Cervical cytology screening

How can we improve rates among First Nations women in urban British Columbia?

THOMAS GREGORY HISLOP, MD, CM
HEATHER FRANCES CLARKE, RN, PHD
MICHÈLE DESCHAMPS, RN, PHD
RHEA JOSEPH, MSC, BHE
PIERRE ROBERT BAND, MD
JOHN SMITH, MPA
NHU LE, PHD
RICHARD ATLEO, PHD

OBJECTIVE To determine Pap smear screening rates among urban First Nations women in British Columbia; to identify facilitators and barriers; and to develop, implement, and evaluate specific interventions to improve Pap smear screening in Vancouver.

DESIGN Computer records of band membership lists and the Cervical Cytology Screening Program registry were compared to determine screening rates; personal interviews and community meetings identified facilitators and barriers to urban screening programs. A community advisory committee and the project team collaborated on developing specific interventions.

SETTING AND PARTICIPANTS Purposive sample of British Columbia First Nations women, focusing on women living in Vancouver.

INTERVENTIONS Poster, art card, and follow-up pamphlet campaign; articles in First Nations community papers; community meetings; and Pap smear screening clinics for First Nations women.

MAIN OUTCOME MEASURES Pap smear screening rates among BC First Nations women according to residence and reasons for not receiving Pap smears.

RESULTS Pap smear screening rates were substantially lower among First Nations women than among other British Columbia women; older women had even lower rates. No clear differences were found among First Nations women residing on reserves, residing in Vancouver, or residing off reserves elsewhere in British Columbia. Facilitators and barriers to screening were similar among women residing on reserves and in Vancouver. Many First Nations women are greatly affected by health care providers' attitudes, abilities to provide clear information, and abilities to establish trusting relationships.

CONCLUSIONS Family physicians are an important source of information and motivation for Pap smear screening among First Nations women.

OBJECTIF Déterminer les taux de dépistage par cytologie cervicovaginale chez les femmes des Premières Nations vivant en milieu urbain de la Colombie-Britannique ; identifier les éléments d'incitation et les obstacles ; et développer, mettre en place et évaluer des interventions spécifiques visant à améliorer le dépistage par cytologie gynécologique dans la ville de Vancouver.

CONCEPTION On a comparé les dossiers informatisés provenant de listes des membres des bandes au registre du Programme de dépistage cytologique afin de déterminer les taux de dépistage ; des entrevues personnelles et des rencontres communautaires ont identifié les éléments d'incitation et les obstacles aux programmes urbains de dépistage. Un comité consultatif communautaire et l'équipe chargée du projet ont collaboré à développer des interventions spécifiques.

CONTEXTE ET PARTICIPANTS Un échantillon délibéré de femmes de la Colombie-Britannique appartenant aux Premières Nations, en concentrant sur les femmes vivant dans la ville de Vancouver.

INTERVENTIONS Affiches, cartes artistiques, campagne de suivi utilisant des dépliants, articles dans les journaux communautaires des Premières Nations, rencontres communautaires et cliniques de dépistage cytologique accessibles aux femmes des Premières Nations.

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Dr Hislop *is Senior Epidemiologist in the Division of Epidemiology and Cancer Prevention of the BC Cancer Agency in Vancouver.* **Dr Clarke** *is a Nursing Research Consultant for the Registered Nurses Association of British Columbia in Vancouver.* **Dr Deschamps** *is Head of Nursing Research,* **Ms Joseph** *is Project Manager,* **Dr Band** *is Vice President,* **Mr Smith** *is Data Manager, and* **Dr Le** *is a Statistician, all in the Division of Epidemiology and Cancer Prevention of the BC Cancer Agency.* **Dr Atleo** *is Coordinator of First Nations Studies at Malaspina University College in Nanaimo, BC.*

PRINCIPALES MESURES DES RÉSULTATS Taux de dépistage cytologique chez les femmes des Premières Nations de la C.-B. selon leur lieu de résidence et les raisons invoquées pour ne pas se soumettre aux cytologies gynécologiques.

