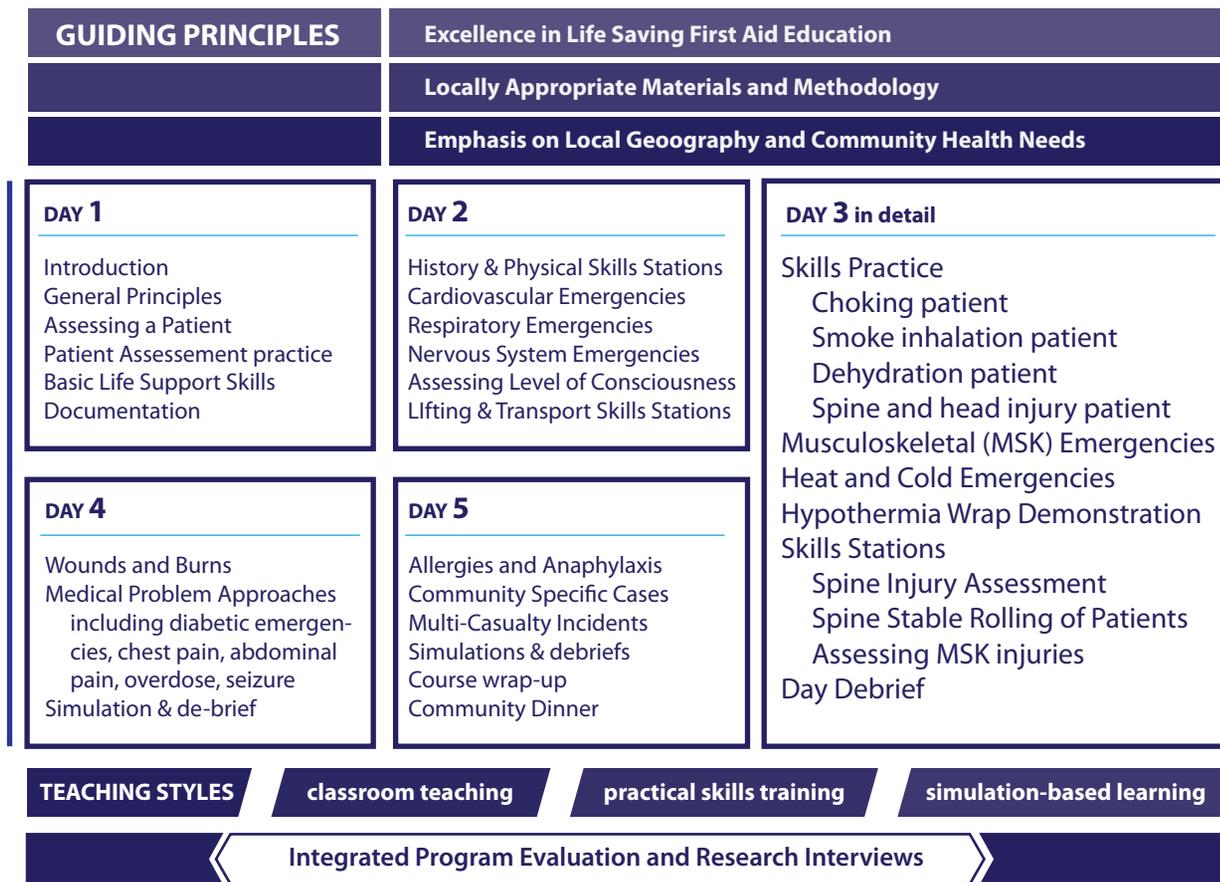


Figure 2. Schematic of life-supporting first aid training curriculum, evaluation, and pedagogical elements.
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unique feature when providing first response in a small community.

