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Inuit women's attitudes and experiences towards cervical cancer and prevention strategies in Nunavik, Quebec

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***Objectives*:** To describe the attitudes about and experiences with cervical cancer, Pap smear screenings and the HPV vaccine among a sample of Inuit women from Nunavik, Quebec, Canada. We also evaluated demographic and social predictors of maternal interest in HPV vaccination.
***Study design*:** A mixed method design was used with a cross-sectional survey and focus group interviews.
***Methods*:** Women were recruited through convenience sampling at 2 recruitment sites in Nunavik from March 2008 to June 2009. Differences in women's responses by age, education, and marital status were assessed. Unconditional logistic regression was used to determine predictors of women's interest in HPV vaccination for their children.
***Results*:** Questionnaires were completed by 175 women aged 18–63, and of these women a total of 6 women aged 31–55 participated in 2 focus groups. Almost half the survey participants had heard of cervical cancer. Women often reported feelings of embarrassment and pain during the Pap smear and older women were more likely to feel embarrassed than younger women. Only 27% of women had heard of the HPV vaccine, and 72% of these women were interested in vaccinating their child for HPV. No statistically significant predictors of maternal interest in HPV vaccination were found.
***Conclusions*:** Our findings indicate that health service planners and providers in Nunavik should be aware of potential barriers to Pap smear attendance, especially in the older age groups. Given the low awareness of cervical cancer, the Pap smear and the HPV vaccine, education on cervical cancer and prevention strategies may be beneficial.

Keywords: *cervical cancer*; *human papillomavirus*; *attitudes*; *experiences*; *Inuit*; *vaccine*.

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The inclusion of cervical cytology screening in the Canadian health care system has led to a great reduction in cervical cancer incidence and mortality (1). Non-compliance to screening guidelines continues to be a major risk factor for invasive cervical cancer (2). In 1998, about 20% of Canadian women aged 20–69 reported not having had a Papanicolaou (Pap) test within the previous 3 years and the majority of cervical cancer cases occur among unscreened or underscreened women (1). Factors that predict underutilization of cervical cancer screening in Canada include older age, lower educational attainment, lower socio-economic status, single marital status, birth place outside Canada, Aboriginal identity, rural residence and negative health and lifestyle characteristics, such as infrequent physical activity and not having a regular family doctor (3–5). Further, Pap smear screening among Aboriginal women has been found to be limited by a lack of knowledge about Pap smears and their importance, feelings of embarrassment and a lack of continuity of care due to a high turnover of health professionals (6,7).

The discovery that the human papillomavirus (HPV) is a necessary cause of cervical cancer has allowed for the development of HPV vaccines as an additional means of

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cervical cancer prevention (8). Although HPV vaccination has the potential to reduce cervical cancer incidence worldwide by 70%, regular cervical cancer screening is still important to prevent the remaining 30% of cancers.

The historically high incidence of cervical cancer among the Canadian Inuit population has declined greatly since the 1990s; however, the Inuit continue to suffer a disproportionate burden of the disease compared to the general population (9). Among the Canadian Inuit, the age-standardized incidence rate of cervical cancer between 1989 and 2003 was 14.7 per 100,000, which was about three times higher than the Canadian average (9,10).

Approximately one-fifth of the Canadian Inuit population resides in the geographic region of Nunavik, the Subarctic and arctic region of northern Quebec (11). In Quebec, the Aboriginal populations face both a higher cervical cancer incidence and mortality rate than the general population (12). Consistent with the high risk of cervical cancer in the Inuit populations of Canada, a high prevalence of HPV has been found among the predominately Inuit populations of Nunavik and the Arctic federal territory of Nunavut (13,14). In Quebec there is no organized cervical cancer screening program and thus in Nunavik, Pap smear screening is done opportunistically. The Pap test is available in all 14 Nunavik communities, and is generally performed by nurse practitioners. Colposcopy, the standard follow-up for abnormal Pap smears, is available at the main health centres located in Kuujjuaq and Puvirnituq, which implies that women from the other 12 communities have to fly to attend referral appointments. In the 2004 Nunavik Health Survey, not having a Pap test in the previous 2 years was associated with a lower level of education and older age (15).

The HPV vaccination program in Nunavik was implemented in 2008 and was linked to the successful school-based hepatitis B vaccination program. First dose vaccine coverage for girls 9 to 17 years was 78.3% for all of Nunavik (Lise Lapierre, Clinical Nurse of Infectious Diseases, personal communication, June 2010).