RÉSULTATS Les taux de dépistage cytologique sont significativement plus faibles chez les femmes des Premières Nations comparativement aux autres femmes de la Colombie-Britannique ; ces taux sont encore plus faibles chez les femmes plus âgées. On n'a pas constaté de différence précise entre les femmes des Premières Nations qui vivent dans les réserves, celles qui vivent à Vancouver ou celles qui vivent ailleurs en Colombie-Britannique mais en dehors des réserves. Les éléments d'incitation et les obstacles furent semblables chez les femmes qui vivent dans les réserves et chez celles qui vivent à Vancouver. Beaucoup de femmes des Premières Nations sont grandement affectées par les attitudes des intervenants, leur capacité à fournir une information claire et leur capacité à établir des relations de confiance.

CONCLUSIONS Les médecins de famille sont une source importante d'information et de motivation concernant le dépistage cytologique chez les femmes des Premières Nations.

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THE HEALTH OF FIRST NATIONS* PEOPLE HAS improved substantially over the last half century, yet it is still poorer than the health of the rest of the population.[1] The profile of serious illnesses among First Nations people also differs from that in the general population.

In British Columbia, mortality from cervical cancer is six times higher among First Nations women than among other BC women,[2] and yet some of these deaths are preventable by regular Pap smear screening. In fact, since implementation in 1955 of the population-based Cervical Cytology Screening Programme (CCSP) in British Columbia, the provincial mortality rate for invasive squamous cervical cancer has been reduced by more than 70%.[3]

Previous studies have shown that cognitive, emotional, and socioeconomic factors are important barriers to women's participation in Pap smear screening for cervical cancer.[4] In 1990, the British Columbia Cancer Agency (BCCA) in partnership with Native Brotherhood of British Columbia initiated a comprehensive program to investigate reasons for elevated cervical cancer mortality among First Nations women and to implement appropriate solutions. Only 50% of age-eligible (between 18 and 69 years) First Nations women living on reserves had received Pap smears at least once within the most recent 3-year period, as compared with 85% of all BC women.[5]

Lack of awareness and knowledge about the Pap smear and about its importance, feelings of embarrassment with Pap smear testing, and lack of continuity of care due to high turnover of physicians in First Nations communities[6] were all found to hinder Pap smear screening of these women. After discussions with First Nations women residing on reserves and health professionals serving these communities, a pilot Pap smear screening clinic initiative was implemented in three reserve communities, increasing the rate of Pap smears to 80% of age-eligible women. Women who attended these clinics expressed appreciation for information given to them about the Pap smear and reported feeling comfortable and relaxed, as the Pap smear was done by a female health care provider in a friendly environment.

The relevance and applicability of these findings cannot be assumed to reflect the reality of First Nations women residing outside reserves, who account for approximately 50% of the BC band–affiliated female population. According to the 1991 census, approximately 5000 women of aboriginal origin reside in Vancouver.[7] Although geographic proximity to health services is not a serious issue to most people living in Canadian cities, health promotion, treatment, and prevention services are used less frequently by urban First Nations people than by the general population.[8-10]

A second research demonstration project focusing on First Nations women living in Vancouver was therefore initiated using an approach similar to that for women living on reserves. The protocol was approved by University and BCCA ethics

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**First Nations is used throughout this article to refer to bands, or sometimes groups of bands, affiliated with a tribal council or cultural group.*

review committees and included ongoing input from a community advisory committee representing nine Vancouver-based First Nations health and social organizations (each member signed confidentiality forms). This paper reports on the extent of Pap smear screening among BC First Nations women residing in different locations, reasons for not receiving Pap smears, and specific initiatives that have been implemented and evaluated in Vancouver to improve Pap smear screening of urban First Nations women. Recommendations and resources for family physicians are summarized.