Second, LSFA education must be relevant to local communities and geographies. One community member relayed, “We ... need training on how properly to transport patients, whether by boat ... or snow machine.” Participants emphasized emergencies arising on hunting and trapping excursions: “We don’t have a nursing station out there in the bush.” Another shared, “The scenarios ... made me realize that it could actually happen to me if I need to help someone. ...When I did [previous training courses] it didn’t really click in with me....This course was set in an environment that it might happen. ... I took it to heart with this type of training...” While conventional urban first aid courses focus on immediate stabilization and activation of professional paramedical services, our curriculum involved prolonged patient care, and improvised equipment, wilderness terrain, and inclement weather. Simulation-based education reinforced principles learned in classroom and small group sessions, and brought real-world situations to life in an

accessible way for all participants, regardless of educational background.

Finally, local participants identified local LSFA training as an important public health and health promotion intervention. Participants identified the longitudinal integration of evaluation, intensive debriefing, and open question-and-answer sessions as important and engaging parts of the program. Combining evaluation and reflection with skills training and practice enhanced a sense of community capacity and growth. Through this approach, not only does LSFA increase confidence in individuals, but also builds community resilience for remote populations. One participant remarked, “I know that there are people spread out across the community. I can call someone closer to respond.” Another indicated, “We’re all going to benefit from it—not only the participants, but the general public from our community.”

Discussion

Our work has convinced us that teaching urban, “standard” first aid in a remote and

underserved setting may deny those populations the skills needed to optimize outcomes or address medical emergencies with appropriate skills and confidence. First aid courses designed for temporary wilderness work or recreation may also be unsuitable for remote populations, and may assume a range of perspectives not present in isolated communities. Delivering first aid courses for remote communities involves re-thinking given notions of wilderness and isolation, especially where wilderness discourses and imagery suggest that life away from an urban tertiary care facility is inherently dangerous. Standard first aid may be an oxymoron: effective basic life support requires adaptation to local clinical, infrastructural, and cultural needs [20].

We found that insights from community members are important to ensure that course design and materials are relevant and sensitive to context. CBPR provides some guidance to engage members of the community and to validate and revisit assumptions drawn from focus groups. Where the “researcher-participant” relationship has long served the needs of the researcher, community-based and partici-

patory health programming and research may contribute to a broad sense of community resilience and local capacity.

SLWEREI trained 5% of the Sachigo Lake population—an intervention comparable to training about 120,000 people in Toronto, Canada's largest city. In a community with no formal paramedical care, this may have an enormous impact on the management of health emergencies.

Our undertaking had limitations. Qualitative research design offers important socio-cultural insights and perspectives on community resilience, but cannot reveal morbidity or mortality effects. Like other similar public health interventions, designing a study to measure morbidity and mortality will be challenging considering the number of confounding variables, and the sample size of critical incidents in a community of 400 people. The public health and capacity-building effects are at once this project's most important outcome and its most challenging aspect to measure. By returning to the community in the future, we will gain a more in-depth and nuanced understanding of the public health impact of training 5% of a remote community in life-supporting first aid. Expansion beyond a single community may permit quantitative measurement of

morbidity and mortality effects, and determine whether lessons learned in Sachigo Lake can be translated to other communities. Isolation defines the initiative, but also challenges effective collaborations, and is therefore an additional limitation. Transportation and shipping costs accounted for nearly 30% of the program budget.

Future Directions and Conclusions

This project offers a novel collaborative approach to LSFA training in remote settings. Local and regional First Nations leaders have articulated an interest in sustaining and expanding the program. In other remote and low-resource communities worldwide, where bystanders and laypeople attend to the immediate needs of patients facing health emergencies, the lessons learned in Sachigo Lake may enhance local emergency first response capacity. A second course will be delivered in Sachigo Lake in 2012 to reinforce and refine teaching strategies, and curriculum. The course curriculum will be refined on the basis of participant and instructor feedback, including new mental health modules. The collaboration will expand to

involve medical trainees from the Northern Ontario School of Medicine. Our team plans to explore opportunities to expand this model for community-specific first response training programs to other remote communities in Canada or abroad.

