URBAN FASD INTERVENTIONS: BRIDGING THE CULTURAL GAP BETWEEN ABORIGINAL WOMEN AND PRIMARY CARE PHYSICIANS

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ABSTRACT

Introduction

There is a cultural gap between urban-based primary care physicians and Aboriginal women. Bridging this gap will improve the physician-patient relationship and facilitate effective FASD interventions. We propose the development of culturally appropriate interventions.

Background

Primary care offices are ideal venues for FASD interventions. However, due to cultural differences, they may be less than ideal for the growing population of Aboriginal women. FASD is permanent, preventable and under diagnosed. Research indicates that rates are higher in Aboriginal populations. There is evidence that binge drinking, possibly the most important risk factor for FASD, is more common among Aboriginal women. There is a need to develop interventions for Aboriginal women.

Methods

We propose the development of brief alcohol interventions that consider the characteristics/needs of physicians and Aboriginal mothers. Researchers would develop the qualitative methods used to introduce information to and learn from stakeholders. The intervention would have six core operational characteristics where the intervention would: i) identify 'at risk' women; ii) assess drinking behaviors; iii) provide information on the harmful effects of drinking above recommended limits; iv) facilitate the decision of women to adopt healthier drinking behaviors; v) monitor changes or progress; and vi) be acceptable to clinicians and easily implemented.

Discussion

Physicians are likely to see increased numbers of Aboriginal patients in their offices. Further funding of intervention development/evaluation research is needed to address this public health issue, not only for Aboriginal people, but also for all Canadians.

INTRODUCTION

Tetal Alcohol Spectrum Disorder (FASD) is a one of the leading causes of preventable birth defects and developmental delay in Canadian children.^{7, 8} Although FASD is not limited to Aboriginal populations, it has been suggested that the prevalence is higher in Aboriginal communities.^{12,13,10,6} For example, the Canadian prevalence rate estimates vary between 1.0 and 10.0 births per 1,000. Abel estimated the rates to be 1.9 and 3.0 births per 1,000. ¹⁴ Koren suggested a rate of 3.0 to 10.0 births per 1,000.⁷ Studies of Aboriginal populations have revealed prevalence rates ranging from 25 to 200 per 1,000 in particular northern isolated communities. 14, 15, 16 However, little is known about the prevalence of FASD in urban environments.

Interventions with women of child bearing age to stop alcohol consumption, the proximal cause of FASD, ideally before getting pregnant or immediately on finding out is a key strategy in prevention. Aboriginal communities consistently report alcohol abuse in women of child bearing as age a major problem.^{3, 6, 1} However, drinking alcohol during pregnancy is not an exclusively Aboriginal problem. Results from the 2000/01 Canadian Community Health Survey indicate that 16.1% of women (15-44 years) and 26% of women (20-24 years) reported binge drinking on 12 or more occasions during the previous year.⁹ Square estimated that 16% of all pregnant women drink enough alcohol to place the fetus at risk of FASD.¹⁰ In a Toronto study of pregnant women

who sought counseling, Gladstone et al. reported that 3.1% of clinic patients and 0.8% of women counseled by phone reported binge drinking (defined as five or more standard drinks per occasion) during pregnancy.¹¹

Aboriginal communities across Canada have developed and implemented FASD prevention initiatives. These interventions typically are designed to address the needs of community members and build upon the strengths and cultural characteristics of the specific communities. However, progress has been slow. Moreover, there is growing migration of aboriginal women to urban centres.^{3,36} Presently more Aboriginal people live in urban centres than in rural areas or on reserve. In the Greater Toronto area, it is estimated that there are between 40,000 and 60,000 Aboriginal People.⁹ In nearby Hamilton, there are an additional 6,270.²⁵

Thus, women living in large urban centres will likely access primary care from non-Aboriginal practices or clinics. These settings may be suitable to deliver clinical interventions to aboriginal women to prevent FASD. However, due to the lack of appropriate systems, negative attitudes, inadequate knowledge and skill, many women at risk, be they aboriginal or non-aboriginal, are neither identified or counseled about the risks of drinking in pregnancy during visits to primary care physicians. Moreover, cultural differences between provider and patient may make it even challenging to implement more effective interventions with these women.