Rates of Pap smear screening

Method. Twenty-seven bands were selected to examine the extent of Pap smear screening among First Nations women by residence location (living on or off reserves, city if off reserve); these included 16 bands from the bands in the first demonstration project that consented to participate in this study and 11 bands randomly selected from the remaining 180 BC bands. Names and birth dates were provided by the Department of Indian Affairs in Ottawa, Ont, for women aged 18 to 69 years on the 1991 band membership lists. These women's names were provided to the appropriate band and reviewed by a band representative in early 1993 to discover where the women resided. When residence was unknown, the names and birth dates were linked with the Medical Service Plan to determine the geographic location of women using physician services between April 1992 and March 1993.

To determine Pap smear screening rates, records of names and birth dates were linked with the CCSP registry for women with known residence. This computerized registry contains the woman's surname, given names, date of birth, and date and result of each Pap smear for all women in the province who received Pap smears after 1976 and for those women with at least one abnormal Pap smear result whose last smear was done before 1976. Two matching levels were used: an exact match requiring the same surname and given names, and either the same birth day, month, and year, or the same birth year but reversed day and month; and a likely match requiring the same surname and given names, and either the same birth year with different month or day, or the same birth day and month but birth year differing by no more than 5 years. A coding system (SOUNDEX)[11] was used to account for different spellings of surnames.[5]

Women were classified as "current participants" in Pap smear screening when their last Pap smear was within 3 years (1990 to 1992), and as "ever participants" when there was any record that they had had a Pap smear. Age-specific Pap smear screening rates were examined separately for women residing on reserves, in Vancouver, and outside reserves but elsewhere in British Columbia. Most (92%) of the matches between band lists and the CCSP registry were exact matches and only 8% likely matches. No significant difference was seen in screening rates between the women of the 16 bands from the first project and those of the 11 randomly selected bands. Hence, Pap smear screening rates were determined for First Nations women combining women from all 27 bands, and both exact and likely matches. Logistic regression controlling for age and the likelihood ratio test were used to test for differences in screening rates by area of residence.

Results. Residence information was obtained from the 27 band representatives for 3469 women and from the Medical Service Plan for a further 325 women. Residence location was unknown for 498 (12%) women, who were therefore excluded from the analysis of both Pap smear rates and reasons for not having a Pap smear. However, their age-adjusted Pap smear rate was similar to that for the final study group. The final study group comprised 3794 First Nations women: 1971 (52%) residing on reserves, 310 (8%) in Vancouver, and 1513 (40%) outside reserves elsewhere in British Columbia. The CCSP registry contained names of 3120 (82%) of these women (ie, ever participants); 2285 (60%) were current participants.

The age- and residence-specific Pap smear screening rates for current and ever participants

Table 1. **Pap screening rates for participants in the CCSP among BC band-affiliated First Nations women by age and location of residence**

			LIVING OUTSIDE RESERVES				
	LIVING ON RESERVES		VANCOUVER		ELSEWHERE IN BC		BC GENERAL POPULATION
AGE (Y)	NO.*	RATE (%)	NO.*	RATE (%)	NO.*	RATE (%)	RATE (%)
CURRENT PARTICIPANTS							
18-19	62/108	57	8/18	44	70/110	64	—
20-29	445/592	75	73/110	66	385/554	70	89
30-39	394/579	68	66/86	77	261/423	62	90
40-49	164/325	51	37/68	54	132/245	54	80
50-59	86/215	40	10/21	48	43/128	34	69
60-69	35/152	23	2/7	29	12/53	23	54
Age-standardized rate[†]		62		62		58	84
EVER PARTICIPANTS							
18-19	62/108	57	8/18	44	71/110	65	—
20-29	501/592	85	98/110	89	457/554	83	—
30-39	531/579	92	80/86	93	369/423	87	—
40-49	281/325	87	58/68	85	203/245	83	—
50-59	158/215	74	15/21	71	91/128	71	—
60-69	107/152	70	4/7	57	26/53	49	—
Age-standardized rate[†]		84		81		80	—

**Numerator – number of women screened, denominator – number of women registered with study bands.*

[†] Age standardized by direct method using the final study group as the referent population.

are presented in *Table 1*. The age relationship for current participants was evident in all three residence groups with much lower rates for older women ($P < 0.001$). Although statistically significant ($P < 0.001$), this age relationship was less apparent for ever participants, as more than 80% of women between the ages of 20 and 49 years old (ie, childbearing years) had at least one previous Pap smear. Fewer women older than 50 years had a record of previous Pap smear. The differences in frequency of screening among the three residence groups for both current and ever participants were small, differing by only 3% to 4%, of borderline statistical significance ($P = 0.02$ and $P = 0.06$, respectively), and of little clinical significance.