Context and community-specific LSFA training may contribute not only to patient outcomes in medical emergencies, but may also develop participant self-confidence and contribute to community resilience. Developing first response training programs in partnership with target communities and integrating longitudinal evaluation and community reflection into training curricula may further enhance these effects. LSFA education, developed and delivered with community collaboration, may provide a beneficial local health promotion intervention in remote and underserved settings.

Author Contributions

Analyzed the data: AO DV KB JB. Wrote the first draft of the manuscript: AO DV. Contributed to the writing of the manuscript: AO DV KB MW SS JB. ICMJE criteria for authorship read and met: AO DV KB MW SS JB. Agree with manuscript results and conclusions: AO DV KB MW SS JB.

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Teaching wilderness first aid in a remote First Nations community: the story of the Sachigo Lake Wilderness Emergency Response Education Initiative

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Objective. To understand how community members of a remote First Nations community respond to an emergency first aid education programme.

Study design. A qualitative study involving focus groups and participant observation as part of a community-based participatory research project, which involved the development and implementation of a wilderness first aid course in collaboration with the community.

Methods. Twenty community members participated in the course and agreed to be part of the research focus groups. Three community research partners validated and reviewed the data collected from this process. These data were coded and analysed using open coding.

Results. Community members responded to the course in ways related to their past experiences with injury and first aid, both as individuals and as members of the community. Feelings of confidence and self-efficacy related access to care and treatment of injury surfaced during the course. Findings also highlighted how the context of the remote First Nations community influenced the delivery and development of course materials.

Conclusions. Developing and delivering a first aid course in a remote community requires sensitivity towards the response of participants to the course, as well as the context in which it is being delivered. Employing collaborative approaches to teaching first aid can aim to address these unique needs. Though delivery of a first response training programme in a small remote community will probably not impact the morbidity and mortality associated with injury, it has the potential to impact community self-efficacy and confidence when responding to an emergency situation.

Keywords: *first response; Aboriginal health; access to trauma care; community-based participatory research; qualitative research*

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Elevated accident trauma rates are a documented health concern in remote First Nations communities in Canada (1). The effects of geographic isolation on timely response in many remote First Nations communities have also been reported (2,3).

Timely access to high quality trauma care has been demonstrated to save lives (4). However, for many remote First Nations communities, injury burden is magnified by a lack of timely access to first response, as well as significant distances from secondary, tertiary or quaternary health care services.

In remote First Nations communities, access to urgent care provided by physicians within a hospital setting is often available only by air transport. These communities also lack paramedic capacity. While some First Nations communities have developed teams of first responders and logistics for dealing with emergencies, there are challenges, such as limited training and logistical support for these teams.

The Sachigo Lake Wilderness Emergency Response Education Initiative (SLWEREI) was motivated by the evidence demonstrating a higher burden of trauma,

coupled with the challenge of access to high quality first response in many remote communities (3). The purpose of this project is to better understand the challenges around first response and work with the Sachigo Lake community to develop and deliver a regionally and culturally appropriate training programme.

In this article, we briefly describe SLWEREI, with a focus on the question, “what is the response of a remote First Nations community to an emergency first aid course?”

Results provide insights into understanding emergencies within the remote First Nations context and describe how a course that engages community members in its development and design can help fill a knowledge and resource gap.

Materials and methods

Research setting

Sachigo Lake (population 400) is situated in the subarctic boreal forest of Northwest Ontario, located 425 km north of Sioux Lookout, which is a hub of transport and services for the remote reserves in the region. Like most of the 28 Oji-Cree reserves in this 3,00,000 square km region, Sachigo Lake is accessible by plane year-round or ice roads during the winter.

Basic primary care is provided through a nursing station, funded by Health Canada, which is generally staffed by 3 nurses and community health workers. A family physician, based in Sioux Lookout, visits the community for 3–4 days per month and is available for telephone consultations when not in the community. Transport times to hospital services and specialist care in Sioux Lookout, Thunder Bay or Winnipeg are seldom less than 4 hours, and with weather or other delays, transport times can be significantly longer.