Increased access to aboriginal physicians would be an ideal solution. However, it is estimated that there are now only about 150 Aboriginal physicians in Canada.²¹ Moreover, only about 50% of Aboriginal physicians are involved in Aboriginal health. The Canadian Medical Association indicated that the ratio of Aboriginal physicians to the Aboriginal population was about 1:30,000 compared with 1:600 in non-Aboriginals.^{17, 18} While the enrollment of Aboriginal individuals into medical school is gradually improving the number of Aboriginal medical students is still considered significantly low. For example, a recent study found that the number of Aboriginal medical students was "only 1/6th of what one would expect from the Canadian population".²⁰

Thus, given the demographic shifts, the demonstrated need, and the fact that FASD is

preventable, the development of culturally appropriate office-based strategies to prevent FASD are timely. This paper will discuss this need and suggest an approach to bridging the cultural gap between Aboriginal women and primary care physicians.

BACKGROUND

1. What do we know about FASD?

Scientific knowledge regarding alcohol as a teratogen has been extensive since publications by French²⁸ and American researchers^{27, 28} who first reported characteristics commonly found among children prenatally exposed to alcohol. Patterns of alcohol consumption are important to fetal outcomes, with either binge drinking or frequent heavy drinking (\geq 2 standard drinks per day) being harmful.^{29, 30} Frequency, quantity and patterns of use are important issues from an individual behavioural viewpoint to prevent the occurrence of FASD.

Evidence suggests that binge drinking by pregnant women, where the woman consumes several alcoholic drinks (> four or five standard drinks) in a short period of time and reaches a high peak blood alcohol concentration, may be more risky than total volume over a longer period of time.³⁴ For example, in animal experiments, Ikonomidou demonstrated that a single exposure to high levels of ethanol (200mg per deciliter of blood – slightly higher that twice the legal limit for driving under the influence for adults in the United States) can kill nerve cells in the developing brain.³² Although frequency, quantity and patterns of use of alcoholic beverages are important risk factors, it is also important to consider social and cultural characteristics, maternal age,^{33, 34} poverty, non-dominant culture status, social disparity, poor nutrition, drug abuse including tobacco use. and psychiatric morbidity.^{35,7,60,61} The injury to the child, family, and community associated with FASD is devastating. Children suffer permanent brain damage, they experience learning disabilities, psychiatric morbidity, hyperactivity, speech impairments, behavioral disorders, and are more likely to have legal problems. Family stress levels and cost of care are higher. In the United States, the annual cost was estimated to be \$2.1 billion and in Canada the current and future costs of

caring for people with FASD is estimated to be in the billions.³⁶ The social and economic costs of FASD make it an important public health issue.

2. What do we know about alcohol consumption of Aboriginal women of childbearing age?

Not much is known about the alcohol consumption of Aboriginal women living in large urban centres such as Toronto. Most of what is known comes from studies of Aboriginal communities in non-urban areas (i.e. reserves). Alcohol abuse and FASD in Aboriginal communities can find its roots in the history of Canada. The deterioration of traditional selfgoverning political and social institutions; the suppression of traditional spirituality, culture, and language; the loss of land and traditional economic systems; and the forced assimilation of Aboriginal children is a legacy of Canada's colonial past.³⁵ In Addition, Aboriginal women are more likely to be poorer than other Canadians.² Poverty and a non-dominant culture status have been identified as health risk factors for preconceptual/prenatal periods.²¹

In a recent study commissioned by the Ontario Federation of Indian Friendship Centres. researchers reported that more mothers drank alcohol during the pregnancy of their second child than during their first pregnancy (26% in the 2nd pregnancy versus 17% in the 1st pregnancy).⁵⁹ Godel et al. found binge drinking to be more frequent among NWT Native and Inuit women than non-Native mothers.¹³ In a Quebec study, Lavallee and Bourgault found that compared to the general population, fewer Aboriginal women were drinking; however, those who drank consumed greater quantities per occasion with two thirds drinking five or more drinks on a day they consumed alcohol.⁴⁴ In addition, citing data from the Ontario First Nations Regional Population Health Survey, MacMillan et al. reported that significantly more Aboriginal females reported having five or more standard drinks on one occasion than their counterparts in the general Thus, the evidence Canadian population.⁵ suggests that drinking during pregnancy is an issue and that binge drinking, which may be the most important risk factor for FASD, is more common among Aboriginal women who drink.

3. What do we know about Aboriginal women living in urban centres that suggests the need for an intervention developed specifically for this population?

