The Journal of Aboriginal Health is an official peer-reviewed publication of the National Aboriginal Health Organization (NAHO).

Copyright/Permission to Reproduce
The Journal of Aboriginal Health is covered by the Canadian Copyright Act and international agreements (all rights reserved). Written permission is required to reprint, reproduce, modify or redistribute any information or articles, in whole or in part, published in the Journal of Aboriginal Health for any purpose other than personal photocopying.

Disclaimer
The Journal of Aboriginal Health is intended for education and informational purposes only. The articles and contents herein represent the views of the authors and do not necessarily reflect the views of NAHO. NAHO assumes no responsibility or liability for damages arising from any error or omission, or from the use of any information or advice, contained in this publication.

Subscription
The Journal of Aboriginal Health is distributed free of charge (price is subject to change with notice). To receive your free subscription, please contact NAHO or sign up online (www.naho.ca). Changes of address should be forwarded to the editorial office (see contact details in masthead).

Submissions
The Journal of Aboriginal Health accepts article submissions on the topic of Aboriginal health on an ongoing basis. All submissions should be directed to the attention of the Managing Editor. Articles are published in the language in which they are submitted.
What is HPV?

Am I at risk?

How do I know if I have it?

Can genital warts be treated?

How does HPV affect young Canadians?

Did you know that 75% of Canadians get HPV?

Everyone has questions. We’ve got answers.

The human papillomavirus (HPV) is the most common sexually transmitted infection in the world today. HPV can lead to cervical cancer. Aboriginal women have a higher incidence of cervical cancer related mortality than women in the general population. HPVinfo.ca has evidence-based information for health-care professionals, educators, adults, parents and youth on prevention, vaccination, screening, diagnosis and treatment.

hpvinfo.ca

SexualityAndU.ca

Every day, Aboriginal women face sexual and reproductive illness that can be prevented. At the Society of Obstetricians and Gynaecologists of Canada, improving access to culturally-competent health services is a priority.

Whether you’re a health-care professional, community member, educator, parent, woman, youth or elder, our website has something for you.

AboriginalSexualHealth.ca

A solid foundation for change.
The National Aboriginal Health Organization (NAHO) gives thanks to all parts of creation and all contributors who made this issue possible—the authors who submitted papers, the reviewers, the editorial board, its staff, and the production team. Also, thank you to the Public Health Agency of Canada (PHAC) and Health Canada for contributing funding, expertise, and social networks to this special issue.

Since 2004, the Journal has explored a wide range of themes, from the decolonization of health through indigenous knowledge and practice to First Nations communities in crisis. For the winter of 2012, NAHO is delighted to bring you this special issue in collaboration with PHAC.

According to the Society of Obstetricians and Gynaecologists of Canada, HPV is the most common sexually transmitted infection in the world. HPV infections can lead to diseases such as cervical cancer, the cause of an estimated 350 deaths in 2011 according to the Canadian Cancer Society. There is no national data on the incidence and mortality of cervical cancer for First Nations, Inuit, and Métis, however regional studies indicate that the incidence of cervical cancer for Aboriginal women is higher compared to women in the general population.

Cervical cancer can be prevented with vaccination and screening. However, there is a paucity of information about HPV vaccination and screening rates for First Nations, Inuit, and Métis women. The articles contained within these pages are a step towards filling these information gaps, and can inform and tailor policies, programming, and healthcare for First Nations, Inuit, and Métis people.

JAH is the leading open-access and peer-reviewed journal on First Nations, Inuit, and Métis health. It publishes research articles, methodological articles, community reports, book reviews, and other substantive material. The Journal is accessible through the NAHO website and searchable academic databases such as Scirus, Index Copernicus, and Google Scholar.

On behalf of all those involved, I hope you enjoy this special issue. I also hope you will become a future part of this publication by sharing your research, subscribing to the Journal, and most importantly, joining us as we walk with our ancestors towards better health.

Nia:wen,
Simon Brascoupe
Acting Chief Executive Officer
National Aboriginal Health Organization
Ottawa, ON
Introduction

Cheminer avec nos ancêtres

Nombre de membres des Premières nations croient que nous cheminons dans la vie accompagnés par l'esprit de nos ancêtres. Chaque jour, leurs savoir et pratiques autochtones guident nos pas sur la voie de la santé, vers une « vie saine ». Pour vivre une vie saine, nous devons travailler et cheminer ensemble comme en témoigne ce numéro spécial du Journal de la santé autochtone (JSA); en effet, un groupe diversifié d’une soixantaine de personnes, notamment des médecins et des membres de la communauté, se sont réunis pour faire avancer notre corpus de connaissances sur la prévention des infections au virus du papillome humain (VPH) et des maladies connexes.

L’Organisation nationale de la santé autochtone (ONSA) remercie toutes les parties de la création et les personnes ayant contribué à la réalisation de ce numéro : les auteurs d’articles, les réviseurs, le comité de rédaction, le personnel et l’équipe de production. Nous remercions également l’Agence de la santé publique du Canada (ASPC) et Santé Canada d’avoir contribué à ce numéro spécial par leur financement et leur savoir-faire, ainsi que les systèmes sociaux.

Depuis 2004, le Journal a exploré une grande variété de sujets comme la décolonisation de la santé, le savoir et les pratiques autochtones et les communautés des Premières nations en difficulté. En cet hiver 2012, l’ONSA, en collaboration avec l’ASPC, est ravie de vous présenter ce numéro spécial.


La vaccination et le dépistage peuvent aider à prévenir le cancer du col utérin. Il existe cependant une pénurie d’information sur les taux de vaccination et de dépistage du VPH chez les femmes métisses, inuites et des Premières nations. Les articles que nous vous présentons ici sont un moyen de combler cette lacune en ce qu’ils peuvent contribuer à une élaboration informée de politiques, programmes et soins de santé adaptés aux membres des Premières nations, aux Inuits et aux Métis.


Au nom de tous les collaborateurs du Journal, j’espère que ce numéro spécial vous plaira. J’espère également que vous contribuerez aux prochains numéros en nous communiquant le fruit de vos recherches, que vous adopterez notre Journal, et par-dessus, que nous emprunterons ensemble et avec nos ancêtres la voie de la santé.

Nia:wen,
Simon Brascoupé
Président-directeur général intérimaire
Organisation nationale de la santé autochtone
Ottawa, ON
Exploring HPV Infections and Cervical Screening With Multiple Lenses

This issue of the Journal of Aboriginal Health (JAH) explores human papillomavirus (HPV) infections and cervical screening in First Nations, Inuit, and Métis populations from a holistic perspective. This vantage point recognizes that health is a balance among the physical, mental, emotional, and spiritual aspects of life. This issue also acknowledges that health is influenced by more than personal health practices, including socioeconomics, access to care, and other social determinants of health.

HPV is one of the most common sexually transmitted infections (STIs) and it is estimated that 70% to 75% of people will be infected over their lifetime. HPV infections can cause genital warts or cancers including cervical cancer. Most HPV infections will disappear on their own and regular cervical screening, most commonly using the Papanicolaou (Pap) test, can prevent cervical cancer by catching abnormalities early before they become cancerous.

A greater proportion of First Nations, Inuit, and Métis women are diagnosed with cervical cancer than women in the general population. Factors that may account for this are explored in two of the articles in this issue. The other articles explore ways to increase the acceptance of cervical screening among Aboriginal women, including an alternative method of screening and the creation of “ethical space.”

One of the themes of this issue is the influence of personal history on acceptance of HPV screening. The health of First Nations, Inuit and Métis people in Canada has been deeply impacted by colonization and its resultant intergenerational traumas. These traumas—and the general feeling of mistrust they caused—along with limited transport and child care support may represent barriers for accessing cervical screening. Elias and collaborators used the Manitoba First Nations Regional Longitudinal Health Survey to examine the association between traumatic life experiences (abuse, addiction, or other trauma) and access to healthcare, including cervical screening. They found that First Nations women who reported traumatic histories were more likely to have had a Pap test. This may be due to these women’s more frequent use of healthcare services, which in turn increased their likelihood of engaging in cervical screening.

On the other hand, Russell and Leeuw, who used a very different methodology to survey a small group of marginalized Aboriginal women living in northern British Columbia, identified traumatic life experiences as a barrier to cervical screening for many participants. Participants showed an increased awareness of HPV and cervical cancer after taking part in workshops that used creative arts to help convey the information. Their study also showed that healthcare provider sensitivity, access to culturally relevant education resources, child care support, and transportation are factors that may positively influence screening rates.

Cerigo and colleagues provided the results of their survey on the acceptance of and preference for self-collection of cervicovaginal samples for HPV testing among a sample of Inuit women from Nunavik, Quebec. Their findings showed a preference for self-collection among the majority of participants, suggesting a better way to offer cervical screening to women who may be uncomfortable having a cervical sample taken by a healthcare provider.

Zehbe and colleagues investigated the foundation for the development of an “ethical space” in collaboration with First Nations communities in northwest Ontario. The authors used a participatory action research approach based on respectful and meaningful collaboration with First Nations women, healthcare providers, leaders, and other community members. Through a series of engagements with community members, the authors designed a study that was both scientifically sound and accepted by the communities involved.

While there are still gaps in our understanding of HPV and its impacts on First Nations, Inuit, and Métis people, this issue of the Journal expands our knowledge and points to possible best practices for the prevention of HPV-related diseases, including cancer. Notably, in the context of HPV infections and cervical screening, this issue highlights the importance of culturally relevant and gender-sensitive
screening programs.

It is important to continue building partnerships to explore the acceptability, accessibility, understanding, and uptake of HPV immunization in First Nations, Inuit, and Métis communities. Available vaccines can prevent up to 70% of cervical cancers caused by HPV and are recommended for girls nine years and older, as well as males between nine and 26 years of age, including males having sex with males. Obstacles such as those identified in this issue’s studies may hinder the dissemination of knowledge about and access to HPV vaccination. However, the studies point to a number of ways to identify and mitigate barriers to HPV immunization, helping to bring good health closer to the grasp of Aboriginal women in Canada.

Integrated HPV Working Group of the Federal Government
**Exploration des infections au VPH et de dépistage du col utérin avec des lentilles multiples**

Ce numéro du *Journal de la santé autochtone* (JSA) explore d’un point de vue holistique les infections au virus du papillome humain (VPH) et le dépistage du cancer du col utérin chez les populations métisses, inuites et des Premières nations. Selon cette façon de voir, on comprend que la santé provient d’un bon équilibre entre les aspects physiques, intellectuels, affectifs et spirituels de la vie. Le présent numéro reconnaît que la santé découle de facteurs au-delà des simples pratiques de santé personnelles, y compris des considérations socioéconomiques, de l’accessibilité des soins et d’autres déterminants sociaux de la santé.

Le VPH est l’une des infections transmissibles sexuellement (ITS) les plus répandues et on estime que 70 à 75 % des gens en seront infectés au cours de leur vie. Les infections au VPH peuvent causer des verrues génitales, le cancer, y compris le cancer du col utérin. La plupart des infections au VPH disparaîtront d’elles-mêmes et un dépistage régulier du cancer du col utérin, la plupart du temps au moyen du test de Papanicolaou (frottis), permet de prévenir le cancer du col utérin en décelant les anomalies bien avant qu’elles ne deviennent cancéreuses.

Un plus grand nombre de femmes inuites, métisses et des Premières nations que de femmes de l’ensemble de la population sont diagnostiquées comme atteintes du cancer du col utérin. Cela peut être attribuable à certains facteurs qui seront étudiés dans deux des articles du présent numéro. Les autres articles explorent les façons d’augmenter l’acceptation du dépistage du cancer du col utérin parmi les femmes autochtones, y compris une méthode de dépistage de rechange et la création d’un « espace éthique ».

L’un des thèmes traités dans le présent numéro est l’influence des antécédents personnels sur l’acceptation du dépistage du VPH. La santé des membres des Premières nations, des Inuits et des Métis du Canada a été profondément touchée par la colonisation et les traumatismes intergénérationnels qui en ont résulté. Ces traumatismes, avec le sentiment de méfiance général qu’ils ont engendré, de même que des moyens de transport limités et le peu de ressources permettant de prendre soin des enfants, représentent autant d’obstacles possibles au dépistage du cancer du col utérin. Elias et ses collaborateurs ont utilisé l’enquête régionale longitudinale sur la santé des Premières nations du Manitoba pour examiner le lien qui existe entre les expériences de vie traumatisantes (violence, toxicomanie et autres traumatismes) et l’accès aux soins de santé, y compris le dépistage du cancer du col utérin. Ils ont constaté que les femmes des Premières nations ayant rapporté des antécédents de traumatisme étaient plus susceptibles d’avoir subi un frottis. Cela s’explique peut-être du fait que ces femmes ont davantage recours aux services de santé, ce qui rend plus probable leur participation plus fréquente au dépistage du cancer du col de l’utérus.

Par contre, Russell et Leeuw, des chercheurs ayant appliqué une méthodologie très différente dans leur enquête auprès d’un petit groupe de femmes autochtones marginalisées vivant dans le nord de la Colombie-Britannique, ont indiqué que les expériences de vie traumatisantes constituaient un obstacle au dépistage du col de l’utérin chez de nombreuses participantes. Après avoir pris part aux ateliers utilisant la créativité comme moyen de véhiculer l’information, les participantes ont fait preuve d’une plus grande sensibilisation envers la question du VPH et du cancer du col utérin. L’étude menée a également fait ressortir que la sensibilité des dispensateurs de soins de santé, l’accès à des sources d’information adaptées à la culture, le soutien en matière de soins prodigués aux enfants et le transport sont autant de facteurs pouvant influer positivement sur les taux de dépistage.

Cerigo et collaborateurs ont fourni les résultats...
de leur sondage sur l’acceptation et la préférence pour l’autoprélèvement de spécimens cervicovaginaux pour le dépistage du VPH parmi un échantillon de femmes inuites du Nunavik, au Québec. Ils ont constaté que la majorité des participantes préfèrent l’autoprélèvement, ce qui suggère une meilleure façon de procéder au dépistage du cancer du col utérin auprès de femmes pouvant être mal à l’aise avec le fait que ce soit un dispensateur de soins de santé qui effectue le prélèvement d’un spécimen cervicovaginal.

Zehbe et collaborateurs ont étudié le bien-fondé de l’élaboration d’un « espace éthique », en collaboration avec les communautés des Premières nations du nord-ouest de l’Ontario. Les auteurs ont utilisé une approche de recherche fondée sur une collaboration respectueuse et significative avec les femmes des Premières nations, les dispensateurs de soins de santé, les chefs de file et d’autres membres de la communauté. En prenant une série d’engagements envers les membres de la communauté, les auteurs ont conçu une étude valable sur le plan scientifique, que les communautés impliquées ont su accepter.