Study population

Course participation was purposive and under the discretion of the community research partner, who is the Director of the Health Authority, member of the band council and Sergeant of the local detachment of the Canadian Rangers (5). The community research partner selected course participants based on his own discretion and related to his view of who would benefit from the course. Participants were purposively selected from various backgrounds in the community and included community health workers, Canadian Rangers, educators, maintenance workers, Band Council members and employees of the community store. Some course participants had multiple roles, for example, being both a staff member at the school and a member of the Band Council. There were 20 participants in total (5% of the community population), including 3 research

partners. Thirteen men and seven women participated in the course.

The course content and design is described elsewhere (6).

Data collection and analysis

The programme design and research process employed community-based participatory research (CBPR) methodology. CBPR is a framework that can be applied to gain better understanding of the social context related to a phenomena being studied and aims to work with community partners to facilitate ownership of the research process and use the results to improve the community (7,8).

The CBPR process followed key principles of participation and equity of the community, sensitive to the needs and interests of the community partners. These principles are: (a) integration of community members, participants, research and programme delivery team as equal partners in every phase, (b) structural and functional integration of the intervention and evaluation components, (c) a flexible agenda, responsive to the demands from the broader environment and (d) create a project representing learning opportunities for all involved.

The research team met with community partners and stakeholders in May 2010, which focused on learning about community needs and past critical medical events in the community, as well as establishing relationships and trust between partners. The choice of methodology was based on input from community members, who expressed a preference for participant observation, focus groups and sharing circles. Researchers engaged in CBPR projects with First Nations communities in Canada have developed Research Agreements to codify and clarify expectations, control of data, roles and responsibilities of researchers, community research partners and community members, and to set out a mutually agreed upon knowledge translation and dissemination plans of the research (8). Principles for the Research Agreement were discussed during the site visit and finalised in November 2010.

At the outset of the course, the researcher conducted a short presentation outlining the key aspects of consent in plain language for the participants.

Eight focus groups, generally with 4 participants each, took place on the first and third day of the course. Each of these focus groups were approximately 45 minutes in duration. In addition, a sharing circle with all participants ($n=20$) took place during the final day of the course at the closing banquet. Both the focus groups and sharing circle were facilitated by an embedded researcher, who conducted participatory observation throughout the course duration.

The sharing circle is a process, where people speak in turns. Sharing circles have been used in research with First Nations for seeking consensus in decision-making, resolving conflicts and building trust (9). Focus groups

were the preferred method of course participants, and course participants were told that focus groups were not mandatory; however, attendance was 100%. Themes were then discussed with community research partners (n = 3). Community research partners included the local Health Director as well as two members of the community who participated in the course, selected by the Health Director. These individuals had no training in qualitative research; however, during meetings they reflected on key themes drawn from focus groups. Themes were discussed between the researcher, research partners and Health Director.

Focus groups are often used as a mode of data collection in research with First Nations' communities (10). The language used to describe themes is drawn from health research and evaluation literature. For example, the term, resilience, is used to describe how First Nations individuals and communities attain positive outcomes in a climate of risk and adversity, based on the legacies of past colonialism, dislocation and exploitation (11). Similarly, self-efficacy has been defined as the belief that one can perform specific activities in specific situations. Self-efficacy is rooted in context and varies based on situations, environment and context (12). The concept of self-efficacy has been applied to similar research projects. For example, the Sandy Lake Health and Diabetes Project used a scale of dietary self-efficacy to measure the impact of a culturally appropriate, school-based dietary intervention among children in that community (13).

A semi-structured interview guide (Table I) with questions focused on the course experience was used during the focus group. As per the wishes of participants, in lieu of recording, the researcher took detailed and often verbatim notes (14).

Results

Twenty community members were purposively selected to participate in the course. The results represent the views of the course and research participants alone (n = 20).