More Aboriginal persons live off reserve than on reserve with the majority in urban centres.²⁵ However, it is the on reserve population that has traditionally been studied.³⁷ The Aboriginal population is younger, has a higher fertility rate, and experiences more mortality/morbidity than the general Canadian population.^{1, 2,3,4} In addition, a study that evaluated pregnancy patterns of highrisk Canadian urban women (injection drug users), found that Aboriginal women were more likely than non-Aboriginal women to report a pregnancy.³⁷

Demographic and health information indicate the need for both new interventions and improvements to existing approaches. It is important to recognize the root causes of substance abuse by Aboriginal people and in particular Aboriginal women. Loos suggested that it was necessary to understand and address the meaning of health and pregnancy within the specific culture or the program will likely fail.²¹ In an American study, Ma et al. found that the immediate family was the most influential factor in determining alcohol use by adolescent Native Americans.⁴⁰

An intervention developed for this specific population is needed because the strengths of the target group, the need for community selfdirection, differing belief and value systems, and causes of alcoholism all indicate that the programs and approaches developed for other target populations might be misdirected. For some women, FASD may be a multi-generational problem where pregnant women and young mothers themselves may be at risk of being prenatally affected by alcohol. For these women, programs and instruments should be designed to address the needs of women who are learning disabled because of FASD.⁴¹

In an effort to create a more effective intervention for urban dwelling Aboriginal women who come from diverse backgrounds, it is important to consider and or include: a) adopting holistic approaches that interrelate physical, mental, emotional, and spiritual aspects of the individual; b) incorporating the values and views of the urban Aboriginal community; c) being aware of the determinants of health such as socioeconomic conditions or housing; d) involving the immediate family and building on family knowledge; e) recognizing differing communication patterns, and f) not making women feel guilty for drinking.^{43,21,42,2}

4. Why choose a secondary prevention approach that targets women with young children? (Or, why use a brief intervention method?)

In a Health Canada report, on FASD and substance use during pregnancy, key informants representing 13 provincial/territorial jurisdictions ranked identification and treatment for women in the top half of their list of gaps and challenges in the national effort to address FASD.⁴⁶ FASD is associated with increasing maternal age and is less likely to occur in the first pregnancy.³⁴ Therefore, the optimal time to identify high-risk women and to prevent fetal injury in subsequent pregnancies may be during or after the first pregnancy. The results from the Ontario Federation of Indian Friendship Centres study support this approach. More women reported drinking during the second pregnancy compared to the first.⁵⁹

This suggests the need for an intervention which targets the period between pregnancies. This unique approach addresses significant challenges. First, mothers who are at risk for continued alcohol use can be identified through birth events, such as pre or post-natal checkups. Second, because many women who are at highest risk for alcohol use during pregnancy are least likely to seek medical care early in pregnancy,²² post-natal visits might be an ideal opportunity or even a rare opportunity to introduce an intervention. Third, with the intervention taking place prior to subsequent pregnancies, the unfortunate problem, of being too late to be 100% effective, can be avoided.²¹ And fourth, given that women with young children are more likely to have another child than women with older children, resources can be more effectively allocated and may have a benefit to the outcome of subsequent pregnancies.

Evidence indicates that brief interventions are beneficial, cost-effective, and versatile.⁴⁷ Brief interventions have been successful in reducing heavy alcohol consumption across various targeted drinking behaviours. This success has been demonstrated in different populations using a variety of delivery methods, and delivery by different interveners.⁴⁷⁻⁵² Brief alcohol interventions have successfully demonstrated significant long-term reductions in alcohol consumption among women of childbearing age. In addition, one of the only economic evaluations conducted on brief alcohol interventions in primary care settings demonstrated positive net benefits for patients, the health care system, and society.⁵³

5. What do we know about the characteristics of physician offices in large urban centres and Aboriginal women's perceptions of care? (Or, why do we need an intervention that is specifically designed to address both?)

Primary care physician's offices can seem busy and impersonal to patients. Patients often feel intimidated by physicians and frustrated by the short time actually spent with the physician and the lack of effective two-way communication. In a Canadian study, women expressed the need for greater respect, more accessible, holistic services, and for better communication in the patientphysician relationship.⁵⁴ Aboriginal women frequently report that they encounter access problems, racism, and cultural insensitivity when accessing health services.² Research has indicated that some Aboriginal women were reluctant to return for regular care, despite the presence of intense pain, due to previous treatment they considered to be disrespectful.⁵⁵ Thus, Aboriginal women want more to be done to ensure that health professionals interact with them in a more respectful fashion. For this to take place, it is necessary to communicate the characteristics of "respect" from the perspective of Aboriginal women. Generally, primary care physicians do not receive extensive training in FASD diagnosis and do not routinely screen their patients for alcohol use.⁴⁵ Medical students receive minimal training in alcohol-related problems and residency programs do not consistently provide training in the initial diagnosis and management of substance use disorders.^{56,57}