Bien que nous ne comprenions pas encore parfaitement le VPH et ses répercussions sur les gens des Premières nations, les Inuits et les Métis, le présent numéro du Journal vise à élargir nos connaissances et à faire ressortir les meilleures pratiques possible pour prévenir les maladies en lien avec le VPH, notamment le cancer. En particulier, pour ce qui est des infections au VPH et du dépistage du cancer du col utérin, ce numéro met en lumière l’importance de programmes de dépistage adaptés à la culture, et qui tiennent compte de la spécificité des sexes.

Il est important de continuer à consolider les partenariats pour pouvoir étudier l’acceptation, l’accessibilité, la compréhension et la mise en œuvre de l’immunisation contre le VPH dans les communautés inuites, métisses et des Premières nations. L’accès à un vaccin peut prévenir jusqu’à 70 % des cancers du col utérin causés par le VPH et on le recommande aux filles âgées de neuf ans ou plus, ainsi qu’aux mâles âgés de neuf ans à 26 ans, y compris aux hommes qui ont des rapports sexuels avec d’autres hommes. Les obstacles répertoriés dans les études présentées dans ce numéro peuvent entraîner la diffusion des connaissances sur la vaccination contre le VPH et son accessibilité. Ces études laissent toutefois entrevoir un certain nombre de moyens permettant de repérer et d’atténuer les obstacles à l’immunisation contre le VPH, rendant ainsi la santé plus accessible aux femmes autochtones du Canada.

Groupe de travail VPH intégré du gouvernement fédéral
When the Data Does Not Match the Story:
Do Trauma Histories and Addiction Issues Really Characterize Poor Cervical Cancer Screening Uptake Among Manitoba First Nation Women Living On-Reserve?

Dr. Brenda Elias, University of Manitoba, Faculty of Medicine, Department of Community Health Sciences, Winnipeg, Manitoba

Madelyn Hall, University of Manitoba, Faculty of Medicine, Department of Community Health Sciences, Winnipeg, Manitoba

Say P. Hong, University of Manitoba, Faculty of Medicine, Department of Community Health Sciences, Winnipeg, Manitoba

Erich V. Kliewer, University of Manitoba, Faculty of Medicine, Department of Community Health Sciences, CancerCare Manitoba, Winnipeg, Manitoba; BC Cancer Agency, Vancouver, British Columbia

Lyna Hart, Southeast Resource Development Council Corp.

ABSTRACT
First Nations women have historically used cervical Papanicolaou (Pap) screening services less than non-First Nations women, and have correspondingly higher rates of cervical cancer compared to non-Aboriginal women. It has been suggested that trauma/mental health histories and addiction behaviours may present barriers and result in less use of Pap screening. This study examined the potential influence of trauma/mental health histories and addiction on self-reports of Pap screening. Data from the Manitoba First Nations Regional Longitudinal Health Survey 2002/2003 were used to explore the association of social demographic characteristics, trauma history, and addiction behaviours with Pap screening among a sample of 1,707 First Nations adult women living on-reserve in Manitoba, Canada. Women younger than 50 years, those who reported suicidal thoughts and/or attempts over their lifetime, and those with polysubstance addictions were more likely to have been screened in the three years prior to the survey. Contrary to the perceptions of some older First Nations women, women with a challenging past were indeed engaging in Pap screening. Trauma histories and addiction behaviours did not reduce the use of cervical screening for First Nations women in this study. Screening uptake, however, is still less than optimal for older women and women with less than high school education. Culturally appropriate and gender-
sensitive communication and health service efforts are required to undo existing misperceptions, and to encourage women, regardless of age or current or past circumstances, to participate in cancer screening for their own wellbeing.

KEYWORDS
First Nations women, cervical screening, trauma history, addiction behaviours

INTRODUCTION

Human papillomaviruses (HPVs) are a group of more than 150 related viruses (National Cancer Institute [NCI], 2011). Over 40 types can be sexually transmitted, with some causing genital warts and other, high-risk strains causing cancer. At least 15 HPV types are linked to the pathogenesis of cervical cancer, including less common cancers such as vaginal, vulvar, anal, penile, and upper aerodigestive tract cancers (Muñoz et al., 2003; Gillison & Shah, 2003; NCI, 2011). Persistent infections with high-risk HPVs are the primary cause of cervical cancer. The Canadian Cancer Society’s Steering Committee on Cancer Statistics (2011) reports that cervical cancer is the 13th most common cancer among Canadian women.

With the introduction of cervical cancer screening using the Papanicolaou (Pap) test method more than 25 years ago, the rates of death from cervical cancer in Canada have decreased by nearly 50% (Health Canada, 2009). Despite this, research shows that Aboriginal (First Nations, Inuit, and Métis) women have higher rates of cervical cancer compared to non-Aboriginal women (Health Canada, 2009; Young, 1991; Young, McNicol, & Beauvais, 1997; Young, Kliewer, Blanchard, & Mayer, 2000; Pakula, 2006). In Manitoba, First Nations women have 3.6 times the age-standardized rates of invasive cervical cancer, and 1.8 times the risk of in situ cervical cancer compared to the provincial population (Young et al., 2000). First Nations women also have higher mortality rates from cervical cancer than non-First Nations women (Clarke et al., 1998).

Health Canada (2009) recommends that women be first screened for cervical cancer at 18 years of age or as soon as they become sexually active, with a second screening one year later. If there are no abnormalities, women should be re-screened every three years until the age of 69. Historically, research has shown that Aboriginal women use cervical cancer screening to a significantly lesser degree than other women (Young et al., 2000; Pakula, 2006; Wilson, 2002). For example, Wilson reported that from 1993 to 1996, only 43% of First Nations women had one or more screening tests compared to 60% of non-First Nations women. Health Canada reported that Aboriginal women may be at higher risk for developing cervical cancer because they have been screened irregularly or not at all. Other recent surveys suggest that screening rates are now comparable (McDonald & Trenholm, 2010; Statistics Canada, 2005; Waters, 2008; Amankwah, Ngwakongwii, & Quan, 2009), but also that differences can still occur within population groups (Elias et al., 2011).

A number of studies have looked at cervical cancer screening among Aboriginal women. Using administrative data to explore rates of cervical cancer and Pap testing, Young et al. (2000) found that Aboriginal women have higher rates for cervical cancer and were less likely to have had a Pap test within the preceding three years. The authors stressed the need for organized screening programs for Aboriginal women. Hislop et al. (1994) examined whether inadequately prepared Pap smears might explain higher rates of cervical cancer coupled with lower rates of screening among British Columbia Aboriginal women, but found they did not. In a study from Ontario, Fehringer et al. (2005) found a positive association between higher education and screening. Young et al. (1997) examined the prevalence of HPV infection among low-income women and found that marital status and overall number of sexual partners were significant independent predictors of infection, but found no differences between Aboriginal and non-Aboriginal women. A study in the United States (Farley, Golding, & Minkoff, 2002) examined the influence of childhood experience of sexual abuse, natural disasters, adult-inflicted terrorism, or break-ins on cervical screening among women aged 21–64. In their sample of predominantly white European American women, those who had been sexually abused as children were less likely to have had a Pap test in the preceding two years. This was the only statistically significant trauma...
predictor of reduced likelihood of Pap screening.

In British Columbia, Clarke et al. (1998) found that First Nations women have difficulty accessing culturally appropriate health care services and respectful, consistent health professionals. Wilson (2002) also found that cultural beliefs, physical and/or emotional discomfort, embarrassment, and discomfort with male physicians were factors. She concluded that awareness of cultural beliefs, values, and customs are necessary for effective screening programs. One study to identify facilitators and barriers for screening programs concluded that “many First Nations women are greatly affected by health care providers’ attitudes, abilities to provide clear information, and abilities to establish trusting relationships” (Hislop et al., 1996). Pakula (2006) also stressed the need for effective practitioner approaches when working with vulnerable populations. These findings are supported by the Native Women’s Association of Canada, which has suggested that Canadian Aboriginal women face barriers not experienced by non-Aboriginal women. These include decreased access to information, services, and culturally relevant gender-sensitive programs and services (Native Women’s Association of Canada, 2011).

Several older First Nations women attended the International Centre for Infectious Diseases workshop on improving HPV prevention among Aboriginal Peoples held in Winnipeg in December 2008. They commented that HPV surveillance often excludes Aboriginal women, and that those with trauma/mental health histories and addiction issues may be less likely to have Pap tests (International Centre for Infectious Diseases, 2008). This perception, which could stem from underlying knowledge of the long-term effects of residential school including possible sexual abuse, adds another layer to our understanding of issues related to the uptake of cervical cancer screening, considered by many women to be a particularly invasive test.

Despite the wide array of studies reviewed, no study has yet examined whether trauma/mental health histories and addiction issues may account for lower uptake of cervical cancer screening among First Nations women in Canada. This study is therefore the first to explore the association of socio-demographic characteristics, trauma history, and addiction behaviours with Pap test screening among First Nations women in Manitoba, Canada.

METHODS

Data from the adult survey (ages 18 years and older) of the Manitoba First Nations Regional Longitudinal Health Survey (RHS) 2002/2003 were used to explore potential predictors of Pap smear testing among First Nations women living on-reserve. The Manitoba First Nations Centre for Aboriginal Health Research, in partnership with the Assembly of Manitoba Chiefs, implemented the 2002/2003 wave of the RHS. A multi-stage stratified random sampling approach was used to select a representative sample of on-reserve First Nations communities in Manitoba. Small (population < 500), medium (population 500–999), and large (population > 1000) communities were randomly selected from seven Tribal Council regions. The adult survey was implemented in 27 communities, and the sample was stratified by age and gender. In each community, interviewers randomly selected households and interviewed, where possible, two adults living in the household (one male and one female) and all adults aged 55 years and older. The survey had a response rate of 77%, with 60% of the communities achieving a response rate of over 80%. The survey sample used for this paper includes First Nations women aged 18 years and older (N = 1,707).

Measures

Binary Outcome Variable:
The outcome measure for this study was derived from a survey question asking if the woman had a Pap smear test within the past three years (yes vs. no).

Potential Covariates:
Socio-demographic variables included the woman’s age (grouped as 18–34 years, 35–49 years, and 50+ years), if the respondent was a lone parent (yes vs. no), and if she had completed high school or its equivalent (yes vs. no). Trauma histories included a variable indicating a lifetime history of abuse, derived from the question: “Have you ever experienced any form of physical, mental, emotional or sexual abuse or violence, either as a child, in an adult relationship, or at any other time?” (yes vs. no). Other trauma variables included attendance at a residential school by the respondent and/or her parents or grandparents (yes vs. no), and a history of suicidality, i.e., if she had contemplated and/or attempted suicide over her lifetime (yes vs. no). Addiction behaviours surveyed were current smoking (yes vs. no); binge drinking, defined as five or more drinks on one occasion, (yes vs. no); illegal drug use, which included use of marijuana, cocaine, crack, PCP, heroin, LSD, etc. (yes vs. no); and polysubstance use, defined as two or more of smoking, drinking, and/or illegal drug use (yes vs. no).
When the Data Does Not Match the Story

Statistical Analysis:
A bivariate chi-square test was initially conducted for the outcome measure with all potential predictors. All covariates were then modeled against the outcome using stepwise logistic regression. The final model included significant independent predictors at \( p < 0.15 \). Potential interaction terms among the remaining predictor variables were investigated but none were found. SUDAAN (Research Triangle Institute, version 10) software was used to compute the logistic regression models. The Taylor linearization method was used for variance estimation, and the Wald chi-square statistic was used to test significance.

RESULTS

Bivariate Results
At the bivariate level, age, high school completion or equivalent, abuse history, suicidality history, binge drinking, illegal drug use, and polysubstance use were all significantly associated (\( p < 0.1 \)) with having had a Pap test in the preceding three years (Table 1). About 8 of every 10 women under the age of 50 had been tested while only one in two aged 50 and over had been tested. Eighty percent of the women who had completed high school or the equivalent had a Pap test compared to 70% of those who had not completed high school. Nearly 80% of the women who reported lifetime abuse had Pap testing compared to 68% of women who had not experienced abuse. Similarly, Pap testing was more likely for women who reported a history of suicidal thoughts or attempts (82%) compared to women with no history of suicidality (68%). Binge drinking, illegal drug use, and polysubstance use were also significantly associated with Pap testing: 79% of binge drinkers vs. 69% of non-binge drinkers, 84% of illegal drug users vs. 70% of women who did not use illegal drugs, and 81% of polysubstance users vs. 68% of women who were not polysubstance users had undergone recent Pap testing.

Logistic Regression Results
All covariates were included in a stepwise multivariate regression model, with a cutoff point of 0.15. Five covariates met the criteria for inclusion: age, high school completion or equivalent, history of suicidality, smoking, and polysubstance use.

In the final analysis, age younger than 50 years, a history of suicidality, and polysubstance use remained as significant (\( p < 0.05 \)) independent predictors of Pap testing for the First Nations women in our sample. High school completion or equivalent and smoking were not significantly associated (Table 2) with Pap testing. Those aged 18–34 were three times more likely, and those aged 35–49 were 2.5 times more likely, to have had a Pap test within the past three years compared to women aged 50 and over. Women who had experienced thoughts of suicide and/or had attempted suicide were 1.8 times more likely than those with no history of suicidality to have had a Pap test, and those who were polysubstance users were 1.6 times more likely than non-users to have had a Pap test.

DISCUSSION AND POLICY IMPLICATIONS

Our analysis confirmed that First Nations women are having Pap smear testing, but the uptake is less than ideal. While about 8 of every 10 First Nations women under the age of 50 had been tested within the three years prior to the survey, only one in two women aged 50 and over had been tested.

Our examination of the perceived link among trauma histories, addiction issues, and limited screening uptake was instructive. Both a history of suicidality and polysubstance addiction predicted a greater likelihood of Pap screening. These findings are contrary to the perceptions of older First Nations women who had attended the Winnipeg HPV workshop, and suggest that being a young woman and having a challenging past may not always be a barrier to cervical cancer screening. One possible explanation is that these women may have more frequent contact with the health system, thus increasing their awareness of screening programs and their access to screening.