Reasons for not having a Pap smear

Method. To understand First Nations women's perceptions and experiences with Pap smears and to obtain their suggestions about ways to improve health care services, phenomenological methods were considered most appropriate.[12] Eleven women were interviewed at least once by a trained First Nations woman using a semistructured format. The purposive sample of women agreeing to participate in the study met the following criteria: resided in

Vancouver, were between 18 and 69 years old, and represented both current and ever participants in the CCSP.

Questions addressed specific aspects of the Pap smear, as well as knowledge, beliefs, and practices regarding health promotion and disease prevention. All interviews were audiotaped and transcribed. Content analysis was performed according to Holsti[13] and Miles and Huberman[14] using "Ethnograph," a program for the management and analysis of text-based data.[15] Findings were presented and discussed in three community meetings with other First Nations women residing in Vancouver to validate the findings and extend understanding of the problem.[12]

Results of both interviews and community meetings were discussed with the community advisory committee as they became available in order to obtain advice on the project team's interpretation of the women's suggested initiatives and ways to implement them. This participatory approach was deemed important to the overall goal of the demonstration project[16]: to bring about change in health care services to First Nations women so as to increase Pap smear screening and subsequently reduce women's mortality rate from cancer of the cervix.

Results. Generally, the Pap smear was considered a subject not "brought out in the open, not talked about" with family members and friends. Women usually had their first examination with no or limited knowledge about the test, being caught in the health care system during childbearing years. The little they learned was from their physicians at the time of their first gynecologic examination.

Women's knowledge was primarily related to what they had to do and how the test was clinically performed. They knew little about the cancerous process and the purpose of the Pap smear (confusing it with a test for sexually transmitted diseases) or its optimal frequency. Few women mentioned the role of the Pap smear in detecting precancerous changes or were able to describe accurately the technical aspect of the test (ie, obtaining cervical cells for subsequent microscopic examination). Some women thought that the Pap smear was a prerequisite to obtain birth control pills.

Overall, women reported being very embarrassed and uncomfortable, both psychologically and physically, when having Pap smears, especially if examined by male doctors. Women related these feelings to being taught to be modest about "the sexual part" of the body and not to expose themselves. Furthermore, women's experiences of physical and sexual abuse by men made them "afraid to open up to any male." Only a few women indicated that they were "fearful and scared" about the possible positive outcome of the Pap smear. Although some women reported that over time it became easier to have Pap smears, most had to psychologically prepare and remind themselves that "the test was for health reasons only."