Thus, there is a need for a specifically designed intervention that targets the interaction during the patient-physician visit. For this intervention to be successful, it must bridge the needs of Aboriginal women with the characteristics of a primary care practice and the current training and treatment approaches of physicians. For Aboriginal women this means the intervention must be culturally appropriate, accessible and non-threatening. For health professionals in a primary care practice, this means the intervention must: a) be easily adopted, flexible and aligned with standard office procedures, b) be perceived as effective and valuable in addressing an important health issue, c) be compatible with current clinical practice patterns, and d) not be resource intensive (i.e., time and materials). The training should also address the attitudes health care professionals have towards women who use drugs and or drink while pregnant.

6. How should FASD interventions be developed that would work well with Aboriginal women and primary care physicians?

Brief interventions derive alcohol from motivational interviewing and cognitive behavioral therapy modes and typically consist of one or more short counseling sessions that focus on changing behaviour according to how ready the patient is to change. These inherently patient centered methods of care require a respectful attitude towards patients. To work well, officebased systems and interventions should be designed to improve the relationship between non-Aboriginal physicians (including other office staff) and Aboriginal mothers. Specifically, it is important to address ways of improving trust, respect and communication. Intervention content and procedures should be acceptable to both parties and culturally appropriate, and address the characteristics and needs of women with young children. At a minimum, the intervention should have the following core operational characteristics where the intervention will:

- Identify 'at risk' women;
- Assess drinking behaviors;
- Provide information on the harmful effects of drinking above recommended limits;
- Employ a method of delivery that facilitates the decision of women; to adopt healthier drinking behaviors;
- Monitor changes or progress; and

• Be acceptable to clinicians and easily implemented.

One approach that should be considered would involve all stakeholders in the development of the intervention. Examples of appropriate stakeholders include: a) primary care physicians, b)Aboriginal women, c) Aboriginal organizations, d) allied health care providers, e) mental health/addictions professionals, and f) academic researchers. Representatives from each of the stakeholder groups would bring different but necessarv perspectives to the process. Participation would involve single stakeholder groups for some phases and multi-stakeholder groups for other phases of the intervention development process. Involvement would consist of a variety of methods including informal surveys, key informant interviews, mixed and single stakeholder focus groups, and pilot testing.

In this approach, academic researchers could develop the qualitative methods used to both introduce information to and learn from the different stakeholders. Existing evidence on FASD and brief alcohol interventions would be introduced. For example, documents to be evaluated could include the National Institute on Alcohol Abuse and Alcoholism's "Prevention of Fetal Alcohol Exposure and Treatment of At-Risk Drinking: A Guide for Primary Care Clinicians Who Care for Women of Childbearing Age". 58 Previously developed interventions such as those implemented by Ockene and Fleming would also be evaluated.^{50, 23} These interventions were not specifically designed to be culturally appropriate for Native persons or any specific race or ethnic population. However, much can be learned by evaluating the characteristics of these and other interventions.

The needs and characteristics of Aboriginal women and physicians' practices would be investigated in the focus groups and key informant interviews. Aboriginal organizations that serve women in urban centres would provide information the needs valuable on and characteristics of the women they serve and may also help identify geographic locations of greatest need. Mental health and addictions professionals would provide expertise on current modalities as well as relating their experiences with this growing population. Thus, an approach that

involves all main stakeholder groups and focuses on the needs and characteristics of the physicianpatient relationship will result in an intervention that will work well with Aboriginal women and primary care physicians

DISCUSSION

In this paper, we suggest that the cultural gap between urban primary care physicians and Aboriginal women needs to be bridged to improve the physician-patient relationship. It is also a necessary prerequisite for an office-based FASD intervention to be effective with this population. The joint development of evidence based, culturally appropriate interventions will require active participation from a variety of stakeholders. This method of intervention development will have the elements of respect, inclusiveness and a holistic approach to health promotion without the use of shame and blame. It is likely that this will resonate well with both aboriginal women and urban primary care physicians who work with these women. The development of this intervention will be the first step in the clinical prevention of FASD in the next generation of urban Aboriginal people in Canada.

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Urban FASD Interventions: Bridging the cultural gap between Aboriginal women and primary care physicians

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