On the other hand, while it is known that smoking can increase a woman's risk of developing cervical neoplasia—the precursor to cervical cancer (Gadducci, et al., 2011)—this study found no difference between smoking status and screening uptake. Also, while binge drinking and illegal drug use were associated with screening at the bivariate level, only polysubstance use was found to be an independent predictor of Pap screening in the final analysis. This finding suggests that women were undergoing Pap screening regardless of their substance abuse status. While this finding may appear to be positive, the data suggest a high proportion of First Nations women are engaged in substance abuse, particularly tobacco and alcohol use, which are known cancer risk factors. With such high numbers reporting smoking and/
TABLE 1. SAMPLE CHARACTERISTICS AND PAP SMEAR TEST IN THE LAST THREE YEARS

<table>
<thead>
<tr>
<th>Column One</th>
<th>Column Two</th>
<th>Column Three</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample Characteristics</td>
<td>Chi-square</td>
<td>Unadjusted odds ratio</td>
</tr>
<tr>
<td></td>
<td>Freq (weighted %)</td>
<td>(95% C.I.)</td>
</tr>
<tr>
<td>Age</td>
<td>8.56 *</td>
<td></td>
</tr>
<tr>
<td>18–34 years</td>
<td>489 (81.0)</td>
<td>3.94 (2.57–6.02)</td>
</tr>
<tr>
<td>35–49 years</td>
<td>331 (78.1)</td>
<td>3.29 (2.26–4.80)</td>
</tr>
<tr>
<td>50+ years</td>
<td>171 (52.0)</td>
<td>—</td>
</tr>
<tr>
<td>Lone Parent</td>
<td>0.96</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>607 (72.7)</td>
<td>—</td>
</tr>
<tr>
<td>Yes</td>
<td>350 (76.3)</td>
<td>1.21 (0.80–1.84)</td>
</tr>
<tr>
<td>High school completion/equivalent</td>
<td>5.20 *</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>560 (69.8)</td>
<td>—</td>
</tr>
<tr>
<td>Yes</td>
<td>421 (80.5)</td>
<td>1.78 (1.17–2.73)</td>
</tr>
<tr>
<td>Lifetime abuse history</td>
<td>8.72 *</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>381 (68.5)</td>
<td>—</td>
</tr>
<tr>
<td>Yes</td>
<td>499 (79.4)</td>
<td>1.78 (1.16–2.71)</td>
</tr>
<tr>
<td>Attended a residential school and/or had parents or grandparents who attended</td>
<td>2.55</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>347 (70.6)</td>
<td>—</td>
</tr>
<tr>
<td>Yes</td>
<td>635 (76.3)</td>
<td>1.34 (0.90–2.00)</td>
</tr>
<tr>
<td>Suicidality history</td>
<td>12.78 *</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>539 (68.1)</td>
<td>—</td>
</tr>
<tr>
<td>Yes</td>
<td>382 (82.4)</td>
<td>2.19 (1.51–3.18)</td>
</tr>
<tr>
<td>Smoking</td>
<td>2.52</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>319 (70.8)</td>
<td>—</td>
</tr>
<tr>
<td>Yes</td>
<td>664 (75.6)</td>
<td>1.28 (0.93–1.76)</td>
</tr>
<tr>
<td>Binge drinking</td>
<td>4.50 *</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>442 (69.2)</td>
<td>—</td>
</tr>
<tr>
<td>Yes</td>
<td>454 (79.1)</td>
<td>1.69 (1.13–2.52)</td>
</tr>
<tr>
<td>Illegal drug use</td>
<td>11.88 *</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>658 (69.5)</td>
<td>—</td>
</tr>
<tr>
<td>Yes</td>
<td>316 (83.7)</td>
<td>2.25 (1.53–3.31)</td>
</tr>
<tr>
<td>Polysubstance use</td>
<td>10.47 *</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>468 (67.8)</td>
<td>—</td>
</tr>
<tr>
<td>Yes</td>
<td>463 (81.1)</td>
<td>2.04 (1.49–2.79)</td>
</tr>
</tbody>
</table>

*p < 0.1
or heavy drinking, other types of culturally appropriate and gender-sensitive cancer risk prevention programs are urgently required in addition to cervical cancer screening.

To address these issues, the Canadian Partnership Against Cancer (2009) hosted a forum for First Nations, Inuit, and Métis organizations, as well as government health planners and cancer agencies, to identify major themes needing to be addressed for the First Nations, Métis, and Inuit populations. Recommendations emphasized a holistic, person-centered approach to health and cancer care, culturally relevant educational materials and services to meet the needs of diverse communities, community-led programming, innovative approaches to education and service provision in rural and remote areas, and strengthening the capacity of communities to understand and apply research results. In addition, the Native Women’s Association of Canada (2011) stresses the need for programs and services that are presented in a culturally safe and respectful manner, and ongoing recognition and support for cultural practices and traditional healers.

In summary, our research has shown that on-reserve First Nations women are using cervical cancer screening services regardless of trauma histories or addiction behaviours. The perceptions of the First Nations women at the Winnipeg HPV workshop, however, tell another story. This disconnect suggests that more research is required to understand First Nations women’s perceptions of who is getting screened and who is not, particularly across generations. For instance, one study suggests that cervical cancer screening compliance in older age groups tends to be significantly associated with annual clinical breast examinations, compliance with mammography screening, and regular contact with a physician (Miedema & Tatemichi, 2003). For older First Nations women, a

### TABLE 2: FINAL LOGISTIC REGRESSION MODEL

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Column One</th>
<th>Column Two</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pap smear test (N = 1266)</td>
<td>Adjusted odds ratio (95% CI)</td>
<td></td>
</tr>
<tr>
<td>\textbf{Age}</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–34 years</td>
<td>3.04 (1.75–5.26)§</td>
<td></td>
</tr>
<tr>
<td>35–49 years</td>
<td>2.54 (1.61–4.01)§</td>
<td></td>
</tr>
<tr>
<td>50+ years</td>
<td>Ref</td>
<td></td>
</tr>
<tr>
<td>\textbf{High school completion or equivalent}</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Ref</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.44 (0.96–2.17)</td>
<td></td>
</tr>
<tr>
<td>\textbf{Suicidality history}</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Ref</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.80 (1.20–2.70)†</td>
<td></td>
</tr>
<tr>
<td>\textbf{Smoking}</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Ref</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.71 (0.45–1.14)</td>
<td></td>
</tr>
<tr>
<td>\textbf{Poly-substance use}</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Ref</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.64 (1.10–2.45)‡</td>
<td></td>
</tr>
</tbody>
</table>

\(§ p < 0.001 \quad † p < 0.01 \quad ‡ p < 0.05\)
culturally appropriate, safe, comfortable, and accessible primary health care system, and support for engaging this system regularly, could also result in greater uptake in screening. Further qualitative research is therefore required to explore this dynamic, particularly among older women living on-reserve. Culturally grounded research, knowledge translation, and mobilization efforts are also required to undo existing misperceptions and to support First Nations women, regardless of age or current or past circumstances, to engage in cancer screening for their own wellbeing.

LIMITATIONS

While this study yielded important findings, it did have some limitations. First, the RHS only surveyed First Nations living on-reserve. The findings therefore are not necessarily applicable to First Nations women living off-reserve. Second, the measures were based on self-reports. While research suggests that some measures such as self-reported smoking may have more accuracy, other self-reported behaviours such as a history of abuse and addiction behaviours such as drinking and use of illegal drugs measures may not (Newell & Girgis, 1999).

ACKNOWLEDGEMENT

The Manitoba First Nations Regional Longitudinal Health Survey was a joint partnership of the Assembly of Manitoba Chiefs and the Manitoba First Nations Centre for Aboriginal Health Research (Dr. Brenda Elias). Funding from the Canadian Institutes of Health Research (#AQC-83508) supported the analyses undertaken for this paper. The results and conclusions are those of the authors and no official endorsement by the Assembly of Manitoba Chiefs is intended or should be inferred.

REFERENCES


McDonald, J. T., & Trenholm, R. (2010). Cancer-related health behaviours and health service use among Inuit and other residents of Canada's north. *Social Science and Medicine, 70*(9), 1396–1403.


Planning Committee:

Pierre Lessard, MD, FRCSC, CSPQ, FACOG
Don Wilson, MD
Diego Garcia, MD, Assembly of First Nations
Melissa Maracle, CHIR, CDPW
William Ehman, MD

Jonathan Hey, MBChB, CCFP, FCFP
Dean Leduc, MD
Andrée Gagnon, MD, CCMP
Roseanne Goodine, MD, CFPC(F)
Kerry Roberts, BScPharm

Learning Objectives:

• Approach the topic of HPV immunization and protection with an Aboriginal patient.
• Discuss some of the key factors that could influence HPV protection in Aboriginal patients.
• Review some unique aspects of Aboriginal culture that may influence counselling and discussions with healthcare providers.
• Discuss the role of the different HPV vaccines in the protection of different Aboriginal women.

This program meets the accreditation criteria of The College of Family Physicians of Canada and has been accredited for up to 1 Mainpro-M1 credit.

This event is an Accredited Group Learning Activity (Section 1) as defined by the Maintenance of Certification program of the Royal College of Physicians and Surgeons of Canada, and is valued at 1 hour of continuing professional development.

Production of this document has been made possible through a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

Please visit www.AdvancingIn.com to participate in this program.

AdvancingIn.com is open to all healthcare professionals across Canada.
Physicians • Nurses • Pharmacists • Medical Students • Residents • Educators • Therapists
Intimate Stories: Aboriginal Women’s Lived Experiences of Health Services in Northern British Columbia and the Potential of Creative Arts to Raise Awareness About HPV, Cervical Cancer, and Screening

Virginia L. Russell, BSc (hons), MSc, Graduate of the Community Health Sciences Program, University of Northern British Columbia

Sarah de Leeuw, BFA, MA, PhD, Assistant Professor at the Northern Medical Program, University of Northern British Columbia. Faculty of Medicine, University of British Columbia

ABSTRACT

Guided by feminist and community-based participatory methodologies and by efforts to decolonize health research practices, and undertaken with qualitative research methods (interviews, open-ended questionnaires, and analysis of arts-based expressions like storytelling, journaling, and picture-making), this research identified challenges and barriers that (predominantly Aboriginal) women in northern British Columbia faced when trying to access sexual health care services related to HPV and cervical cancer screening. The research also examined the possible effectiveness of creative or arts-based strategies to promote cervical health and screening awareness among young and/or traditionally underserved or marginalized women. We review findings from data gathered over six months during multiple interactions with 22 women from a wide range of ethnic backgrounds. Results confirm that ethnicity, finances, and formal education are determinants in women’s awareness about, access to, and use of cervical screening services, and that experiences of gendered victimization, feelings of disempowerment, and life circumstances all influenced women’s comfort levels with, access to, and use of cervical cancer screening services.

KEYWORDS

Sexual health promotion, creative art(s), HPV, cervical cancer, Aboriginal women, community-based approaches
INTRODUCTION

Dee,¹ who was born in British Columbia's interior, is a middle-aged Cree Métis woman raised by multiple foster families in northern British Columbia. Dee's history is not uncommon: Aboriginal children make up 40% of children in care, while only representing 6% of the total population of children in British Columbia (BC Aboriginal Childcare Society, 2007). The Northern Health Authority has the highest percentage of Aboriginal people in the province, translating into significant numbers of people who have experienced state intervention at the family and individual levels (Blackstock, 2007, 2011). Due to ongoing abuse inflicted on her as a child, Dee left “home” at the age of 14 to live on the streets. She worked in the survival sex trade industry for most of her teen and adult life while simultaneously struggling with addiction issues and repeated victimization. When asked about her relationship with physicians, Dee spoke about a particular moment that has stayed with her: “He looked at me like I was a junkie… he doesn't have to say anything. All he has to do is look at you and like, we are from the streets—we can read every little thing you do, right?” (Dee, personal communication, June 2010). For Dee, that single interaction affected the future of her health care, particularly health care involving what she described as “intimate” care (i.e., sexual health, HPV, and Papanicolaou [Pap] smears).

Dee is not alone in being an Aboriginal woman whose life circumstances (which, as this paper explores, are in part determined by a series of sociocultural and economic drivers, including colonialism) result in a disconnect with the health system that, in great part, hold the potential to impact rates of HPV infection and cervical cancer. Understanding the challenges that women with similar life circumstances to Dee face, and then theorizing how to bridge the disconnect between women like Dee and the health care system, was the goal of research explored in this paper.

BACKGROUND

Aboriginal people’s health is deeply impacted by social determinants (Loppie-Reading & Wien, 2009; Hankivsky & Chrisoffersen, 2008; Marmot et al., 2008) including colonization and its resultant intergenerational traumas. Colonial encounters have resulted in many Aboriginal people feeling mistrust or alienation toward “Western” or non-Aboriginal structures, including the medical system (Provincial Health Officer of British Columbia, 2009; Thibodeau & Peigan, 2007; Reading, Kmetic, & Giddion, 2007; Smylie, 2009; de Leeuw, et al., in press). This feeling of alienation can stand in the way of Aboriginal people using services or feeling confident in fully expressing an array of health needs to health care providers. Aboriginal people also often encounter a health care system insensitive to their unique health needs and experience the naïveté of many (particularly non-Aboriginal) health care providers about realities specific to Aboriginal people (Adelson, 2005; de Leeuw & Greenwood, 2011; Elliot & de Leeuw, 2009).

The challenges faced by Aboriginal people in accessing health services are exacerbated in northern British Columbia. British Columbia is home to 198 separate and unique First Nations, the highest number of distinct communities in comparison to all other provinces and territories in Canada. Aboriginal people in British Columbia represent approximately 4.8% of the total population (Province of British Columbia, 2008) and approximately one-third of Aboriginal people in British Columbia live in the northern areas of the province (British Columbia, 2009). In British Columbia, mortality from cervical cancer was significantly higher among Status Indian women compared to other women for the period 2002 to 2006, which is three times the rate of all other residents (British Columbia, 2009). This research took place in the Northern Health Authority, which has higher relative incidence rates and hazards associated with cervical cancer than all other health authorities in the province (BC Cancer Agency, 2007).

¹ Like all participant names in this paper, “Dee” is a self-selected pseudonym and not the participant’s real name. The research was approved by the University of Northern British Columbia’s Research Ethics Board (REB) and supported by the organizations from which many of the participants were recruited.

² Research questions included: (a) What is your comfort level with physicians? (b) Describe what the word “trust” means to you, (c) Do you trust health care professionals… why or why not? and (d) Please describe your comfort of your last Pap smear. This research is not, however, meant to guide clinical policies or physician practices. Nor is the research meant to be reproducible or generalizable. It is a (principally) qualitative inquiry into a small population’s experience around accessing sexual health services, notably those linked to cervical cancer screening and HPV prevention. We believe the in-depth and experiential nature of participants’ stories can serve to illuminate broader discussions about how to make cervical cancer screening and HPV prevention strategies more relevant to and respectful of multiply marginalized Aboriginal women.
RESEARCH METHODOLOGIES AND METHODS

Decolonizing, anti-racist, and feminist research methodologies, in addition to intersectionality theory and social determinants of health perspectives, have recently compelled health researchers—particularly health researchers focused upon Aboriginal peoples and communities—to conceptualize and undertake health research in new ways (Green 2007; Hankivsky & Chrisoffersen, 2008, Smith, 1999). There is awareness that research must account for its role in (re)producing social inequities and that (particularly women’s) health is intimately linked with broader sociocultural systems of power (Brown & Strega, 2005; Green, 2007; Smith, 1999; Wilson, 2008). With these methodological imperatives in mind, and as feminist researchers, one of whom is a young Aboriginal woman, we wanted to understand how women in our community experienced their “health worlds.” Consequently, and in line with community-based research principles (Brown, 1991; Brown & Strega, 2005; Christopher et al., 2008; Grunfeld, 1997), we invested time to build relationships within the community where we undertook research and worked with young women in the community to create health education workshops about cervical cancer. The success of using community-based participatory research (CBPR) approaches to health problems has been well-documented, particularly when working with marginalized populations (Brown, 1991; Brown & Strega, 2005; Grunfeld, 1997).

