# CERVICAL CANCER SCREENING STRATEGIES FOR ABORIGINAL WOMEN<sup>1</sup>

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#### **ABSTRACT**

**Background.** Cervical cancer mortality in Canada has been reduced by 70% over the past 50 years; however Aboriginal women in BC are estimated to have Pap rates of 50% compared to 85% for all BC women. Mortality from cervical cancer is six times higher among Aboriginal women than other women in BC. Previous qualitative research studies examined reasons for the reduced rate of screening among Aboriginal women, and recommended interventions to improve screening rates among this population. This research project built on previous studies and focused on awareness and evaluation of current interventions to encourage cervical cancer screening among Aboriginal women.

**Methods.** A qualitative research design was used, and purposive sampling was employed to identify key informants. Key informant interviews were conducted.

**Results.** Findings include these suggestions to increase Aboriginal women's participation in cervical cancer screening: 1) build partnerships in Aboriginal communities; 2) educate women from a young age about the importance of

**Note:** In this paper, the term "Aboriginal" refers to any person who self-identifies as being of Aboriginal heritage, whether First Nations or Métis, on-reserve or off-reserve.

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Ethics approval for this project was received from both the Simon Fraser University Research Ethics Board and the University of British Columbia-British Columbia Cancer Agency Research Ethics Board, which includes meeting the CIHR Guidelines for Health Research Involving Aboriginal People.

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cervical cancer screening and the importance of the human papillomavirus (HPV) vaccine in preventing cervical cancer; 3) create brochures and other educational material that reflect the lives of Aboriginal women; 4) organize a day or week dedicated to Pap screening; 5) bring services to the women who live in remote communities; 6) offer drop-in appointments; and 7) use creative technology for hard-to-reach populations.

Conclusion. Fostering cultural respect and cultural safety are central to building relationships in Aboriginal communities. Aboriginal health agencies are very receptive to the idea of working together with provincial health programs to design and carry out projects of mutual concern and benefit, including projects related to cervical cancer screening. Qualitative research can play an important role in informing and supporting the work of provincial health programs.

#### Introduction

Cervical cancer incidence in Canada has declined by 70% over the past 50 years, largely due to the work of provincial screening programs that have promoted screening widely and made cervical cancer screening services readily available and free of cost (Health Canada, 2004). Screening for cervical cancer is usually conducted through the use of the Papanicolaou, or "Pap test," in which a nurse or physician removes cells from the client's cervix to detect abnormal cell growth. In British Columbia, the Cervical Cancer Screening Program (CCSP) has greatly increased rates of cervical cancer screening among most of BC's female population, yet Aboriginal women in BC are estimated to have Pap rates of 50% compared to 85% for all BC women (Hislop et al., 1996). Mortality from cervical cancer is six times higher among Aboriginal women than other women in BC (Hislop et al., 1996). In Manitoba, Aboriginal women were found to have 1.8 and 3.6 times the rate of in situ and invasive cervical cancer, respectively, while 43% of Aboriginal women had received one or more Pap tests in the previous three years, compared to 60% of non-Aboriginal women (Young et al., 2000).

The CCSP does not collect data on the racial or ethnic background of women participating in cervical cancer screening, and current rates of Pap screening among Aboriginal women are difficult to determine from other available data sources. I embarked on this project in the belief that, as Hislop et al. discovered in 1996, Aboriginal women in BC are participating in cervical cancer screening in smaller percentages than non-Aboriginal women.

Previous qualitative research studies have examined reasons for the reduced rate of screening among Aboriginal women, and recommended interventions to improve screening rates among this population (Clarke et al., 1998; Pakula, 2006). Clarke et al. (1998) found that barriers to Aboriginal women's participation in cervical cancer screening included not knowing where to get screened, medical offices and clinics devoid of First Nations influences, prevention as an abstract concept, and insensitive care by health workers. Among the recommended interventions noted by Clarke et al. (1998) were culturally specific advertisements for Pap screening, education of health care providers about meeting the needs of Aboriginal clients, special Pap clinic days once a month for First Nations women, and training nurses to perform Pap tests on First Nations reserves.

In a systematic literature review of strategies to increase cervical cancer screening, Black et al. (2002) found that characteristics associated with low screening rates included age, education, poverty, rural address, being an immigrant or Aboriginal, and speaking neither official language. Black's study found the most successful interventions included those that "combined mass media campaigns with direct tailored education to women and/ or health care providers" (2002, p. 386).

Social determinants of health, such as poverty and Aboriginal status, often promote poor health (Raphael, 2009) and prevent participation in health promotion programs like Pap tests. Raphael's recent research confirms that "living conditions are the most important factors shaping health and predicting the onset of disease and premature mortality" (2009, p. 193), while Byers and colleagues recently reported that cancer mortality is 35% higher among clients with a lower socioeconomic status (as cited in Gandey, 2008).

This research project built on previous studies of Aboriginal women and cervical cancer screening, and explored the question: "What interventions currently exist, or have been proposed, to encourage participation in cervical cancer screening among Aboriginal women, and what are the barriers and facilitators to implementing these interventions?" The interviews focused on awareness and evaluation of current interventions to encourage cervical cancer screening among Aboriginal women. Interview responses were compiled into a list of suggested interventions to increase Aboriginal women's participation in cervical cancer screening.

The objective of this research was two-fold: to provide provincial cancer screening programs like the CCSP with an evaluation of the current state of

cervical cancer screening interventions for Aboriginal women, and to offer suggestions for organizing outreach efforts to increase cervical cancer screening among Aboriginal women.