Despite the higher incidence and mortality rates of cervical cancer among Aboriginal women worldwide, there have been relatively few studies describing Aboriginal women's knowledge, attitudes and experiences regarding cervical cancer and its prevention (16–18). This paper aims to describe the attitudes about and experiences with cervical cancer, Pap smear screening and the HPV vaccine among a sample of Inuit women from Nunavik, Quebec. We also evaluate demographic and social predictors of women's interest in HPV vaccination for their children. Such knowledge can assist in the planning of future cervical cancer screening and vaccination programs.

Material and methods

From March 2008 through June 2009, a convenience sample of 175 Inuit women aged 18–69 years was recruited from common gathering places in 2 communities of Ungava Bay, Nunavik. Nurse practitioners from the communities were responsible for recruitment and questionnaire administration. The survey contained 59 questions divided into 7 sections: (1) sociodemo-graphics, health and lifestyle characteristics; (2) use of health services; (3) knowledge, attitudes and beliefs about HPV; (4) knowledge, attitudes and beliefs about cervical cancer; (5) knowledge, attitudes and beliefs about the Pap test; (6) sexual behaviour and self-perceived risk of STI; and (7) knowledge and purpose of HPV vaccines. This paper focuses on outcome variables from sections 4, 5 and 7 and on the covariates measured in sections 1, 2 and 6. Analysis of the outcome variables from section 3 has been presented elsewhere and includes details about the questionnaire administration, validation and translation (19).

Previous awareness of cervical cancer was defined as a response of "Yes" to the question "Have you heard of cervical cancer?" whereas a response of "Yes" to the question "Have you heard of a vaccine against HPV?" defined awareness of the HPV vaccine. Maternal interest in HPV vaccination was defined as a response of "Yes" to the question "As a parent, would you be interested in having your child/children vaccinated for HPV?"

Women's attitudes and knowledge about cervical cancer and the HPV vaccine were only determined among women who reported being previously aware of cervical cancer and the HPV vaccine, respectively. Likewise, women's previous experiences with Pap smears were only reported for women who stated that they had a previous history of cervical cancer screening.

Basic descriptive statistics and frequency calculations were performed on all variables. As age, education and marital status have been shown to affect women's cervical cancer and HPV vaccine awareness and knowledge (20,21) and as it was hypothesized that women's attitudes and experiences would vary by these factors, χ^2 tests were used to explore differences in women's responses to questionnaire items by these stratifying variables. Fisher's exact tests were used when the cell count was less than 5. Variables were stratified as follows: age (less than 35 years vs. 35 years and older), education (13 years of education or more vs. less than 13 years of education) and marital status (married or living with a partner vs. not married or living with a partner).

Unconditional logistic regression was used to determine predictors of maternal interest in HPV vaccination. Odds ratios and their respective 95% confidence intervals were calculated. Statistical significance was set at 5% for

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all tests and regressions. Statistical analysis was carried out with SAS version 9.2.

In conjunction with the questionnaire data, focus groups were conducted in the 2 recruitment communities between June and October 2008. Recruitment into the focus groups was based on convenience sampling and was advertised via radio broadcast, a popular medium in these communities. Focus groups lasted about 45 minutes and were facilitated by 1 investigator (PB). The focus group guide included the following domains: barriers/facilitators to Pap smear attendance, use of safe-sex practices, awareness of cervical cancer, purpose of Pap smears, perceptions about HPV vaccination and ways to promote the vaccine. Each session was recorded, transcribed and then coded with NVivo computer software. Thematic content analysis of the transcripts was used to organize the data.

Written informed consent was obtained from all participants. Women were compensated with $20 after they completed the survey and after they participated in the focus group. Ethical approval was obtained from the McGill Institutional Review Board and the Tulattavik Health Centre.

Results

Selected demographic characteristics are displayed in Table I. A complete description of the study sample has been reported previously (19). The mean age of the sample was 34.3 with a range of 18–63 years. The two focus groups consisted of a total of 6 participants; 1 group had 2 participants and 1 group had 4 participants. The average age of focus group participants was 40.7 years (range: 31–55).

Table I. Selected demographic characteristics of study participants, Nunavik, 2008–2009 (n = 175)

Characteristics	All women (n = 175) n (%)
Age[a]	
18–29	70 (40.00)
30–39	47 (26.86)
≥40	58 (33.14)
Years of education	
6 years or less	31 (17.7)
7–12 years	119 (68.0)
13 years or more	25 (14.3)
Relationship status	
Single	65 (37.1)
Married/common law/living with partner	99 (56.6)
Widowed/separated/divorced	11 (6.3)
Number of sexual partners in the last year	
0	22 (12.6)
1–5	121 (69.1)
6–10	5 (2.9)
Unsure/refuse to answer	27 (15.4)

[a]Mean (standard deviation): 34.3 (11.7), range: 18–63.