Feminist methodologies acknowledge that research should be for and by women rather than on or about women (Ironstone-Catterall, et al. n.d). As a result, our research aimed to be inclusive of voices that are often silenced (e.g., women in the sex trade industry), was conscious about the need to build capacity in the women with whom we worked, and resulted in usable information that participants took ownership of. Specific to marginalized women and cervical cancer prevention, Christopher et al. (2008) demonstrated the importance and success of a community partnership intervention approach, rather than the traditional public health approach that they argue “ignore[s] a substantial part of the dynamic and social nature of public health programs” (p. 831). Engaging in CBPR provides opportunities for women who are vulnerable to develop skills and achieve a sense of self and ability concerning improving important health issues both within their community and within their own lives (Brown & Strega, 2005; Christopher et al., 2008).

Methodologically, we acknowledge the importance of using an equity-based or social justice framework for research and then advocating for the emancipation from social oppression, marginalization, and stereotyping in society and health care. By listening to women’s stories, whether through questionnaires, journals, photos, storytelling, or art, we were able to better understand some of the barriers women feel they face in access to or use of cervical screening.

Prevention of cervical cancer rests on early detection, which relies on holistic and culturally appropriate education strategies (Bigby et al., 2003; Shoveller, Chabot, Soon, & Levine, 2007; Shoveller et al., 2009). This requires listening to women about raising awareness about HPV and cervical cancer (Barnett & Shoveller, 2011). We undertook a six month-long community-based research project organized into three stages. The first stage focused on building understanding about research. The second stage involved gathering information about levels of understanding about HPV by participants, all of whom were traditionally marginalized women. The third stage focused on assessing how best to raise awareness among traditionally marginalized women about HPV and cervical cancer. In adherence to a community-based research model, and with a commitment both to building capacity and to working with as opposed to on the participants, we trained four women as research assistants and community educators.

Women were recruited during the first stage of the project, primarily by word of mouth, from the New Hope Society (a non-profit drop-in centre and safe space for women working in the survival sex trade industry), and the Elizabeth Fry Society (an organization dedicated to working with women at-risk for criminalization and/or victimization). Although participants did come from outside these two organizations, most had connections with women who accessed the two agencies. In the first stage, women completed questionnaires that explored their understanding about health determinants and their medical and Pap smear history, as well as their experiences with and perceptions about the health care system. Stage two entailed recruiting
women from the community interested in attending six months of regularly scheduled arts-focused group workshops with discussions about cervical health. If needed, attendees were provided with childcare and transportation; snacks, beverages, and remuneration for women's time were also provided. The purpose of group sessions was both to document if women's awareness about cervical cancer and research techniques increased through creative art engagement, and to better understand women's lives and lived experiences in relation to sexual health, the health care system, and HPV and cervical cancer. Participants learned about HPV, cervical cancer and screening and, with the intent to build future capacity and make the research useful to a broader community, prepared to lead other arts-based workshops. Finally, in stage three, women took part in two peer-led and arts-based cervical health community workshops during "Pap Awareness Week," a promotional initiative of the Cervical Cancer Screening Program "Live Aware. Create Empowerment." (LACE) Campaign.

In total, five data sets were combined for qualitative analyses to yield the research results explored in this paper. Data sets included hand-written and transcribed notes from the twenty-two women who completed questionnaires, three journals ranging from 14 to 28 pages in length, 52 photos taken by group members, one recorded women's health group discussion, and 34 art pieces made by participants. During the first stage of the research, numerical data gathered from the questionnaires was entered into a statistical analysis program (Statistical Package for the Social Science [SPSS]) and later analyzed using this program. Demographics and aspects of participants' lives, such as self-reported health, stress, financial positions, cervical cancer screening use, levels of trust comfort and awareness about HPV, and cervical cancer scores, were generated using SPSS. Once the project was complete in November, 2010, coding ensued by combining the data sets and using a thematic approach (Braun & Clarke, 2006; Aronson, 1994) to generate themes, with particular attention to women's awareness about cervical health and barriers to use of or access to cervical screening. Women's stories were then pieced together to form a comprehensive picture of their collective experiences (Aronson, 1994). For validation, the findings from the qualitative data were reviewed and agreed upon by two of the women who regularly participated in the women's health group.

RESULTS AND DISCUSSION

Demographics
A total of 22 women aged 19–29 and two women aged 45–56 years filled out questionnaires during the first stage of the project. Fifteen women self-identified as having Aboriginal heritage including two Métis women, one Cherokee woman, and 12 women from the following communities: Takla, Lake Babine (Nat’oot’en), Sechelt (Shíshálh), Horse Lake, Stoney Creek (Saik’uz), Kwatasha (Tsëk̓éne), and Nakazdli First Nations. Seven of these women explicated identified themselves as having First Nations status. Four women participated in stage two of the project, which involved monthly arts-based cervical health groups (sexual health awareness training) for six months.

Comfort with health care providers
Of the 22 women, 15 had a regular family physician and seven women did not. Six of the seven Status First Nations women did not have a regular health care provider. The length of time spent as a patient with family physicians varied between one and 23 years ($M = 9.64$, $SD = 8.1$, $Mdn = 7$). The comfort experienced with family physicians also varied among each woman. Three women said they felt “extremely low” or “below average” levels of comfort with their family physician. Six felt “average” levels of comfort, four felt “above average,” and three felt “extremely comfortable” with their family physicians. When asked, 14 women said they had a general trust of health care professionals while eight said they did not.

Cervical cancer screening use
Twenty research participants had participated in cervical cancer screening services at least once in their lifetime while two never had. The regularity of women's participation in screening varied. Many women (11) said they were screened yearly. One woman went in “every six months” and four went “every two years.” One woman said her last Pap smear took place “too long ago to remember” and five women said they had “rarely” or “never” had a Pap smear: cervical screening had occurred once, more than 3 years ago. Comfort with the last Pap smear varied: six of the women had “extremely low” levels of comfort during their last Pap smear, five women experienced “below average” levels of comfort, and nine women felt “average,” “above average,” or “extremely high” levels of comfort.
Awareness about HPV and cervical cancer

Women's awareness about HPV and cervical cancer was assessed using a series of eight “true” or “false” statements about HPV and/or cervical cancer. Women were asked to answer “true,” “false” or a use question mark (?) if they were not sure what the answer was. We also wanted to know if formal education played a role in women's awareness about these sexual health topics. Results are displayed in Table 1 with the frequency and percent of correct and incorrect responses received for each statement.

Half of the participants knew that HPV can cause cervical cancer, while the other half were not sure of the relationship between HPV and cervical cancer. Women indicated low levels of awareness, in general, about HPV including its asymptomatic nature (59% incorrect) and the existence of various strains (50% incorrect). The cumulative awareness scores for the women ranged from 0 to 8. Five women answered all eight questions correctly. Two women answered seven questions correctly, while 12 women answered four or fewer questions correctly. Of the 13 women with below high school education levels, an average of 2.85 (SD = 2.5) questions were answered correctly. Participants with high school level-education and above answered an average of 6.44 (SD = 1.7) questions correctly. Women in this project with higher levels of formal education had higher levels of awareness about HPV and cervical cancer. However, in general women who participated in the questionnaire had somewhat low awareness about HPV.

Post-workshop HPV awareness

Before and after questionnaires were also filled out by women participating in stage two (group workshops) of the research who had not participated in stage one (awareness building). The scores from both data sets—women who had also participated in stage one (n = 8) and additional women who attended the workshops (n = 11)—were combined (N = 19). Women’s scores pre-workshop (M = 4.39, SD = 2.89) significantly improved after attending (M = 7.16, SD = 1.61), indicating that women's awareness about HPV and cervical cancer significantly improved after attending an arts-based workshop. Most tellingly, the statement “HPV can cause cervical cancer” was answered incorrectly by half of the women before attending the group workshops. After the workshops, only one woman answered this question incorrectly.

Themes

Using thematic analysis and the theoretical frameworks mentioned above, four relevant and validated themes emerged from the data: (a) experiences of gendered victimization, (b) feelings of (dis)empowerment, (c) life circumstances, and (d) lack of awareness. These had an impact on all aspects of women’s interactions with HPV and screening opportunities, shedding light on barriers women experience when accessing services that could prevent cervical cancer.

Experiences of gendered victimization

Thirteen women spoke, wrote, or made art about experiences with victimization and directly related them to (dis)comfort receiving sexual health information and HPV screening services from health care professionals. Women’s stories of victimization included discussions about emotional, physical, and sexual abuse ranging from childhood to current day. Patricia describes Pap smears as “the worst thing you can get done” (Patricia, personal communication, June 2010). Petra, who had recently moved to northern British Columbia from her community, spoke about childhood episodes that made her feel distrustful. Although Petra had been with the same family doctor for about 10 years, she says that trust is “sacred” and that she did not trust anyone, “not even my own doctor.” Petra was sexually molested when she was seven years old and spoke about how this contributed to her discomfort with her physician, particularly having Pap smears: “I was molested when I was younger; my discomfort has got a lot to do with somebody just touching me” (Petra, personal communication, June 2010). Sharon also talked about a traumatic childhood. She ran away from home when she was 11 years old because of the physical and sexual abuse. At 14 years of age, she began “working the streets,” observing she had a “long history of addictions.” She describes trust as “loyalty… just believing in someone… having faith”, of which she says she has “very little.” “I’ve learned the hard way,” said Sharon, “[that] on the streets there is really nobody to trust. I trusted a lot of people in my life and a lot of shit has happened to me” (Sharon, personal communication, June 2010). Consequently, Sharon also says that she does not trust health care professionals. The last Pap smear that Sharon received was during a mandatory examination at a treatment centre. She had never self-initiated a Pap smear.

Broad agreement existed among women that (a) women were commonly victims of abuse in a variety of forms, (b) these experiences have enormous impact on women's
formation of trusting relationships, and (c) cervical cancer screening, due to its highly intimate nature, requires trust and is used less often and with much less comfort when there is a lack of trust or a male doctor: “So many women that I know don’t go for Pap smears because of the lack of female doctors. . . . Women are lagging for so many reasons and some of them are just not in their hands, really” (Ann, personal communication, June 2010). A large proportion of women, particularly Aboriginal women, have experienced victimization (Brennan, 2011; Perreault, 2011). It is extremely important that health professionals account for experiences of victimization when providing services. Continuity of care was an important aspect for women undergoing cervical cancer screening. They needed to build trusting relationships and ultimately feel more comfortable with their health care professionals when either accessing information or having a Pap smear, and this too must be accounted for.

Feelings of (dis)empowerment

The second theme that emerged was that of (dis)empowerment. Women felt disempowered or disadvantaged because power relations shaped their choices and opportunities in health care. They described events in which they felt ignored by their physicians while presenting concerns and spoke of not being listened to about their treatment options. Some women felt their health care professionals dissuaded them from accessing health services. Cadence, a 28 year-old First Nations women said she “kept trying to talk to them [the nurses and doctors at a local health centre] but they wouldn’t even try to help or nothing” (Cadence, personal communication, June, 2010). Cadence felt powerless about health decisions being made about her, which continues to affect her. Deb works in the survival sex-trade industry and has a long history of addictions. She told a similar story and observes that stereotyping affects women’s care:

It’s almost like a lot of these doctors now are labeling people so no one wants to give anyone a hand, right? I’m trying to heal myself and get places, but I can’t if my physician is not standing behind me. . . . I notice a lot of girls on the street have a fear of speaking up (Deb, personal communication, July 2010).

Patricia’s trust toward her family doctors is “extremely low” because she does not feel her needs were being met or her voice heard. During a recent appointment, she requested a conversation with her physician about decreasing her antidepressant dosage. She said her physician refused and insisted to her, “You need to be on them” (Patricia, personal communication, June, 2010). As a result, Patricia took herself off the medication and had been experiencing adverse side effects such as extreme anxiety. Negative interactions with a health care professional commonly resulted in reduced access to sexual health information, lowered use of screening services, and/or nonadherence to medication.

Life circumstances

Life circumstances emerged as a third cause of challenges women faced in accessing and using health care services.
These included lack of transportation, parenting, and childcare. Of the 22 women who filled out the questionnaire, seven said they did not have reliable transportation, a critical component of women’s lives in northern geographies (Thien & Hanlon, 2009). Of the 13 mothers who completed the questionnaire, seven were single parents, three of whom said they did not have reliable and/or trustworthy childcare for their children.

Tracy, a mother of two young children who relies on public transit, talked about the unreliability of the transit system: “Buses don’t run often enough, early or late enough, or have enough routes” (Tracy, personal communication, November 2010). Accessing health services was considerably more difficult for women during harsh winter conditions. Mickey, a 25-year-old Aboriginal woman and single parent of three, said “transportation is one of the biggest issues,” or barriers, (Mickey, personal communication, June 2010) she faces in access to sexual health services and education. Ann, a single parent of three children all under the age of six years, also says she feels enormous life circumstances pressures. She parents her children alone, and receives no financial support from the children’s father. During the research project her basic home services (including telephone and power) were disconnected. She had been given an eviction warning from her landlord, as she had not had the finances available to pay her rent on time. She felt like she was “drowning” in responsibilities. Chantal, a mother of four children, had stress associated with single parenting: “I haven’t had a good break for a long time. My husband took off on me, this is the fourth time he did this to me. . . That’s why my kids were taken away overnight. . . This is what stress is to me” (Chantal, personal communication, August 2010). Transportation, parenting, and childcare are important in women’s ability to attend or participate in a plethora of activities, including health care education and services. Finances played an important role in women’s ability to take a break from parenting and access to reliable transportation. Having access to reliable, trustworthy, and affordable childcare, therefore, is extremely important to increasing cervical screening services use for young and/or vulnerable women with children. Good transportation and supported childcare also reduces levels of stress, a known predictor of better overall health.

Lack of awareness

Women who participated in the research project, as well as their friends and family, had fairly low levels of awareness and expressed confusion about HPV, cervical cancer, and screening. Ann wrote in her journal: “I want to learn more about HPV and women’s health because it isn’t something that I have talked about with anybody, so I don’t understand much about HPV or any other things about sexual health” (2010, p. 1). Similarly, Tracy wrote: “One of my hopes with this project is to learn a bit more about women’s health and wellness. Just by the first meeting I realized how much I didn’t know” (2010, p. 2). Ann said she spoke to a woman who had very little understanding about HPV, did not know the reason behind having Pap smears, and felt confused about the vaccine:

Most women didn’t even know the purpose of a Pap smear. Most women only get checked because they are told to by doctors. The importance of the Pap smear is not even discussed. Also the HPV vaccine that’s available . . . most parents didn’t even know what it’s for or what it does (2010, p. 9).