Table I. Sample interview guide

Interview date	Sample questions
Courses days 1–3	Can you share a story about something that you experienced that you learned about today? Is there something today (from specific session) that you didn't understand? Why? Is there something about the course (specific session) that you felt was more relevant to certain groups in the community?
Courses days 4–5	Can you share a story from the course where you learned something new that will help you in an emergency situation? Can you share a story from the course where you felt that what you were learning really will not help you in a real emergency situation? Can you provide an example about how or what you will do differently given your course learnings? What do you think makes a course effective in your community?

The findings of this study are grouped into two main themes, the first focused on participant's response to the course personally and as community members, and the second on the community response and context for the course.

Personal context

Throughout the course, stories about personal experiences with injury, illness or death were shared. Stories were used as a way to learn and the course included scenarios.

The scenarios that we did kind of made me realize that it could actually happen to me if I need to help someone. The reality set in for me especially when we were doing the scenarios. When I did first response [training in the past] it didn't really click in with me it didn't feel like it was going to happen. It's not real. This course was set in an environment that it might happen. (Participant) [Day 5, Sharing Circle]

To many course participants, scenarios and course material also brought forth memories of past experiences.

Doing CPR on baby reminded me of when they did this on my 2 month old granddaughter. They took her and were doing it on the washing machine. I didn't know how to do that. (Participant) [Day 1, Participant Observation]

In contrast to the panic described in previous experiences with injury, illness or death some noted that course participation influenced their confidence.

I just want to thank everybody for participating, thank the instructors a lot: we have 3 doctors present here today and a researcher. I want to thank them for coming and giving us I guess the confidence for us to know what to do in emergency situations. I have boosted up my confidence level if I should see an emergency I'm capable of what I can do. (Participant) [Day 5 Sharing Circle]

Course participants shared stories with underlying messages of self-sufficiency and independence.

Everyone goes out alone. That's what happened to my grandpa once. He dislocated his [points to hip] he was out in the cabin . . . he managed to crawl out to his boat, crawl up the hill.

(Participant) [Day 3 Focus Group]

However, participants noted informal ways to keep track of individuals when they go into the bush (wilderness), as well as informal reinforcements and support during a crisis. Participants described how when groups go into the bush, there are informal systems in place, such as having an estimated time of return, to ensure safety.

Participant 1: personally I know that I have this knowledge . . . what I just learned this past week and if I were somewhere if somebody did get hurt or get sick I would know what to do. And what is that stable and unstable.

Participant 2: It's the same in other communities. (Researcher asks: Why?) I think we're just being taught the same . . .

Participant 3: The upbringings . . . the teachings of our parents and grandparents. Be self sufficient in all aspects of life.

[Day 5 discussion with research partners]

Expressions of self-confidence and self-sufficiency were contrasted with descriptions of barriers and challenges in accessing health services and information. A number of participants expressed concerns in accessing care in the community. In the below quote, the participant notes trouble in accessing prescriptions, alluding to prescription opioid abuse and misuse.

To this day I'm scared to get severe headaches again. I went through . . . it was awful. I was here getting stuck. I saw my face twisting and my eyes . . . But I kept going to the nursing station and she told me use hot compresses at home.

That's what they say.

They say you just want a prescription drug.

That's what's stopping the nurses. That's what the abuse is doing to people. You can't even get Tylenol now.

[Day 2 Course, participant observation]

The notion of confidence can also be ascribed beyond the individual to the community, which leads into the second theme group of community context and impact.

Community context

Participants suggested that knowledge acquired from the course was shared, and that the course provided collective gain.

Participant 1: If they have to sent out a rescue party it will feel that someone with this knowledge will get called upon. We can go out as rescue party. I may

forget some stuff. He [referring to another participant] may forget some stuff but together we can share ideas.

Participant 2: I know that there are people spread out across the community. I can call someone closer to respond to that emergency closer to get there. We have to keep this group active.

. . . .