Experiences, attitudes and beliefs about cervical cancer

Almost half of the survey study sample reported having previously heard about cervical cancer (47%). The cervical cancer attitudes and beliefs among these women are summarized in Table II. Most women who had heard of cervical cancer correctly identified a risk factor for the disease (73%), with the largest proportion of women identifying the risk of multiple sexual partners (42%). The majority of women reported that they thought early detection of cervical cancer would increase the chances for a cure (59%), although another 38% of women did not know if it would make a difference. About 45% of the subgroup of women who were aware of cervical cancer believed they were at average risk for developing cervical cancer.

A significantly higher proportion of women 35 years and older thought they were at a higher risk for cervical cancer (17%) than did women under 35 years (0%) ($p = 0.009$). No statistically significant associations were found when responses to questionnaire items on women's experiences, attitudes and beliefs about cervical cancer were stratified by education and marital status.

Pap smear history, understanding and experiences

Almost all women reported a history of previous Pap smear (96%), with 80% of all study participants reporting that their last Pap smear was within the past year (Table III). The majority of women intended to go for a Pap smear in the coming year (72%). The correct purpose of the Pap smear (cervical cancer screening) was known by 46% of study participants, but another 30% believed that it is a test for sexually transmitted infections (STIs).

Responses to the questionnaire items regarding experiences with Pap smears are displayed in Table III for the subset of women who reported a previous history of Pap smears. Previous abnormal Pap smears were reported by 20% of the women who reported having a Pap smear; however, almost one-third of these women were unsure of their results. Feelings of embarrassment during Pap smears were experienced by 37% of women who reported having a previous Pap smear. Over 60% of women would prefer if the nurse or doctor explained each step of the examination during the test. Pain during Pap smear tests was reported by 49% of women, although 41% experienced pain only sometimes.

The majority of women would be most comfortable undergoing a Pap smear if it was administered by a female practitioner, although another 19% reported that they did not have a preference. This sentiment was also described by one women from one focus group, who said, *''Some people don't go [to get Pap smears], maybe they're*

Table II. Experiences, attitudes and beliefs about cervical cancer among those women participants who had heard of cervical cancer, Nunavik, 2008–2009 (n = 85)

	n (%) (n = 85)
Do you know anybody who had cervical cancer?	
Yes	27 (31.76)
No	58 (68.24)
What increases the risk of cervical cancer?[a]	
Failure to use condoms	11 (12.94)
Smoking	12 (14.12)
Taking the contraceptive pill	3 (3.53)
High number of sexual partners	36 (42.35)
Do not know	23 (27.06)
Self-perceived risk of developing cervical cancer	
Very low	16 (18.82)
Low	23 (27.06)
Average	38 (44.71)
High	8 (9.41)
Do you think that when cervical cancer is detected early in its course, it:	
Does not make any difference	3 (3.53)
Increases the chance for cure	50 (58.82)
Do not know	32 (37.65)

[a]Women were allowed to choose only 1 response.

shy . . . all of my friends don't go probably because they are shy or sometimes they don't want to [be] checked by a man, if it is a man that is a nurse''.

Feelings of embarrassment were more commonly reported among women 35 years and older (45%) than those under 35 (29%) (P = 0.028). When women's responses to questions about Pap smears were stratified by educational and marital status, no statistically significant associations were found.

Attitudes towards the HPV vaccine

A total of 47 (27%) study participants reported previously hearing about the HPV vaccine prior to this study. The attitudes towards the HPV vaccine among women who had heard about the vaccine are displayed in Table IV. Of the women who were aware of the vaccine, almost 70% knew that the potential benefits of the vaccine were protection from cervical cancer and 87% knew that Pap smear tests would still be necessary after the vaccine.

Women would most likely go to their health practitioner for further information about HPV and the HPV vaccine (68%), and 81% of the women reported that their decision to get the vaccine, if indicated, would be influenced by a health professional. The majority of women believed that the vaccine should be given to teenagers before the onset of sexual activity (68%). Maternal interest in HPV vaccination was reported by 72% of the participants, but about one-quarter were

Table III. Study participants' Pap smear history, intentions, understanding and experiences, Nunavik, 2008–2009 (n = 175)