Like other participants, Tracy knew little about HPV: “I never heard anything before reading about it now, this stuff. You don’t hear it advertised that men carry it at all” (Tracy, personal communication, July 2010). During the same group meeting, Ann described a recent talk that had taken place with her family members: “Pretty much every woman that I spoke to, like there are a lot of women in my family that I spoke to about HPV and all that, knew nothing about it” (Ann, personal communication, July 2010). Women who took part in this research commonly expressed a lack of awareness about HPV and, in particular, the asymptomatic and contagious nature of HPV and its relationship to cervical cancer. Women felt that increased understanding about these sexual health issues would make women feel empowered, an important factor in women’s comfort with and decision to have Pap smears.

CONCLUSIONS AND RECOMMENDATIONS

This research arose from concerns that inequitable access to information and use of primary sexual health services existed for women inhabiting northern, racialized, and impoverished marginalized geographies. Feminist and anti-racist methodologies, intersectionality theory, and social determinants of health perspectives underpinned the ways the project was planned and conducted. Overwhelmingly, social determinants including ethnicity, sociocultural and
spatial locale, education, and poverty had an impact on women's lives. Multiply marginalized women represented the highest proportion of those who did not trust health care professionals. Distrust correlated with lower levels of awareness about HPV and cervical health and lowered usage of screening services. Experiences with victimization were commonly associated with low levels of comfort and trust. Women wanted to feel listened to, respected, and in charge of their health decisions.

Research results demonstrated that low levels of awareness about sexual health topics like HPV and cervical screening existed before the community- and arts-based training and workshops were offered. Women in the project used the arts (e.g., journaling, photography, collage, and painting) to participate in a dialogue about their realities, lives, and lived experiences. After having engaged the issues through art-based means, women reported feeling “empowered” and “more comfortable” about having Pap smears. Women’s levels of awareness about HPV and cervical cancer also improved after participating in art-centered endeavours, demonstrating the power of the arts, storytelling, and personal connections in the formation of trusting relationships needed to normalize traditionally “taboo” sexual health subjects.

Low levels of awareness about HPV, cervical cancer and use of screening is—especially for multiply marginalized and Aboriginal women—an important public health issue that must be addressed. Increased public sexual health education is needed for vulnerable women. Employing creative and/or holistic approaches to understanding, listening, and teaching is an underutilized and under-theorized method with great potential, particularly for Aboriginal women and within Aboriginal communities where creative traditions may represent culturally appropriate strategies. There is a need for Aboriginal-specific cultural sensitivity when working with women who have experienced victimization, more female health care professionals, continuity of care among health providers, and pragmatic services such as child care and transportation to increase women’s Pap smear participation, particularly in northern landscapes and geographies with large numbers of Aboriginal women. We believe the women in this research are worth it.

ACKNOWLEDGEMENTS

This research was supported by a community grant from the BC Cancer Agency, Cervical Cancer Screening Program.

REFERENCES


Intimate Stories


Join the HPV Vaccine Global Community of Practice

http://hpv-vaccines.net

The HPV Vaccine Global Community is an online global network of people who share an interest in preventing cervical cancer and in the role of HPV vaccines in health programs.

Join the HPV Vaccine Global Community of Practice to:

SHARE and exchange knowledge and experience with colleagues around the world with the goal of enhancing access to and delivery of HPV vaccines.  
CREATE opportunities to share and exchange challenges, success stories and lessons learned with local, regional and international colleagues who are preparing for the introduction of HPV vaccines.  
ENHANCE your knowledge and participate in a process of collaborative learning to improve policy and practice.  
PARTICIPATE through emails in our on-line discussion forums to share your experience, raise questions, seek answers and collectively use our knowledge and experience to improve HPV vaccination practice and programs for the prevention and management of cervical cancer.  
DISCUSS technical and programmatic issues with experts and colleagues around the world.

We welcome Global Community of Practice members to...

Join the Indigenous HPV Research & Education sub-community:

This network will support a focus on HPV issues among Indigenous peoples; promote dialogue between interested parties; encourage sharing of information, materials and practices; and share innovative methods of engaging Indigenous populations in HPV prevention activities on an international level.
HPV Detection by Self-Sampling in Nunavik, Quebec: Inuit Women’s Sampling Method Preferences

Helen Cerigo MSc, Department of Epidemiology, Biostatistics and Occupational Health, Faculty of Medicine, McGill University

Mary Ellen Macdonald PhD, Division of Oral Health and Society, Faculty of Dentistry, McGill University

Eduardo L. Franco PhD, Department of Epidemiology, Biostatistics and Occupational Health, Faculty of Medicine, McGill University, and Division of Oncology, Faculty of Medicine, McGill University

Paul Brassard MD MSc, Department of Epidemiology, Biostatistics and Occupational Health, Faculty of Medicine, McGill University, Department of Medicine, Faculty of Medicine, McGill University

ABSTRACT

There is a higher incidence of cervical cancer and prevalence of genital human papillomavirus (HPV) infection among the Inuit in Canada than the general population. Self-sampling of cervicovaginal cells for HPV testing has the potential to increase cervical cancer screening coverage in this population, but only if it is acceptable to women. We sought to determine acceptance of and preference for self-collection of cervicovaginal samples for HPV testing in comparison with provider-collection, and to explore demographic characteristics of preference for self-collection among a sample of Inuit women from Nunavik, Quebec. Women aged 18–69 years were recruited from a previously formed cohort on the natural history of HPV in Nunavik. Both self-collected and provider-collected specimens were collected with polyester-tipped swabs, and women completed a short written questionnaire immediately after specimen collection. Logistic regression was used to estimate predictors of preference. Of the 109 eligible women who were approached to participate, 93 (85%) accepted. Self-sampling was preferred by 56% of the women over provider-sampling. Education was the only predictor of preference for self-sampling, where having at least a grade 9 education was inversely associated with preference for self-sampling (OR = 0.29, 95% CI [0.09, 0.92]). Self-sampling has the potential to increase cervical cancer screening coverage, but any implementation of self-sampling should be concurrent with an education campaign on the importance of cervical cancer screening, the relationship between HPV virus and cervical cancer, and the accuracy of self-sampling.
INTRODUCTION

Inuit in Canada face a three-fold higher cervical cancer incidence rate than the general population of Canada (Gaudette, 1991; Kelly et al., 2008). About one fifth of the Inuit population in Canada lives in Nunavik, the subarctic and arctic region of Northern Quebec. Nunavik’s population of 11,000 is distributed among 14 communities on the coasts of Hudson Bay, Hudson Strait, and Ungava Bay (Statistics Canada, 2007). Consistent with the high rate of cervical cancer among Inuit populations throughout Canada, Inuit living in Quebec experience a higher cervical cancer incidence and mortality rate than the general population of the province (Louchini & Beaupré, 2008). Additionally, Inuit in Quebec are at high risk of human papillomavirus (HPV) infection, a necessary cause of cervical cancer (Bennett, Coutlee, Roger, Franco, & Brassard, 2010; Hamlin-Douglas et al., 2008; Hamlin-Douglas et al., 2010; Walboomers et al., 1999). The Papanicolaou (Pap) smear, a method of cervical cancer screening using cervical cytology, has been used for over 50 years and has greatly reduced cervical cancer mortality. In the 2004 Nunavik Inuit Health Survey, 82% of respondents self-reported having a Pap smear in the previous two years, although estimates from a chart review conducted between 2002 and 2007 suggest that coverage of cervical cancer screening was more likely in the range of 70% (Dodin & Blanchet, 2007; Hamlin-Douglas et al., 2008).

HPV DNA testing on self-collected specimens of cervicovaginal samples has been suggested as a way to increase the screening coverage among women who have traditionally avoided Pap smears. Self-sampling has been shown to be comparable to provider-directed sampling for the detection of virological (Petignat et al., 2007) and disease endpoints (Sellors et al., 2000; Seo et al., 2006; Szarewski et al., 2007), although self-sampling has a somewhat lower sensitivity to detect cervical disease than provider-sampling. However, for a self-sampling-based program to increase screening coverage and therefore reduce cervical cancer mortality, it is important that women find it acceptable.

Although studies suggest that women generally report a high acceptance of self-sampling, preference for self-sampling has been shown to range from 27% to 94% in different populations (Anhang, Nelson, Telerant, Chiasson, & Wright, 2005; Barbee et al., 2010; Dzuba et al., 2002; Hillemanns, Kimmig, Huttemann, Dannecker, & Thaler, 1999; Kahn et al., 2005; Khanna et al., 2007). Given the variability of women’s attitudes toward self-sampling and their ability to collect adequate samples (Anhang et al., 2005; Barbee et al., 2010; De Alba et al., 2008; Kahn et al., 2005; Khanna et al., 2007; Tisci et al., 2003; Waller et al., 2006), it is important that the comparability and acceptability of self-sampling be assessed in a population before it is integrated into their cervical cancer screening program. Despite numerous reports on self-sampling, there are currently no published studies on its feasibility, comparability, or acceptability among Inuit in Canada. This paper aims to evaluate the socio-demographic and behavioural predictors of preference and examine reasons for sampling method preference among Inuit women from Nunavik, Quebec. This analysis is part of a larger study on self-sampling, where we examine the comparability of self-collected specimens for HPV testing to provider-collected specimens among the same sample of women; the comparability analysis, however, will be presented elsewhere.

METHODS

Women were recruited to this study from an ongoing cohort formed between 2002 and 2008, comprised of 554 Inuit women between the ages of 15 and 69 living in Nunavik, Quebec (Hamlin-Douglas et al., 2010). Women were originally recruited to this cohort to examine the natural history of HPV in Nunavik (Bennett et al., 2010; Hamlin-Douglas et al., 2008; Hamlin-Douglas et al., 2010). Women aged 18–69 years were recruited for this self-sampling sub-study between December 2007 and June 2010 in two communities of Ungava Bay, Nunavik. When cohort participants, who were not already a part of this sub-study, came to a health clinic for visits requiring a Pap test, nurse practitioners systematically asked them if they would like to enrol.
Participants were asked to collect a sample of cervicovaginal cells with a polyester (Dacron®)-tipped swab, unsupervised, in the examination room just before the nurse practitioner conducted a pelvic examination that included direct cervical cell sampling. Women were asked to squat or put one foot up on a chair and insert a sterile 15-cm dry polyester-tipped swab (Copan™ 159C) into the vagina as far as it would go and rotate it three times. Participants completed a short standardized questionnaire after both methods of specimen collection were finished. Women were asked which sampling method they preferred, with an open-ended question asking about the reasons for their preference. Socio-demographic characteristics, reproductive and sexual history, medical history, and lifestyle factors for participants were obtained from a questionnaire administered at cohort entry and a baseline medical chart review. Details on questionnaire validation and translation are available elsewhere (Bennett et al., 2010; Hamlin-Douglas et al., 2008).

The covariates used in this study were age, marital status, employment status, education level, smoking status, alcohol use, number of lifetime deliveries, use of birth control, history of Pap smear testing in the previous three years, self-reported history of sexually transmitted infections, age at first sexual intercourse, and number of lifetime sexual partners. Educational level attainment was originally categorized on the baseline questionnaire as less than grade 9, at least grade 9, or graduated high school. As few women (n = 9) reported that they had graduated from high school, they were grouped with those who had at least a grade 9 education.

Logistic regression was used to estimate the odds ratio (OR) and 95% confidence intervals (95% CIs) for the association between preference for self-collection and each covariate. Each variable that was found to be significant after adjusting for age, as well as other variables that have been previously shown to have an effect on preference—such as age (De Alba et al., 2008; Dzuba et al., 2002), education (Anhang et al., 2005; De Alba et al., 2008; Tisci et al., 2003), and marital status (Waller et al., 2006)—were included in a final multivariate analysis. History of Pap smear testing in the previous three years was also included because it was found to be potentially important in one study (Anhang et al., 2005) and has been shown to be associated with acceptance of HPV testing (De Alba et al., 2008). A multivariate logistic regression was performed using all variables selected for inclusion in the final model. The presence of effect-measure modification was investigated by including an interaction term in the multivariable model and examining the effects on regression estimates and CIs.

Given the small amount of missing data for many covariates, multiple imputation was used to assign values for missing data. Imputation is the practice of “filling in” missing data with probable values to create a complete data set to analyze. Multiple imputation fills in each missing value with a set of probable values that represent the uncertainty about the true value. Twenty data sets were created by allowing information from all covariates included in the complete case analysis to predict the values for each missing variable. All regression analyses were carried out on both the complete and imputed datasets. As there were no substantial differences between the complete case analysis and the multiple imputation analysis, however, only the pooled results of the multiple imputation analysis are presented here.

Multiple imputation and subsequent analysis with the multiple imputed datasets were conducted in R version 2.11.1 with the MICE package (van Buuren & Oudshoorn, 2000). Data management was performed with SAS version 9.2 and all statistical analyses were conducted in R version 2.11.1. Statistical significance for regressions was set at 5%. Written informed consent was obtained from all study participants and ethical approval for this study was obtained from the McGill University Institutional Review Board.

RESULTS

A total of 111 women were approached to participate in the self-sampling study, with 16 women (14.4%) declining to participate. Two women approached did not meet study eligibility criteria and were therefore excluded: one was younger than 18 years and one was not part of the original cohort. Of the 109 women who were eligible, 93 women (85.3%) agreed to participate. The women in this study had been part of the cohort study for an average of 4.9 years (SD = 1.7) prior to study entry, ranging up to 8.2 years. During this time, the women returned an average of 3.6 times (range: 0–8) before entering the self-sampling study. At the time of cohort entry, all participants reported that they had previously had sexual intercourse.

The sampling-method preference questionnaire was completed by 86 of the 93 study participants (92.5%). Self-sampling was preferred by 48 (55.8%; 95% CI [44.7%, 66.5%]) of these respondents while the other 38 (44.2%; 95% CI [33.4%, 55.3%]) women preferred provider-collection. Table 1 presents the socio-demographic, lifestyle, reproductive, and sexual history characteristics of study participants.
participants by sampling method preference. The most striking difference was educational attainment. There was a higher proportion of women who had at least a grade 9 education among women who preferred provider-sampling (78.9%) compared to the women who preferred self-sampling (56.3%), although the difference was not significant.

No socio-demographic or lifestyle characteristics were found to be significantly associated with preference for self-sampling in the univariate analysis of the multiple imputed datasets (Table 2). The age-adjusted (data not shown) and complete case analysis, however, suggests that there is an association between education and sampling method preference. In the final, fully adjusted model using the imputed data, educational attainment showed an inverse association with preference for self-sampling \((OR = 0.29, 95\% CI [0.09, 0.92])\) (comparable to complete case analysis; data not shown). The respective associations between preference and age, marital status, and history of Pap smear testing were of large magnitude in this model, but remained insignificant.