Participant 3: And the other thing is that (Participant 5) knows the east side [of the outlying areas from the community] and (Participant 1) knows the north side [of the outlying areas from the community] we have people that we can know how to navigate the lake and the river at any time [of the year].

Participant 1: That's the thing with this community that people know the lay out of the land. The territory. Not everyone knows.

Participant 4: It's not just the territory it's the wind, the currents, different parts of the land.

[Group 2, Day 3 Focus Group]

The theme of collective gain and knowledge emerged in many conversations with participants.

Participant 1: When we were doing these scenarios there was some things that we forgot and my partner was there to correct me. He would say what else could be done . . . With that way, the way that it came together, I guess he heard what (Participant 2) said we live right across the community. If something happened on the west side the people there who got the training they'd be the first ones. While they are assessing then others could come and see what's not right they could step in and correct and see what's not right.

Participant 2: Team work . . . ya in each community. The community comes together and works together as one. [Day 5 discussion with research partners]

Course material is meaningful when grounded in the community context. This is a challenge as conventional wilderness first aid courses are developed with the assumption that participants do not live in remote or wilderness areas. Participants were interested in the applicability of the course to their context, which includes periods of time spent in the areas outlying the community, "the bush". Scenarios were tailored to the community context. Conventional courses employ scenarios where "rescuers" happen upon "victims" who are strangers. In the Sachigo Lake community, there are no strangers.

Participant 1: being outside helps me remember . . . its more realistic.

Participant 2: Here things happen in any weather, in snow and in blizzards.

[Participant Observation Notes Day 3]

. . .

We should get someone to jump in the lake for hypothermia . . . lets make it real.

(Participant) [Participant Observation Notes Day 2]

The research methods and small sample size limit the ability to answer the question of whether the course was effectively tailored to the community. However, participants reminded instructors about their context and questioned its relevance, particularly during the first two days of instruction.

This is a good program but most of the time we're out there with no highways, no nursing stations, so I want some answers around how to take care of people when they are sick. (Participant) [Day 2 Participant Observation Notes]

I don't know what you guys consider wilderness ... for us its when we go outside. We don't have a nursing station out there in the bush. (Participant) [Day 3 Participant Observation Notes]

Participants would adapt scenarios to reflect their own experiences. The quote below was in response to a question asking what participants would like to learn more about, suggesting a need for scenarios that commonly occur in the community context.

I had to splint up my daughters' arm last week. They are rough with each other nowadays. The scenarios involved mostly adults. [Day 3, Focus Group]

Participants reflected on the importance of collaboration on course content.

If you want to learn something it goes both ways. That's the attitude these people have brought here with them. They have something to teach and they have something to learn from us. That's what I appreciate from this one here. (Participant) [Day 3 Focus Group]

Discussion

The responses to a wilderness first response course in a remote First Nations community were grouped into two main themes, personal and community contexts.

The personal context focused on sharing of stories related to injury and illness, and the ways in which prior experiences to injury influenced individuals. Research has demonstrated that Aboriginal populations in Canada bear a disproportionate burden of trauma and other critical health emergencies in Canada (1,15). While scenarios are an important part of first response teaching and learning, they can bring forth painful recollections of previous experiences.

Empowerment was a significant theme – with participants expressing a strong sense of empowerment from knowledge gained in the course; this contrasted with sentiments of participants related to challenges in accessing health services.

The community context was focused on two themes, the first around the course providing shared community knowledge, with participants' feeling of being part of a community response to injury. The community context

also has implications for pedagogy and highlighted the importance of community input around course content. Grounding content in community context through appropriate scenarios was a means to enhance relevance.

Limitations

There are a number of limitations to this study related to the practical challenges of conducting participatory action research in remote First Nations communities, as well as the challenges in making general statements based on experiences within one community.