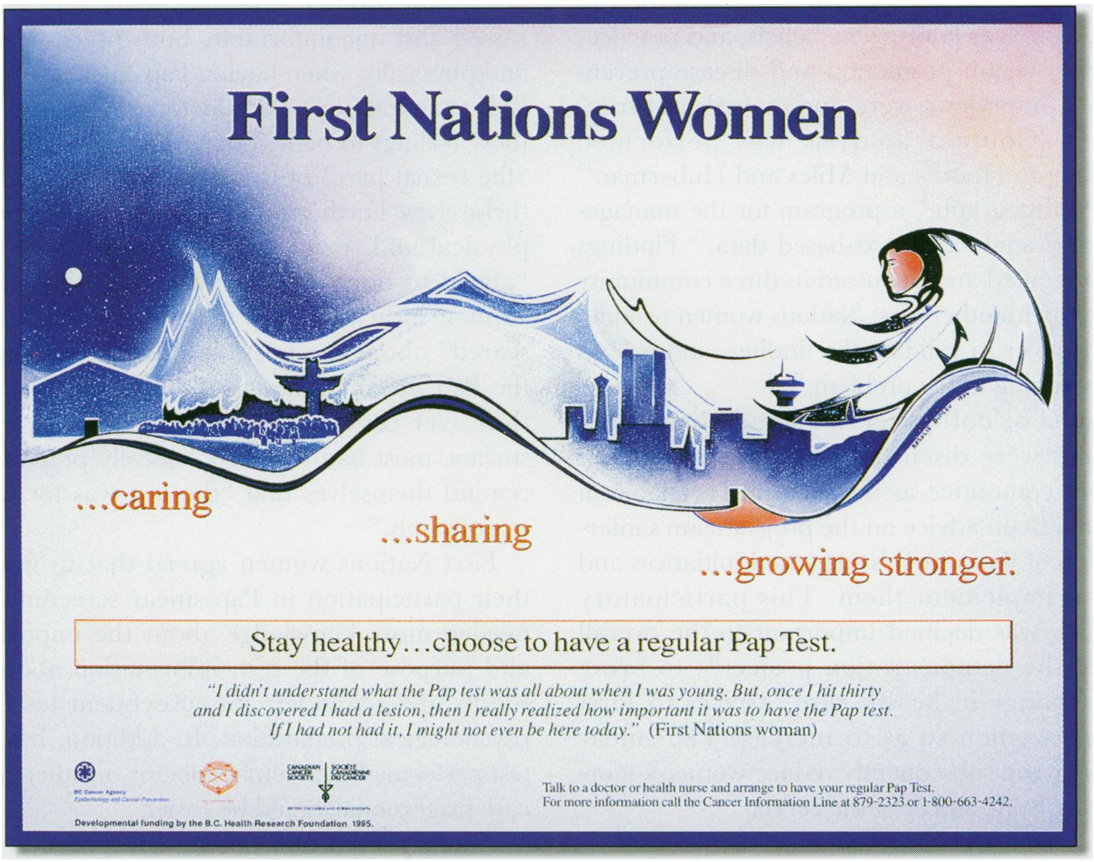
First Nations women agreed that to improve their participation in Pap smear screening they needed more knowledge about the importance and purpose of the test, information about the results and reminders for subsequent tests, and psychological preparation. In addition, having a test performed by a female doctor or other health care professional would be easier.

Another important finding concerned general health beliefs of First Nations people. Prevention is not a meaningful concept to them. Failure to prevent a disease, even though the prescribed activity is carried out, results in guilt and blame whereas promoting one's health, emphasizing a sense of balance and holism, is meaningful. Making choices for oneself and future generations is central to their health promotion philosophy. Women regarded the right to choose to have a Pap smear and when to have it as critical to their psychological preparation.

Demonstration project

These findings and suggestions made by women during the interviews and community meetings were used to develop several initiatives to target First Nations women living in Vancouver's East Side, where most live. A visual image representing a positive health promotion approach and

Figure 1. **Poster developed as a specific initiative**



First Nations Women

...caring
...sharing
...growing stronger.

Stay healthy...choose to have a regular Pap Test.

"I didn't understand what the Pap test was all about when I was young. But, once I hit thirty and I discovered I had a lesion, then I really realized how important it was to have the Pap test. If I had not had it, I might not even be here today." (First Nations woman)

BC Cancer Agency
Epidemiology and Cancer Prevention

Canadian Cancer Society | Société canadienne du cancer

Talk to a doctor or health nurse and arrange to have your regular Pap Test.
For more information call the Cancer Information Line at 879-2323 or 1-800-663-4242.

Developmental funding by the B.C. Health Research Foundation 1995.

Available from the Canadian Cancer Society, British Columbia and Yukon Division.

linking urban and rural First Nations communities was created by a Salish artist to be used on all educational and promotional material. A poster (*Figure 1*), an informational art card, and an educational follow-up pamphlet were developed. The art card describes the Pap smear and answers common questions, such as "Who needs a Pap test?" "Why is cervical cancer much higher among First Nations women?" and "Why is a regular Pap test important?" The follow-up pamphlet explains common terms used to describe Pap smear results and follow-up care and includes illustrations of cell changes.