Table 3 displays women’s reasons for sampling method preference, grouped into themes based on responses to the open-ended section of the post-sampling questionnaire. The most common reason for preferring self-sampling was that it was faster and more convenient than provider-sampling (25%). Grouped into this dimension of “convenience” were three responses by women who noted the convenience of performing the self-sampling at home. The privacy aspect of self-sampling was the most important reason for preferring self-collection for 11 (23%) women. The dimension of “more comfortable” was the primary reason for preference of self-sampling for nine women (18.8%), and it included the responses of self-sampling being “less embarrassing” and “less painful” than provider-sampling. Seven women (14.6%) preferred self-sampling because it was easy to do and nine women (18.8%) did not give a reason for their preference.

The most common reason for preferring provider-sampling was the fear of collecting a sample incorrectly and the belief that a provider does it more accurately (31.6%). Eight women (21.1%) stated that their reason for preferring provider-sampling was that it was easier to have a provider to collect the sample. Five women (13.2%) gave responses that fit into the dimension of “uncomfortable with self-sampling” as their reason for preference for provider-collection. This dimension included responses like “it feels weird doing it,” “don’t like to do it,” and “afraid to hurt myself.” Two women (5.3%) found provider-sampling more convenient, because they had other reasons to visit the clinic and could have multiple tests done at one time. A large proportion (29%) did not give a reason for their preference for provider-collection.

To understand the association between education and sampling method preference, reasons for preference were stratified by level of education (Table 4). The most common reason for women with at least a grade 9 education to prefer provider-sampling \((n = 30)\) was that they worried about their ability to do the self-sample correctly, whereas the top reason for these women to prefer self-sampling \((n = 27)\) was that it was faster and more convenient. Women who had less than a grade 9 education stated that their main reason for preference for provider-sampling \((n = 7)\) was that they were uncomfortable with the self-sampling method, but women who had less than a grade 9 education and preferred self-sampling \((n = 17)\) did so because it was more private than provider-sampling.
TABLE 1. BASELINE CHARACTERISTICS OF ALL STUDY PARTICIPANTS AND CHARACTERISTICS BY SAMPLING METHOD PREFERENCE

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>All Women (N = 93)</th>
<th>Self-sampling (n = 48)</th>
<th>Provider-sampling (n = 38)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean SD) †</td>
<td>33.57 (11.4)*</td>
<td>33.94 (12.1)</td>
<td>33.63 (11.3)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single/divorced</td>
<td>44 (47.3)</td>
<td>19 (39.6)</td>
<td>18 (47.4)</td>
</tr>
<tr>
<td>Married/living with partner</td>
<td>46 (49.5)</td>
<td>27 (56.3)</td>
<td>19 (50.0)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (3.2)</td>
<td>2 (4.2)</td>
<td>1 (2.6)</td>
</tr>
<tr>
<td>Educational attainment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; Grade 9</td>
<td>24 (2.5)</td>
<td>17 (35.4)</td>
<td>7 (18.4)</td>
</tr>
<tr>
<td>≥ Grade 9</td>
<td>64 (68.8)</td>
<td>27 (56.3)</td>
<td>30 (78.9)</td>
</tr>
<tr>
<td>Missing</td>
<td>5 (5.4)</td>
<td>4 (8.3)</td>
<td>1 (2.6)</td>
</tr>
<tr>
<td>Employed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>23 (24.7)</td>
<td>12 (25.0)</td>
<td>9 (23.7)</td>
</tr>
<tr>
<td>Yes</td>
<td>65 (69.9)</td>
<td>32 (66.7)</td>
<td>28 (73.7)</td>
</tr>
<tr>
<td>Missing</td>
<td>5 (5.4)</td>
<td>4 (8.3)</td>
<td>1 (2.6)</td>
</tr>
<tr>
<td>Current smoking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>20 (21.5)</td>
<td>13 (27.1)</td>
<td>6 (15.8)</td>
</tr>
<tr>
<td>Yes</td>
<td>70 (75.3)</td>
<td>33 (68.8)</td>
<td>31 (81.6)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (3.2)</td>
<td>2 (4.2)</td>
<td>1 (2.6)</td>
</tr>
<tr>
<td>Alcohol use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>30 (32.3)</td>
<td>16 (33.3)</td>
<td>13 (34.2)</td>
</tr>
<tr>
<td>Yes</td>
<td>60 (64.5)</td>
<td>30 (62.5)</td>
<td>24 (62.2)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (3.2)</td>
<td>2 (4.2)</td>
<td>1 (2.6)</td>
</tr>
<tr>
<td>Previously given birth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>24 (25.8)</td>
<td>10 (20.8)</td>
<td>11 (29.0)</td>
</tr>
<tr>
<td>Yes</td>
<td>67 (72.0)*</td>
<td>37 (77.1)</td>
<td>26 (68.4)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (2.2)</td>
<td>1 (2.1)</td>
<td>1 (2.6)</td>
</tr>
<tr>
<td>Current use of any birth control</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>52 (55.9)</td>
<td>26 (54.2)</td>
<td>21 (55.3)</td>
</tr>
<tr>
<td>Yes</td>
<td>37 (39.8)</td>
<td>19 (39.6)</td>
<td>16 (42.1)</td>
</tr>
<tr>
<td>Missing</td>
<td>4 (4.3)</td>
<td>3 (6.3)</td>
<td>1 (2.6)</td>
</tr>
<tr>
<td>History of Pap test in previous three years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>31 (33.3)</td>
<td>13 (27.1)</td>
<td>15 (39.5)</td>
</tr>
<tr>
<td>Yes</td>
<td>61 (65.6)</td>
<td>34 (70.8)</td>
<td>23 (60.5)</td>
</tr>
<tr>
<td>Missing</td>
<td>1 (1.1)</td>
<td>1 (2.1)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Self-reported history of STI</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>28 (30.1)</td>
<td>14 (29.2)</td>
<td>11 (28.9)</td>
</tr>
<tr>
<td>Yes</td>
<td>61 (65.6)</td>
<td>31 (64.6)</td>
<td>26 (68.4)</td>
</tr>
<tr>
<td>Missing</td>
<td>4 (4.3)</td>
<td>3 (6.3)</td>
<td>1 (2.6)</td>
</tr>
<tr>
<td>Age at first sexual intercourse (mean SD))</td>
<td>14.61 (1.8)*</td>
<td>14.76 (1.7)</td>
<td>14.62 (1.9)</td>
</tr>
<tr>
<td>Lifetime # of sexual partners</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 10</td>
<td>51 (54.8)</td>
<td>29 (60.4)</td>
<td>19 (50.0)</td>
</tr>
<tr>
<td>≥ 10</td>
<td>27 (29.0)</td>
<td>13 (27.1)</td>
<td>11 (28.9)</td>
</tr>
<tr>
<td>Missing</td>
<td>15 (16.1)</td>
<td>6 (12.5)</td>
<td>8 (21.1)</td>
</tr>
</tbody>
</table>

* Unless otherwise specified under Characteristic
† At time of self-sampling study entry

* Median: 1.7, range: 18-62
* Mean (SD): 2.0 (1.9), median: 2, range: 0-8
* Median: 14, range: 11-20, n = 84
TABLE 2. UNIVARIATE AND FULLY ADJUSTED ESTIMATES OF THE ASSOCIATION BETWEEN PREFERENCE FOR SELF-SAMPLING AND SAMPLE CHARACTERISTICS (n = 86)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Univariate</th>
<th>Fully Adjusted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (per 10 years)</td>
<td>1.02 (0.71, 1.49)</td>
<td>0.75 (0.46, 1.22)</td>
</tr>
<tr>
<td>Marital status at baseline</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or living with partner</td>
<td>1.00 (Ref)</td>
<td>1.00 (Ref)</td>
</tr>
<tr>
<td>Single/divorced</td>
<td>0.79 (0.33, 1.91)</td>
<td>0.65 (0.23, 1.84)</td>
</tr>
<tr>
<td>Educational attainment at baseline</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; Grade 9</td>
<td>1.00 (Ref)</td>
<td>1.00 (Ref)</td>
</tr>
<tr>
<td>≥ Grade 9</td>
<td>0.39 (0.14, 1.08)</td>
<td>0.29 (0.09, 0.92)</td>
</tr>
<tr>
<td>Baseline employed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00 (Ref)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.86 (0.30, 2.39)</td>
<td></td>
</tr>
<tr>
<td>Current smoking at baseline</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00 (Ref)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.49 (0.16, 1.47)</td>
<td></td>
</tr>
<tr>
<td>Alcohol use at baseline</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00 (Ref)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.97 (0.39, 2.44)</td>
<td></td>
</tr>
<tr>
<td>Self-reported history of STI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00 (Ref)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.96 (0.37, 2.51)</td>
<td></td>
</tr>
<tr>
<td>Age at first sexual intercourse (per year)</td>
<td>1.04 (0.51, 1.34)</td>
<td></td>
</tr>
<tr>
<td>Lifetime # of sexual partners</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 10</td>
<td>1.00 (Ref)</td>
<td></td>
</tr>
<tr>
<td>≥ 10</td>
<td>0.80 (0.30, 2.12)</td>
<td></td>
</tr>
<tr>
<td>Previously given birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00 (Ref)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.55 (0.58, 4.17)</td>
<td></td>
</tr>
<tr>
<td>Current use of any birth control</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00 (Ref)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.93 (0.38, 2.26)</td>
<td></td>
</tr>
<tr>
<td>History of Pap test in previous three years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00 (Ref)</td>
<td>1.00 (Ref)</td>
</tr>
<tr>
<td>Yes</td>
<td>1.71 (0.68, 4.32)</td>
<td>2.11 (0.73, 6.11)</td>
</tr>
</tbody>
</table>
TABLE 3. REASONS FOR SAMPLE METHOD PREFERENCE GROUPED BY RESPONSE THEME (n = 86)

<table>
<thead>
<tr>
<th>Response theme</th>
<th>Preference for self-sampling (n = 48)</th>
<th>Preference for provider-sampling (n = 38)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Self-sampling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Faster and more convenient</td>
<td>12 (25.0)</td>
<td>Uncomfortable with self-sample method</td>
</tr>
<tr>
<td>More private</td>
<td>11 (22.9)</td>
<td>Worried about ability to self-sample</td>
</tr>
<tr>
<td>More comfortable</td>
<td>9 (18.8)</td>
<td>Easier to do (14.3%)</td>
</tr>
<tr>
<td>Easy to do</td>
<td>7 (14.6)</td>
<td>Did not respond (28.6%)</td>
</tr>
<tr>
<td>Did not respond</td>
<td>9 (18.8)</td>
<td></td>
</tr>
<tr>
<td>Provider-sampling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Faster and more convenient</td>
<td></td>
<td>Worried about ability to self-sample method</td>
</tr>
<tr>
<td>More comfortable</td>
<td></td>
<td>Easier to do (14.3%)</td>
</tr>
<tr>
<td>Easy to do</td>
<td></td>
<td>Did not respond (28.6%)</td>
</tr>
<tr>
<td>Did not respond</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TABLE 4. REASONS FOR SAMPLING METHOD PREFERENCE STRATIFIED BY EDUCATION LEVEL (n = 79)

<table>
<thead>
<tr>
<th>Sampling Method Preference</th>
<th>Self-Sampling</th>
<th>Provider-Sampling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational Attainment</td>
<td>&lt; Grade 9</td>
<td>≥ Grade 9</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Sampling</td>
<td>More private</td>
<td>Uncomfortable with self-sample method</td>
</tr>
<tr>
<td></td>
<td>More comfortable</td>
<td>Worried about ability to self-sample method</td>
</tr>
<tr>
<td></td>
<td>Faster and more convenient</td>
<td>Easier to do</td>
</tr>
<tr>
<td></td>
<td>Easy to do</td>
<td>Did not respond</td>
</tr>
<tr>
<td></td>
<td>Did not respond</td>
<td>(n = 17)</td>
</tr>
<tr>
<td></td>
<td>(n = 17)</td>
<td></td>
</tr>
<tr>
<td>Provider-Sampling</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Faster and more convenient</td>
<td>Worried about ability to self-sample method</td>
</tr>
<tr>
<td></td>
<td>Easy to do</td>
<td>Easier to do</td>
</tr>
<tr>
<td></td>
<td>More private</td>
<td>Uncomfortable with self-sample method</td>
</tr>
<tr>
<td></td>
<td>More comfortable</td>
<td>More convenient</td>
</tr>
<tr>
<td></td>
<td>Did not respond</td>
<td>Did not respond</td>
</tr>
<tr>
<td></td>
<td>(n = 27)</td>
<td>(n = 30)</td>
</tr>
</tbody>
</table>
DISCUSSION

We found that among a sample of Inuit women from Nunavik, 56% preferred self-sampling to provider-sampling of cervicovaginal cells. Our study population is comprised of women who are generally dedicated to cervical cancer screening, given that they are part of an ongoing cohort on the natural history of HPV infection. The previous research on sampling method preference has also focused on populations of women who have a history of cervical cancer screening. These studies have found preferences for self-sampling to range from 27% to 94% (Anhang et al., 2005; Barbee et al., 2010; Dzuba et al., 2002; Hillemanns et al., 1999; Kahn et al., 2005; Khanna et al., 2007). Differences in study protocols, target populations, and reporting of sample characteristics make them hard to compare with the results of this study.

Women's reasons for their sampling method preference helped explain why self-sampling preference was not higher. Women's lack of confidence in their ability to collect their own sample was found to be an important reason for preferring provider-sampling in this population, as almost a third of the women who preferred provider-sampling felt this way. Despite this fear, over 97% of participants collected adequate specimens and detection of HPV in self-samples was high (Cerigo, Coutlee, Roger, Franco, & Brassard, 2010), suggesting that this population can accurately collect their own samples. Women's fear that self-collected samples will not adequately detect the risk of cancer has been consistently observed in a variety of populations (Anhang et al., 2005; Barbee et al., 2010; Dzuba et al., 2002; Kahn et al., 2005; Forrest et al., 2004; Waller et al., 2006). Women in our study also felt that it was easier to have a clinician perform the test (22%) and it was more convenient to go to the clinic to address all health concerns at once (5%). This indicates that although these women do not necessarily prefer self-sampling, they might not object to performing self-sampling if necessary. This is not the case for all women, as 14% of women preferred provider-sampling because they were uncomfortable with the self-sampling method.

Women in this study reported that they preferred to collect their own specimens because it was more convenient (25%), private (23%), and comfortable (19%) than when sampling was performed by a clinician. These sentiments toward self-sampling are consistently found in the literature (Anhang et al., 2005; De Alba et al., 2008; Dzuba et al., 2002; Kahn et al., 2005). Some women reported that they preferred self-sampling because it was easy to do (15%), which was also reported by the majority of women in previous studies (Barbee et al., 2010; Anhang et al., 2005; Kahn et al., 2005; Waller et al., 2006; De Alba et al., 2008; Dannecker et al., 2004).