Pap smear history, intentions and understanding	n (%) (n = 175)
Last Pap smear test	
Last year	139 (79.43)
Within the last 3 years	12 (6.86)
More than 3 years	17 (9.71)
Never	6 (3.43)
Did not respond	1 (0.57)
Do you have any intention of going for a Pap smear test in the next year?	
Yes	126 (72.00)
No	7 (4.00)
Maybe	42 (24.00)
What is a Pap smear test?	
Scraping to look for abnormal cervical cells	80 (45.71)
Treatment for cancer	16 (9.14)
Test for sexually and blood-borne transmitted infection	52 (29.71)
A test necessary to get birth control pills prescribed	5 (2.86)
Do not know	22 (12.57)
Experiences with Pap smear among women who have a history of Pap smears	n (%) (n = 168)
Have you ever had a previous abnormal Pap smear test result?	
Yes	34 (20.24)
No	82 (48.81)
Unsure	52 (30.95)
Do you feel embarrassed when undergoing a Pap smear test?	
Yes	62 (36.90)
No	106 (63.10)
Do you prefer if the nurse/doctor explains each step of the examination during the Pap smear test?	
Yes	107 (63.69)
No	28 (16.67)
Does not matter	33 (19.64)
Do you feel more comfortable undergoing a Pap test if the nurse/doctor is:	
A female	119 (70.83)
A male	1 (0.60)
A doctor/nurse you already know	16 (9.52)
Does not matter	32 (19.05)
Do you feel pain when undergoing a Pap test?	
Yes	14 (8.33)
No	85 (50.60)
Sometimes	69 (41.07)

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Table IV. Attitudes towards the HPV vaccine among study participants who had heard of the HPV vaccine, Nunavik, 2008–2009 (n = 47)

	n (%) (n = 47)
What are the potential benefits of the HPV vaccine?	
Protection against cervical cancer	32 (68.09)
Treatment of current cervical cancer	5 (10.64)
Do not know	10 (21.28)
If one gets the HPV vaccine, will one still need to go for Pap tests?	
Yes	41 (87.23)
Unsure	6 (12.77)
Do you believe that the HPV vaccine is safe?	
Yes	30 (63.83)
No	3 (6.38)
Unsure	14 (29.79)
If the HPV vaccine can help you stay healthy, do you see any need for it?	
Yes	27 (57.45)
No	5 (10.64)
Unsure	15 (31.91)
Do you think that the HPV vaccine should be given to teenagers before the onset of sexual activity?	
Yes	32 (68.09)
No	6 (12.77)
Unsure	9 (19.15)
As a parent, would you be interested in having your child/children vaccinated for HPV?	
Yes	34 (72.34)
No	3 (6.38)
Unsure	9 (19.15)
Did not respond	1 (2.13)
If you would like to know more about HPV or HPV vaccines, what would be your main source of information?	
Family	5 (10.64)
Friends	3 (6.38)
Doctor/nurse	32 (68.09)
School	1 (2.13)
Other health professional	5 (10.64)
Internet	1 (2.13)
What would influence your choice of getting HPV vaccination (or not)?	
Nobody	3 (6.38)
Doctor/nurse	38 (80.85)
Friends and family	6 (12.77)

either unsure or were not interested in having their child vaccinated.

There were no significant associations when responses to questionnaire items concerning attitudes to the HPV vaccine were stratified by age, educational status and marital status. None of the demographic characteristics measured in our study significantly predicted the mothers' interest in having their children vaccinated.

Discussion

The components of the survey addressed in this paper assessed women's awareness, attitudes and experiences with cervical cancer, the Pap smear and the HPV vaccine. A low awareness of cervical cancer and the HPV vaccine was found, but almost 80% of the participants stated that they had a Pap smear in the previous year, and 72% intended to get one within the coming year. A similarly high cervical cancer screening coverage rate was reported by the 2004 Nunavik Health Survey, where 82% of respondents reported having a Pap smear in the previous 2 years and 60% in the past 12 months (15). Both our survey and the Nunavik Health Survey used self-reported data and these data may show an overestimation of the coverage rate, given that a previous chart review conducted between 2002 and 2007 showed that 71% of women in Nunavik had a Pap test within the previous 3 years (14).

A sizable proportion of the women were unable to identify a cervical cancer risk factor and were unsure if detecting cervical cancer early would affect the chance for a cure. Further, we found that some women did not fully understand the purpose of the Pap smear as a method of cervical cancer screening, as 30% reported that the purpose of the Pap smear test is to screen for STIs. These results suggest that further education about cervical cancer and its prevention may be beneficial to increase awareness. Higher knowledge about Pap smears has been shown to be associated with higher cervical cancer screening adherence (20,22).