The Sachigo Lake community was approached for this research project in early 2009 through the physician, who shared the idea with the local Health Director, who was a key research partner and champion for this project. The Health Director facilitated access to community resources, selected participants and research partners. The importance of a community research partner who facilitated the collaborative relationship cannot be understated, and may be difficult to replicate. The influence of this research partner and his support for the SLWER-EI was well known amongst participants and community members, and this may have influenced what participants expressed, and their abilities to speak freely and critically. The importance of a strong partnership with First Nations community leaders, who then facilitated access and set the stage for meaningful CBPR has been described elsewhere (16).

The role of an embedded evaluator was as much for continuous quality improvement, as it was for on-going feedback and response. Anecdotally, community members suggested that they valued having an evaluation component as it demonstrated flexibility in the curriculum as well as willingness to make real-time changes based on feedback. While the approach used was based on best practices in qualitative research, there was flexibility, including not recording focus groups and having community research partners with little formal research training. In addition, analysis was based on daily researcher coding, which was then validated through conversations with research partners. To follow CBPR and ensure participation throughout the research process, inter-rater reliability was obtained by consulting individuals not present during SLWEREI.

This study is not a programme evaluation but rather a description of a pilot programme in one community. To conduct a comprehensive evaluation on interventions, such as the SLWEREI, there is a need to look at the programme and responses across multiple communities (17).

Future research

A review of the study's findings suggest that teaching a first aid course in a remote First Nations community should take note of important personal and community contexts.

Establish strong partnerships and collaboration

Early work to establish partnerships, build trust and ensure a collaborative relationship with the community was a critical building block for this project. An initial site visit helped build trust. Efforts to ensure collaborative partnerships were carried through to the course, where participants expressed the importance of reciprocal learning and exchange.

Consider previous experiences with injury and critical emergencies

First aid courses in small remote First Nations communities must be sensitive towards the higher burden of injury in these communities and participants' first-hand experiences.

Consider how self-sufficiency and self-efficacy are taught and conveyed through course material

Remote First Nations communities like Sachigo Lake are by design, and historically, quite self-sufficient. While conventional first aid courses focus on stabilising patients and preparing them for a hand-off to a more qualified or well-resourced professional, these remote communities may not always have this option available. Teaching course material in a way that is cognizant of the tension between communities' self-sufficiency and helplessness in accessing external resources is important. Course participants are well aware of barriers to accessing care and course material needs to be grounded in this context.

Ground course in community context

Conventional first aid courses teach groups of people who work together as a team or who will apply skills as individuals. SLWEREI course participants are neither.

Participants expressed how the course was a way for the whole community to learn and enhance community capacity, rather than individual capacity, in first response. Community members discussed how their knowledge is reinforced by other course participants.

Utilise appropriate community scenarios and simulations

Scenarios are an important aspect of teaching and learning first aid. Simulations were seen as an important modality for learning and a way to make course material "real". Community input into developing these scenarios, and feedback around which are effective, is important.

Fill the research gap

This research is a pilot project. There is a gap in the literature on how a first aid course can build emergency response capacity in remote communities. Conducting a broader evaluation of the course across many communities over time can provide increased depth and breadth to understand key levers to the course's success or failures, and evaluate impact.

Conclusions

This article describes how a meaningful research collaboration and partnership was built, fostered and sustained, and how community input and partnership was key to developing and delivering an appropriate and relevant course.

Understanding context is critical to delivering a course that is appropriate and relevant to participants. Teaching content through scenarios and simulations that are community-specific, and recognising how context can be woven into course materials, is important to ensure the course is relevant. Though delivering a first response training programme in a remote First Nations community may not impact morbidity and mortality associated with injury, it has the potential to impact self-efficacy and confidence surrounding first response.

The findings from this pilot study can help provide insights around how an educational intervention in first aid skills can contribute to building capacity in remote communities for managing critical health needs and emergencies.

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Conflicts of interest and funding

Dr. Orkin and Dr. VanderBurgh have taught for Wilderness Medical Associates International, a wilderness medical educational organisation. Ms. Born and Mr. Beardy have no conflicts of interest to report.

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