The only socio-demographic or lifestyle characteristic found to be a significant predictor of preference for self-sampling in this population was educational attainment. Having at least a grade 9 education was associated with a lower preference for self-sampling compared to having less than a grade 9 education. In a previous study, women with more education were more likely to prefer self-sampling than those with less education (Anhang et al., 2005). Furthermore, higher education has been found to be associated with overall satisfaction with self-sampling experience (De Alba et al., 2008) and comfort while performing self-sampling (Tisci et al., 2003). To understand our unexpected results, reasons for preference were stratified by education level. It seems that among more educated women, there is a stronger concern that self-sampling is not as accurate as provider-sampling; whereas among less educated women comfort during specimen collection (i.e., no embarrassment or pain) was the driving force behind their preferences. Our sample size did not allow for the assessment of statistical differences in these responses, and so the results of this stratification should be considered preliminary and a starting point for future research. A sensitivity analysis was performed for the relationship between preference and education to confirm the validity of the categorizations made to education. The association between preference and education was similar for those who graduated high school and those that had at least some high school education. Because so few women in our study graduated high school, however, this association was not significant and so the binary categorization was reported.

We did not replicate previous findings suggesting that marital status (Waller et al., 2006) and age (De Alba et al., 2008; Dzuba et al., 2002) are associated with preference for self-sampling, although these associations have not been found consistently in the literature (Anhang et al., 2005; De Alba et al., 2008; Karwalajtys, Howard, Sellors, & Kaczorowski, 2006; Khanna et al., 2007). While not a significant association, the association between history of Pap smear within three years and preference for self-sampling was large in magnitude. This trend was also found in a population of American women who had a history of cervical cancer screening (Anhang et al., 2005). It is possible that if self-sampling was instituted in Nunavik, the women who were already regular attendees of cervical cancer screening would be most the likely to switch to

HPV Detection by Self-Sampling in Nunavik, Quebec

National Aboriginal Health Organization (NAHO)
Organisation nationale de la santé autochtone (ONSA)
self-sampling. In this situation, the opportunity for health education by the clinician would be lost. In fact, this concern has been predicted by women themselves in a study of American women. Although 94% of women in the study were willing to accept self-sampling for their yearly screen, they would continue with speculum examination if self-sampling meant that they would not have access to a physician (Harper, Noll, Belloni, & Cole, 2002).

Because there was not an overwhelming preference for self-sampling, it is possible that many women would not want to participate in self-sampling if it became an option in Nunavik. There are, however, certain situations where the use of self-sampling might be appropriate. For example, women in Nunavik often prefer Pap smears done by a female clinician yet circumstances can arise where the only clinician in a community is male (Cerigo, Macdonald, Franco, & Brassard, in press). In such situations, self-sampling may be a beneficial way to increase screening coverage. Moreover, although only 56% of women in the study preferred self-sampling, 85% of eligible women agreed to collect a sample and enter the study. This indicates that more women would self-obtain a sample if required. In a population of Aboriginal women in Canada, researchers found that lack of awareness about the Pap smear and its importance was a barrier to screening (Deschamps et al., 1992). It is likely that the same barrier exists among women in Nunavik. This possibility, as well as the knowledge that many participants felt that sampling was more accurately done by a provider, suggests that implementation of self-sampling in these communities should be concurrent with an education campaign on the importance of cervical cancer screening, the relationship between HPV and cervical cancer, and the accuracy of self-sampling.

The major limitation of this study was that our study population was comprised of regular cervical cancer screening attendees. We were therefore unable to assess the preferences of previously unscreened women in the population. It is possible that more frequent experience with provider-collection during the cohort study might sensitize women who would have originally preferred self-sampling. Despite participation in the cohort, however, the majority of women still preferred self-sampling.

Although non-participation bias may have been present, study participants were similar to the general population of Nunavik for the measured demographic characteristics. Women over the age of 50 years were underrepresented in the study population, possibly because fewer women in this age category participate in cervical cancer screening (Dodin & Blanchet, 2007; Katz & Hofer, 1994; Muckle, Boucher, Laflamme, & Chevalier, 2010; Plaziac & Hamel, 2007; Statistics Canada, 2007).

Socio-demographic characteristics, reproductive and sexual history, medical history, and lifestyle factors for participants were obtained from a questionnaire administered at cohort entry. Women had been in the cohort for an average of 4.86 years and so many of these covariates would have changed over this period, but it was not feasible to re-survey study participants when they entered this study. With this in mind, the associations between baseline characteristics and preference for self-sampling should be interpreted with caution because measurement error is likely present. Baseline education level should be fairly stable throughout the study period, as women were eligible for cohort entry if they were between 15 and 69, past the standard age for entry into grade 9. The estimate for the association between education and preference may still be slightly affected by misclassification, but we can infer that there is a true association between these factors. Another limitation of our study is its small sample size and consequently low precision. We therefore cannot rule out an association between preference for self-sampling and other covariates, such as history of Pap smear testing.

The strengths of this study must be recognized in spite of its limitations. We used preference to measure women's acceptability toward self-sampling, which may give a better idea of potential uptake of self-sampling as opposed to willingness to give a sample and scores based on acceptability scales. We measured women's preferences after they had experienced both sampling methods, whereas some studies have not given women the opportunity to attempt self-sampling. Although self-sampling has been studied in a variety of other populations, this study is the first to look at the attitudes of Inuit women in Quebec toward self-sampling. These results, together with the results of the comparability analysis (which shows that self-sampling has a high recovery of HPV and is highly comparable to provider-sampling), provide valuable insight into the use of self-sampling for cervical cancer screening in this population (Cerigo et al., 2010). It is important to highlight that acceptance and preference for self-sampling does not automatically correspond to future screening behaviour. Furthermore, there is no guarantee that women who have a positive HPV test result will follow up accordingly with their health care providers, which has traditionally been a problem with cytology-based screening programs. Future studies should focus on the effect of self-sampling on cervical cancer mortality, incidence, and screening participation rates.
ACKNOWLEDGEMENTS

Funding for this research was provided by the Canadian Cancer Society and a Team Grant on HPV Infection and Associated Diseases from the Canadian Institutes of Health Research (CIHR). H. Cerigo was supported by a student fellowship from CIHR. P. Brassard was supported by a clinician scientist career award from the Fonds de recherche en santé du Québec (FRSQ).

The authors thank the participating communities, Tulattavik Health Centre, collaborating nurse practitioners, and the Nunavik Regional Board of Health and Social Services for making this research possible.

REFERENCES


Deadline extended!  April 30 2012

CALL FOR PAPERS

Inuit Health Research and Community Innovations

The National Aboriginal Health Organization is calling for papers to be considered for publication in the fall 2012 issue of the Journal of Aboriginal Health. This issue will be devoted to Inuit health and wellness in its broadest sense. Authors may explore this theme in relation to one or more of the following topics.

Research Articles (standard journal article format, maximum 5,000 words):

- Health research concerning Inuit, including studies on determinants of health.
- Community-based research.
- Articles by Inuit post-secondary students.
- Promising practices and models in addressing Inuit research ethics, academic-community collaborations and effective knowledge translation.

Community Stories (narrative and/or photo descriptions, 500 - 2,000 words):

- Experiences in collaboration with research projects.
- Best practices in community-researcher relationships.
- Initiatives and programs that have applied research evidence to solving a community problem.

Book Reviews (of a recent publication that contributes important knowledge, maximum 500 words):

- Research methodology, ethics and techniques.
- Guides to community-based research.
- Indigenous and/or Inuit knowledge.

Complete manuscripts suitable for peer review are due by April 30, 2012. Please refer to the Journal's submission guidelines. Authors will be notified of their acceptance on or before June 30, 2012 via e-mail to the person designated as the corresponding author or contact for the submission.

For more information, please visit the Journal’s website or contact:

Cathleen Knotsch, Senior Research Officer, cknotsch@naho.ca or
Mary Ashoona Bergin, Community Liaison Officer, mbergin@naho.ca

Inuit Tuttarvingat of the National Aboriginal Health Organization
220 Laurier Avenue West, Suite 1200
Ottawa, ON K1P 5Z9
Toll Free: 1-877-602-4445
www.naho.ca/inuit
Ethical Space for a Sensitive Research Topic: Engaging First Nations Women in the Development of Culturally Safe Human Papillomavirus Screening

Ingeborg Zehbe, Probe Development and Biomarker Exploration, Thunder Bay Regional Research Institute, Thunder Bay, Ontario, Canada, Biology Department, Lakehead University, Thunder Bay, Ontario, Canada, Health Sciences Division, Northern Ontario School of Medicine, Thunder Bay, East Campus, Ontario, Canada

Marion Maar, Health Sciences Division, Northern Ontario School of Medicine, Thunder Bay, East Campus, Ontario, Canada

Amy J. Nahwegahbow, School of Public Health, University of Waterloo, Waterloo, Ontario, Canada

Kayla SM Berst, Probe Development and Biomarker Exploration, Thunder Bay Regional Research Institute, Thunder Bay, Ontario, Canada, Biology Department, Lakehead University, Thunder Bay, Ontario, Canada

Janine Pintar, Probe Development and Biomarker Exploration, Thunder Bay Regional Research Institute, Thunder Bay, Ontario, Canada, Biology Department, Lakehead University, Thunder Bay, Ontario, Canada

ABSTRACT

Human papillomavirus (HPV) is a sexually transmitted infection (STI) and the main risk factor for cervical cancer. Cervical cancer is highly preventable with regular screening, especially when using HPV testing. In Canada, an up to 20-fold higher rate of this cancer has been reported in First Nations women compared to the mainstream population, possibly associated with under-screening, barriers to follow-up treatment, and a pervasive lack of access to culturally safe screening services. As a foundation for the development of culturally safe screening methods in First Nations communities in northwest Ontario, we have developed a participatory action research approach based on respectful and meaningful collaboration with First Nations women, community health care providers, and community leaders. Being mindful of the schism that exists between Western public health approaches to cervical cancer screening and First Nations women’s experiences thereof, we adopted Ermine’s interpretation of ethical space to initiate dialogues with First Nations communities on this sensitive topic. We used an iterative approach to continuously widen the ethical space of engagement through
several cycles of increasing dialogue with First Nations stakeholders. This approach resulted in a rich exchange of knowledge between community stakeholders and our research team, leading to the development of a shared plan for First Nations HPV research. Because of this successful engagement process, a pilot study in one First Nations community in northwest Ontario has been completed and there is support from ten First Nations communities for a large-scale study involving up to 1,000 women. Ethical space served as the foundation for a meaningful dialogue in this participatory action research approach and can be adapted to fit other research projects in similar settings.

KEYWORDS
Cervical cancer screening, Pap smear, HPV test, participatory action research, ethical space, First Nations women

INTRODUCTION
Cervical cancer is caused by human papillomavirus (HPV) (Boshart et al., 1984; Bosh et al., 2003; Clifford et al., 2003; Walboomers et al., 1999) and can be prevented with regular screening and follow-up treatment of precancerous lesions. Precancerous cervical lesions precede cervical cancer and can be effectively treated without compromising quality of life. Two tests have been approved for primary cervical cancer screening by Health Canada and the U.S. Food and Drug Administration: the Papanicolaou (Pap) smear and the HPV DNA test. The Pap smear detects morphological changes indicative of a precursor or invasive lesion and currently is the primary screening method in Canada. Regular Pap screening has decreased both incidence and mortality of cervical cancer by 60% over the last thirty years (Ontario Cervical Screening Program, 2005). Nevertheless, in settings like northwest Ontario, more than 50% of women are seldom or never screened due to a reluctance to undergo Pap testing (Fehringer et al., 2005). A contributing factor to high cervical cancer rates includes the lack of well-organized, accessible cervical screening programs as well as poor screening uptake or follow-up on the results of screening tests (Dignan et al., 1995; Spence et al., 2007). Consequently, the majority of new cervical cancer diagnoses is in women with inadequate or no screening history (Goggin et al., 2007).

Rates of cervical cancer are up to 20-fold higher among First Nations women than other Canadian women in Alberta, the Northwest Territories, Manitoba, and Ontario (Colquhoun et al., 2010; Corriveau, 1999; Marrett & Chaudhury, 2003; Young et al., 2000). This is most likely associated with an under-screened population. Possible reasons for under-screening include the remoteness of many First Nations communities lacking local screening facilities and low awareness of the need for screening to prevent cervical cancer. (Zehbe et al., in press). Under-screening may be exacerbated by negative experiences First Nations women may have had with the mainstream health care system. Cultural safety focuses on improving health care experiences by tackling the perceived power relationship that may exist between health care providers and Aboriginal patients (Brascoupe & Waters, 2009). A lack of culturally safe screening services may strongly contribute to women's reluctance to undergo invasive screening methods. More research is needed to investigate the underlying reasons for the high incidence of cervical cancer among First Nations women, and therefore decrease the prevalence of the disease in this population.

There is a general lack of understanding about the transmission of HPV (Friedman & Shepeard, 2007) and the purpose of Pap smears and HPV tests among the general population of various countries, regions, and cultures, including northern Ontario (Brown et al., 2007; Daley et al., 2010; Sandford & Phesant, 2009). Furthermore, as sexually transmitted conditions, HPV infection and cervical cancer are stigmatized in many cultures (Camm, 2005; Waller et al., 2007). Diagnosed women may feel shame because they might be judged as promiscuous (Perrin, 2011; Kwan, 2010; Kahn et al., 2010). The sexually transmitted nature of HPV infection can also have a significant impact on women's sexuality and intimate relationships (Newton & McCabe, 2008). Shame associated with HPV may therefore contribute...
to women’s reluctance to access screening services. These social barriers to screening may be further compounded for First Nations women. There may be fear for loss of privacy when screening results are reported in small community health clinics where friends and family members may be employed. Furthermore, unequal power relationships or distrust between the woman and her health professional may be an issue, especially when non-Aboriginal health care workers are involved. All of these issues contribute to the sensitive nature of HPV research in First Nations women and call for a particularly strong focus on community engagement and respectful knowledge exchange between researchers and community stakeholders during the project planning process. In collaboration with 10 First Nations communities in northwest Ontario, we have initiated a community-based participatory action research (PAR) study, as a follow-up study to a pilot study previously conducted in one of these communities (Zehbe et al., in press). The pilot study showed high client preference (87% of participants) for a new minimally invasive screening tool, namely HPV testing based on self-sampling compared to healthcare provider-collected Pap smears. A follow-up study is planned to confirm our findings in a randomized, two-armed trial and to identify potential screening barriers.

Our goal is to develop culturally safe approaches to promote cervical cancer screening and to increase participation. This in turn may increase early detection of precancerous changes and ultimately lead to a decline of high-grade cervical lesions and cancer in First Nations communities. We are mindful of potential barriers to this research, including the sensitivities of studying STIs and the schism between Western public health approaches to cervical cancer screening and First Nations women’s experiences of these relatively invasive procedures. We used a PAR approach because we are aware of the need for extensive community engagement (that may exceed national guidelines for research with First Nations) in research planning and implementation. Adequate community engagement helps ensure equality between the research team and the community members, as well as promote meaningful community participation. We were also aware of the need to foster high quality collaboration that could be clearly distinguishable from consultation (Warry, 1990). PAR has been extensively used in community-based Aboriginal health research, although it is still a relatively new approach to public health research (Maar et al., 2011). In Aboriginal research, a successful PAR approach is linked to partnership, shared control, mutual benefit, and respect between community stakeholders and academic researchers (Kristen & Kinoshameg, 2008). It requires an understanding of the history, culture, and local context embedded in the social relationships of the community. With PAR, it is imperative that researchers understand and improve on the practices in which they participate and the situations in which they find themselves (Baum et al., 2006).