Feelings of embarrassment and pain during Pap smears were common among our study population and others (23). Among our population, older women reported more feelings of embarrassment than the young women. Health care providers in Nunavik should be aware of this difference in Pap smear experience by age, especially given that older age is associated with a decline in cervical cancer screening in the Canadian population and cervical cancer incidence is the highest among women in their 40s (3,24). Additionally, more women over the age of 35 in our population perceived themselves to be at a higher risk of cervical cancer than women who were younger than 35. We found that Inuit women had a strong preference for having cervical cancer screening performed by female health practitioners and that they wanted explanations to be given to them throughout the Pap smear examination. These preferences were also shown among Aboriginal populations in Canada and the United States (17,25). When planning health services these concepts should be kept

in mind, as Coe et al. (16) found that Pap smear adherence was lower among women who reported that they would refuse a male provider.

Inuit women who had heard of the HPV vaccine generally reported positive views towards the HPV vaccine with the majority of women reporting a belief in the vaccine's safety. However, many women may want further information about the vaccine, as evidenced by those who answered with the "unsure" category to many questionnaire items. Most women agree that the vaccine should be given to younger women before they engage in sexual activity.

The majority of women who had heard of the HPV vaccine were interested in having their children vaccinated, which was also found among the general Canadian population (26) and in a population of Alaska Native parents (18). Although we only measured maternal interest, there was in fact a very high first-dose HPV vaccination uptake in Nunavik. This suggests that the high interest in vaccination reported by mothers was indeed predictive of the future behaviour of parents in Nunavik to provide consent for their children to be vaccinated. The high uptake of the vaccine may be related to the trust in health professionals reported by women in our study, where most women report that they would seek further information on the vaccine from and have their decision to be vaccinated influenced by their doctor or nurse. We were unable to determine if a woman's relationship with her health provider influenced her interest in vaccinating her children, but general trust in doctors and government was previously found to be predictive of vaccine acceptance in a study of British parents (27). It is important to note that the strong acceptance of the vaccine in this population may not be specific to concerns about HPV and cervical cancer, but that it may be more indicative of a general acceptance of vaccination due to the active role nurses play in communities and schools (where the vaccination program occurs) and the historical power differential between the Inuit and health providers. This may be especially true as there is a low level of understanding about HPV and its relation to cervical cancer in this population (19).

No predictors of maternal interest in vaccination were found in our study population. This result may be due to our small sample and that few mothers were definitively uninterested in the vaccination for their children. Despite this, it is possible that there are no predictors of acceptance in this population given the high uptake rate. Previous studies have shown factors such as parental cervical cancer screening behaviour (19,28) and younger parental age (26) to be associated with parental interest in vaccination and adolescent vaccine uptake. Further, vaccine acceptance has been shown to be associated with acceptance of general vaccines (26,27,29) and vaccination rates of hepatitis B are very high in Nunavik.

The main limitation of this study was the non-random recruitment strategy. Women were recruited into this study through convenience sampling. They were frequent health care users and, given their interest in the study, may have a higher understanding of cervical cancer, Pap smears and the HPV vaccine compared to less frequent health services users. It was not feasible to collect information about the women who chose not to participate in the study. Despite our sampling method, our sample had a similar age distribution (30), health behaviours (31,32), health service use (15,33) and educational attainment (30) as the female population of Nunavik. It is possible that our study underestimated women's awareness of cervical cancer and the HPV vaccine, given that the Inuit are often modest about their knowledge and experiences (34). If this was the case, we may have unnecessarily reduced our sample size by focusing our reporting of attitudes and knowledge of cervical cancer, the HPV vaccine and Pap smears on women who had respectively stated they had heard of cervical cancer and the vaccine and on those who had a history of Pap smears. It was decided that this restriction was important to reduce the influence of chance guessing on the estimates. Additionally, these data are self-reported, so we do not actually know what women will do or have done.

Although unintended, participants of both focus groups directed the conversation towards an educational focus due to the limited knowledge about HPV, cervical cancer and Pap smears among participants. This shows that these women have an interest in gaining further knowledge about women's health issues, such as cervical cancer and STI prevention, and further opportunities for education should be made available. As a result of the educational focus of the interviews, we were unable to assess the effect that factors such as a lack of knowledge about Pap smears and their importance and the lack of continuity of care due to a high turnover of health professionals had on Pap smear attendance among women in Nunavik.

This is the first study to attempt to describe women's awareness, attitudes and experiences of cervical cancer, Pap smears and the HPV vaccine in a Canadian Inuit population. Although questionnaire items were of a sensitive nature, there was very little missing information. As almost all study participants stated they had a history of Pap smears, we were unable to assess demographic predictors of Pap smear attendance. Future research such should focus on determining if there are certain subsets of the female population who are underscreened for cervical cancer in Nunavik and how screening coverage can be increased within these groups.

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