These materials were distributed to participating bands, Native Housing, First Nations health and social agencies in Vancouver, and both provincial and national representatives of the Canadian Cancer Society. Evaluation of these materials resulted in some text revisions.

Several articles were published in First Nations community papers to provide general information on cervical cytology screening. Community meetings were held to provide general information about the Pap smear and women's health and to encourage First Nations women to ask questions.

To provide more culturally suitable choices, as requested by some First Nations women, two types of Pap smear screening clinics were set up specifically for them. Both were drop-in or by appointment. One was staffed by a female physician at the Vancouver Native Health Society, while the other was staffed by a midwife at a Vancouver Health Department Unit. Both employed First Nations staff as receptionists. To date, attendance at these Pap smear screening clinics has been sporadic. Although First Nations women suggested the need for a specific First Nations service for some women, many also stated that trusting relationships with their physicians are more important. When the relationship is trusting, they prefer to have their Pap smears done by their family physicians.

Discussion

Current Canadian recommendations for Pap smear screening are that all women between ages 18, or after first sexual intercourse, and 69 be screened at least once every 3 years.[17] For this reason, the group studied for rates of Pap smear screening was restricted to First Nations women 18 years of age and older.

The extent of Pap smear screening was substantially lower among First Nations women than among other British Columbia women, regardless of residence location. Among current participants, older women were less likely to have been screened for cervical cancer, yet they are at higher risk for invasive cancer of the cervix. There were no meaningful differences in Pap smear screening rates among First Nations women residing on reserves, in urban Vancouver, and off reserves elsewhere in British Columbia. Two limitations that could influence these screening rates included name changes, which would hinder linkage with the CCSP registry, and missing residence location. To address the first limitation, band representatives reviewed band membership lists after linkages were made to identify name changes, and this information was used to correct linkages. To address the second limitation, age-specific screening rates for women with unknown residence were compared with those with known residence, and the rates were similar. Hence these limitations should not introduce notable bias into the screening estimates.

The difficulties with Pap smears expressed by First Nations women were similar among women living on reserves and in urban Vancouver. Most women indicated that the health care provider's attitude, ability to provide understandable information, and ability to establish trusting relationships are crucial in making the procedure more acceptable. Women appreciated being informed about the results of their Pap smears, even if they were normal; many expected and waited for a reminder about when their next screening test was due. Many expressed the need for a positive approach encouraging women's choices for staying healthy rather than for preventing cancer. The findings from this study were similar to others with respect to extent of Pap smear screening, mortality rates from cancer of the cervix, experiences with and knowledge about Pap smears, and suggestions for improving First Nation women's health, including early diagnosis of cancer of the cervix.[18,19]

Implications for family physicians

Family physicians are important sources of information and motivation for First Nations women in their attempts to stay healthy. Focusing on health promotion rather than disease prevention is to be encouraged. Culturally appropriate educational materials, available from the Canadian Cancer Society, British Columbia and Yukon Division, include a poster, informational art card, and educational follow-up pamphlet that have proven to be important sources of information for First Nations women. A tear-off sheet depicting the female pelvic anatomy, suitable for making personalized notes on during one-on-one testing, is currently being tested by a sample of family physicians in British Columbia.

First Nations women reported they appreciated being informed about the results of their Pap smear and expected to be reminded when their next screening test was due. In British Columbia, the Pap smear report that is sent from the CCSP to screening physicians includes this information. Of utmost importance is ongoing encouragement of regular Pap smear screening among First Nations women. Cervical cancer mortality can be prevented and the

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health of First Nations women promoted by culturally sensitive and knowledgeable family physicians. ■

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Correspondence to: *Dr T.G. Hislop, Division of Epidemiology, BC Cancer Agency, 600 West 10th Ave, Vancouver, BC V5Z 4E6; telephone (604) 877-6000, local 3059; fax (604) 877-1868*

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