To facilitate a mutual research dialogue about cancer screening between First Nations communities and our research team, we have adopted First Nations scholar Willie Ermine’s interpretation of ethical space of engagement (Ermine, 2007). Ermine explains that “the cultural tensions looming over the Indigenous/West relations, in their historical dimension, are particularly magnified on the contested ground of knowledge production and in particular its flagship enterprise of research” (Ermine, 1995). The concept of ethical space can be used to bridge these tensions by allowing for safe knowledge exchange between two worldviews. Ethical space “is formed when two societies, with disparate worldviews, are poised to engage each other” (Ermine, 2007). Given the sensitive nature of the research topic, facilitating ethical space became instrumental to the development of this collaborative study. Our collective challenge required bridging public health research approaches with First Nations women’s views and understanding of reproductive health and screening procedures. In the following section, we share our experience of creating safe environments for research teams and community members to exchange their perspectives on HPV and cervical cancer screening with the goal of developing a research plan (see Figure 1).

**METHODS**

Working with First Nations communities requires a considerable engagement process prior to starting a research project (Interagency Advisory Panel on Research Ethics, 2010). However, it became clear early on that potential power relationships with respect to women’s reproductive health had to be carefully considered. Ermine succinctly describes how the “monolithic presence” of the Western worldview reinforces existing power structures and social inequalities. He argues that “one of the festering irritants for Indigenous peoples, in their encounter with the West, is the brick wall of a deeply embedded belief and practice of Western universality” (Ermine, 2007). Using his analysis, a potential threat to our study would be an academically driven interpretation of the PAR process, with the result of further disempowering women at risk for cervical cancer.
Creating ethical space was chosen as a promising method to bridge the diversity of knowledge and positions between community stakeholders and the research team.

Ethical space for our project was established through five iterative processes that led to increasing dialogues with First Nations people: 1) the engagement of one First Nations community through informal dialogue with local First Nations health care providers, 2) the formal engagement and pilot research in that community, 3) the extension of the pilot project presented for further dialogue at a regional All Chiefs’ Meeting, 4) the collaborative development of draft research agreements, and 5) invitations from 10 First Nations communities to discuss the proposed research through community visits we called “Meet and Greet” (see Figure 2). This process allowed for increasing dialogues and negotiations of research design, research questions, methods, and planning for knowledge translation, which was critically important for the successful development of the project. Below, we describe the outcome and results obtained through ongoing ethical space dialogue between the research team and participating communities.

RESULTS

From informal dialogue to pilot research

The engagement began with informal discussions around cervical cancer screening with staff of the Dilico Family Health Team in Fort William First Nation near Thunder Bay in northwest Ontario. There were several formal meetings to exchange ideas about the feasibility of HPV research and potential approaches to such a study. The research team learned about the community and appropriate ways to respectfully engage stakeholders, the relative awareness of HPV within the community, and important considerations related to HPV diagnostics. Following this, the research team was invited to present at a band council meeting where the council enthusiastically decided to support the study. A research agreement reflecting our previous knowledge exchange was drafted by the research team and signed by the chief before the commencement of the pilot study. The pilot study was successfully rolled out in late 2009 and provided important information for the current larger study. Most notable was the finding that HPV testing based on the less invasive self-sampling was preferred over Pap testing by 87.2% of the participating First Nations women (Zehbe et al., in press). The team also learned important lessons on how to improve methods employed in the larger study, including improvements for cultural congruency of the questionnaire. The successful completion of the pilot study led to the planned regional study involving up to 1,000 First Nations women for cervical cancer screening.

Dialogue with First Nations leaders in Northern Superior Region

After the successful completion of the pilot study, the research team was invited by the Regional Grand Chief to present the proposed study at the Northern Superior All Chiefs’ Meeting in the fall of 2010. This meeting brought together First Nations communities of the Robinson Superior Treaty region in northwest Ontario. The participating communities are part of one strategic region of the Anishinabek Nation inhabiting the northern shore of...
Lake Superior. The populations of the communities range from 70 to 832 individuals.

Meeting participants included chiefs, band council members, and community employees. All demonstrated a strong interest in learning more about the proposed HPV research. The scientific portion of the research dialogue was short, as the main purpose of the session was to create ethical space for knowledge exchange about cervical cancer prevention research between community leaders and the research team. Community representatives engaged in an active dialogue following our presentation and stated their desire to uncover the reasons for the high rates of cervical cancer among First Nations women. The need for health education and disease prevention activities related to HPV was seen as a priority in many communities. Meeting participants provided information on the desired engagement and research process, which was incorporated into the research approach. Specifically, at this level of dialogue, the research team members were encouraged to: (a) attend community events in order to build a better relationship with the women of the communities, (b) present at annual health fair and cultural celebrations to raise awareness about the study and cervical cancer prevention in general, (c) develop a clearly outlined process for HPV testing that was to remain blinded at the community level to give optimum privacy to participants, and (d) draft research agreements that could be tailored to the needs of the respective communities.

As a follow-up, the researchers sent thank-you letters to all participating chiefs and councils with a summary of the pilot study (Zehbe et al., in press) attached. Communities that had not sent representatives to this meeting were contacted shortly thereafter with an information package and follow-up phone calls. Next, a draft research agreement was sent to each chief and council via email as requested, for review and feedback.

**Development of research agreements**

When working with First Nations communities, it is necessary to obtain support and approval from the chief and band council before commencing any work with individuals of the community (Interagency Advisory Panel on Research Ethics, 2010). This encourages the development of a respectful relationship and in this case led to the development of formal research agreements, detailing roles, responsibilities, benefits, risks, and expectations to be shared by the participating
communities and the research team. The process of finalizing research agreements for the larger study took several months and required diligent attention by the research team and community stakeholders. In November 2010, draft research agreements were sent via email to all interested communities. A follow-up communication was sent within a month to find out if individual communities required customized revisions to the agreement. Based on previous knowledge exchange, it was clear that flexibility was needed to ensure that communities would feel comfortable with the agreement. The communities did not propose any changes, which perhaps speaks to the productive researcher/community knowledge exchange and generation of goodwill associated with the opportunity of dialogue within an ethical space. Later that month, hard copies of the finalized research agreements were sent to all communities, with the exception of one. This community had recently acquired a new chief and council and further communication was needed to present the study to the new political leaders.

In January 2011, the research team began a telephone campaign to follow up with the chiefs to determine if there was sufficient time to review the research agreement, and if they had any questions or feedback. By that time, four communities had returned signed research agreements and one community declined participation due to lack of human resources to lead the project locally. Other communities were kindly requested to return the signed research agreements to the academic team by February 15, 2011, in order to meet closing dates for a funding application. By the deadline, all but two agreements had been signed and received. As soon as research agreements were finalized, the researchers and Health Directors (HDs) or Community Health Representatives (CHR) began to schedule the next cycle of ethical space dialogue, the “Meet and Greet” visits with interested community leaders, health care workers, and community members.

Reengaging communities: A newly elected chief and council

Turnover in leadership must be expected in any First Nations-based project, as Canadian legislation requires frequent elections in First Nations communities (i.e., every two years). Similarly, in this project, one community elected a new chief and council after the engagement process had begun. It was necessary to facilitate dialogue using the ethical space concept with the new community leaders in order to present the project’s background and our anticipated role in their community. It was a privilege for the research team to be invited to the comprehensive Health Services Introduction Presentations in February 2011 arranged by the community’s HD. The chief’s words at the beginning of the day were motivating and expressed the community’s desire to work with various researchers on health-related initiatives such as cancer screening and prevention. The new community leadership expressed the need for active screening in their community to try to decrease the prevalence of HPV infection and cervical cancer. Signing of the research agreement occurred on that same day.

Beyond formalities: “Meet and Greet” community visits

Once all formalities had been taken care of, local stakeholders and researchers met for “Meet and Greet” visits in each community. The local leads were entirely responsible to invite the appropriate leaders, health professionals, and community women. The number of attendees varied between three and thirteen, consisting of health staff and, in five communities, council members. On request, the researchers provided the same information packages that were sent to the chiefs in October 2010. Each meeting lasted between one and two hours.

The research team embraced the learning opportunity provided to them during these face-to-face meetings. Participating community members and employees were eager to discuss specifics of the study and the involvement of their community. The atmosphere was always relaxed, informal, and friendly with a genuine interest and support for the study. At each visit, a research team member initiated the “Meet and Greet” with a short informal overview of the project. Beyond that, there was no rigid meeting agenda. Instead, the objective was to facilitate an unobstructed, free-flowing knowledge exchange between the research team and First Nations community stakeholders. Nevertheless, the research team made sure to convey that the study would take place at no direct cost to the community, although it would require some time commitment from existing staff to support the coordination of the project. It was further communicated that an honorarium should be provided to participants of interviews and focus groups to compensate them for their time and possible expenses. The proposed role of a Community-Based Research Assistant to be hired in collaboration with the members of the Health Care Team and band councils in each community was also negotiated. This position will build further community capacity as well as involve the community throughout the entire project in
keeping with the PAR model. The community partners were very receptive and many looked forward to assisting with the job description.

**DISCUSSION**

The goal of the community visits was to continue the building of relationships between community stakeholders and researchers, beyond the formalities of presentations at regional chiefs’ meetings and development of research agreements. We strongly believe that getting to know each other through respectful, personal, face-to-face dialogues before beginning the actual project helped foster trust and facilitated crucial knowledge exchange between the research team and community members. This approach was met with great interest and openness toward the project at the community level. Many important research aspects were successfully negotiated during these community visits. Study logistics and HPV-related themes were the most prominent topics discussed, but other, more sensitive issues were raised such as sexual abuse and drug use and their perceived association with shame and stigma related to HPV.

The research team learned first-hand that participating communities face significant differences in accessing screening services, despite their close political associations, cultural connections, and relatively close geographical locations. Gaining a thorough understanding of these disparities was important and informed the research plan. The research design now addresses how this phenomenon may affect screening participation in the larger study and how accessibility of services and the invasiveness of a pelvic exam may pose barriers to screening. Access to health care services offering Pap smears varies tremendously among participating communities. In some communities they are provided locally by a visiting physician, but women in other communities have to resort to services in the next larger town with travel times ranging from 15 minutes to three hours. First Nations-based Women's Wellness Clinics offering health education, breast exams, and Pap smears are frequently not sustainable in participating communities due to limited health services budgets. Pap test results of women who receive their test outside of the community are not reported back to the First Nations health centre, disrupting continuity of care. A desired research outcome for communities therefore includes the enhancement of access for local screening and increased community capacity to monitor screening and to support follow-up when required.

The researchers learned further important lessons for the research design. For example, it is impracticable to research the previous screening history of First Nations women due to (a) the lack of comprehensive screening records at the local First Nations health centres, (b) the lack of provincial electronic cervical cancer screening databases in Ontario, and (c) the fact that cervical cancer screening is still not part of an organized cancer screening program in this province.

There was a shared interest to raise community and health provider awareness of HPV infection and transmission in general, as well as HPV vaccines and testing. Community stakeholders suggested that culturally based prevention approaches for STIs should be developed simultaneously with the research project implementation. For example, one could explore incorporating HPV prevention in traditional teachings provided by Elders to young girls. Many questions related to study logistics were negotiated and often resolved, including the health centre’s role in recruitment and other research activities, inclusion criteria for women to participate in the study, and handling of HPV tests. Community partners also provided suggestions for questionnaire domains and requested the inclusion of sexual behaviour and history questions, psychological factors, environmental factors, and health history. There was also an interest to address HPV in the context of First Nations health services, health budgets and medical transportation, the broader impact of the residential schools experiences on HPV infection, and cervical cancer screening. A strong emphasis on protecting the confidentiality and privacy of participating women emerged as another priority in the research design. This has resulted in the adjustment of our research protocol to allow women the choice of having test results sent to their First Nations health centre or alternatively to be contacted by an off-reserve mainstream health provider. Sexuality, residential school attendance, sexual abuse, and drug use have been identified as important factors for the researchers to consider, as these may have an impact on some women and contribute to behaviours that might increase the risk of HPV infection. Multiple partners, early sexual experience (consensual or non-consensual), smoking, childbirth rates, and psychological stress were also perceived as potential risk factors.

In our future research, we hope to explore the possible multi-generational nature of these issues and how they may be connected with low screening, avoidance of Pap testing, fear of cervical cancer, and lack of trust of health care providers performing Pap tests. Alternatively, the self-collected HPV test we propose to further test in our
study does not require an invasive procedure by a physician or nurse practitioner. It is imperative that the academic and community-based researchers collaborate to find ways to support women to respond appropriately to a positive HPV result, despite potential fear and stigma associated with HPV and cervical cancer.

While the ethical space concept proved very beneficial for the development of this research, operating the ethical space for the research team within the structure of Western academia was difficult. First, there is a lack of funding opportunities to finance multi-site pre-research engagement meetings with First Nations. Second, academic research institutions generally do not have a system to “reward” researchers who engage in these important, yet time- and resource-intensive activities. Instead, these activities tend to be tacitly penalized as they take time away from activities such as peer reviewed publications, which are highly rewarded and also make researchers more competitive among granting agencies.

LIMITATIONS

Engaging First Nations Peoples at the political level is necessary prior to any community-based research. Yet, this delayed the engagement of First Nations women for the project until we had formal approval to do so. Despite this necessary formality, the majority of stakeholders with whom the research team worked did consist of First Nations women.

Only 10 communities in a relatively small geographical area with reasonable connections to a major urban centre are involved in the current study. Depending on the outcome of future research, we hope to extend our investigation to more geographically remote communities.

CONCLUSION

Our adoption of Willie Ermine’s theoretical concept of ethical space has successfully assisted us in creating a meaningful and productive dialogue on HPV research in collaboration with 10 First Nations communities in northwest Ontario. It has resulted in the development of a PAR project in partnership with these communities. We hope that by creating the ethical space to negotiate HPV research in participating First Nations communities with community leaders, health workers, and community members, we will also increase the community dialogue about STIs. This process may begin to reduce the stigma and negative social implications for women who test positive for HPV. In addition, it can lead to increased HPV screening rates and lower cervical cancer rates among First Nations women, resulting in healthier women and therefore healthier communities.

ACKNOWLEDGEMENTS

This work was funded by the Northern Health Fund (to I.Z.). We cordially thank the health centre staff and band council members of the participating communities for continuous knowledge exchange and support for our study design to successfully conduct the planned larger study of cervical cancer screening.

REFERENCES


Get your guide today!

To learn more about environmental health issues and tips on how to make changes in your home, visit your local health centre or go to www.healthycanadians.gc.ca/environment