This objective was accomplished by the completion of 16 key informant interviews. The recommendations found in this report may encourage cervical cancer screening among Aboriginal women, thus potentially reducing morbidity from cervical dysplasia, the precursor to cervical cancer, and reducing mortality from cervical cancer. This project also presented an opportunity to demonstrate the effectiveness and usefulness of qualitative research findings in supporting the work and the goals of provincial cancer screening programs.

#### METHODOLOGY

#### STUDY DESIGN

This project involved exploratory research, approached through qualitative research methods that emphasize developing insights and generalizations from the data collected (Neuman, 2006). The project was underscored by a belief that qualitative research methods are well suited for projects that seek to tap into the personal and professional experiences of research participants (Denzin and Lincoln, 2003). This philosophy of research encourages participants to speak freely in interviews, expressing their opinions and telling their stories. The rich descriptive data elicited in qualitative interviews allows a depth of understanding, often lacking in surveys and questionnaires, that can "make the world visible in a different way" (Denzin and Lincoln, 2003, p. 5). For the topic of cervical cancer screening in Aboriginal women, this methodology allowed participants to provide context for their responses, thereby strengthening the researcher's understanding.

Site visits in different parts of the province allowed triangulation, with the benefit of studying cervical cancer screening interventions from multiple points of view. The primary methodological tool employed in this project was key informant interviews, and a total of 16 people were interviewed.

#### **M**FTHODS

#### Interviewees

The people interviewed for this project included physicians, nurses, health authority staff, First Nations band office staff, and others working in the

field of Aboriginal women's health, or those with influence and experience in this field. Interviews were sought with people working with groups of Aboriginal women, rather than interviews with individual Aboriginal women. This decision was made because previous research focused on individual barriers to participation in cervical cancer screening, while this project focused on organizational barriers and facilitators to participation.

Interviewees reported their conversations with clients who defer or decline Pap tests, as well as their experiences with women who participate in Pap screening, and were therefore able to represent the opinions and experiences of those Aboriginal women who do get Paps, as well as those who do not get Paps. Attempts were made to interview Community Health Representatives (CHRs), but the response I received from one local contact was that CHRs in her region were too busy to be interviewed, and were reluctant to participate in research projects because of a perception that these projects have historically returned little of value to their communities. Multiple attempts were also made to achieve band approval to interview health workers and CHRs at bands in northern BC, but there was no response to emails, letters, or phone calls.

Eight of the sixteen people I interviewed self-identified as Aboriginal, and their responses to interview questions sometimes included personal reflections on being an Aboriginal woman in the health care system. The other eight interviewees were chosen because of their work in the field of Aboriginal women's health, or their work directly with groups of Aboriginal women.

#### STUDY SITE AND POPULATION

A purposive sample of several geographical areas was chosen to include both urban and rural regions. Previous research has shown that barriers and facilitators to cervical cancer screening differ among urban and rural Aboriginal women. Areas included in the project were Vancouver, Victoria, Port Alberni, Nanaimo, and Fort St John.

#### SAMPLING PLAN

Key informants in each of the geographical areas were identified through snowball sampling. Key informants consisted of a purposive sample of 16 people, including health authority staff working in the area of Aboriginal women's health, health coordinators hired by First Nations bands, and health professionals providing cervical cancer screening to Aboriginal women.

#### Data Collection Instruments

Interviews consisted of open-ended questions to encourage participants to offer opinions and propose solutions. Interviews with 14 of the 16 participants were tape-recorded. Two interviews were recorded with hand-written notes, because these two interviewees did not wish to be tape-recorded. At three different times, I spoke to two women at a time, at the preference of the interviewees. All other interviews (10) were performed individually.

#### Procedures

Informed consent was received from each participant prior to beginning interviews. The names of interviewees were changed to pseudonyms, and tapes were then transcribed and analyzed.

In Victoria and Vancouver, key informants were identified through snowball sampling, asking for potential interviewee names from others working in the field of Aboriginal women's health. Attempts to include Community Health Representatives (CHRs) for First Nations bands were unsuccessful.

Site visits were conducted in Victoria. Port Alberni. Vancouver. and Fort St John. When in-person interviews could not be scheduled, telephone interviews were conducted with interviewees in Nanaimo, Port Alberni, and Victoria.

#### Analysis Plan

All interviews were conducted following informed consent. Transcriptions of interviews were thematically coded to identify specific barriers and facilitators. Open coding was followed by axial coding to further organize ideas and themes emerging from the interview transcriptions. (Neuman, 2006). Data was coded using Microsoft Word, and results are described in this paper.

#### LIMITATIONS OF THE STUDY

This study is restricted to several geographical areas in British Columbia, and I was not able to interview people in all regions or at all health authorities in the province. The purposive sampling procedure, which did not include interviewees from all parts of BC, limits the degree to which the results and recommendations can be generalized.

The perspectives of individual Aboriginal women accessing the health care system are not included, as interviews were conducted solely with practitioners and administrators in the health care field who worked with Aboriginal women. Because interviews with randomly selected Aboriginal women were not sought, I relied on the 16 interviewees to represent the opinions of the women they serve, and the study results therefore do not encompass the full range of opinions held by all Aboriginal women in BC.

Interviews were requested with persons working in the health sector, either as health professionals, or as employees of health authorities or First Nations bands. This bias towards those within the health care field limits the breadth of opinions gathered in interviews.

#### ETHICAL CONSIDERATIONS

Ethics approval was obtained from the Simon Fraser University Research Ethics Board and the University of British Columbia–British Columbia Cancer Agency Research Ethics Board prior to beginning interviews for this study. Approval by these research ethics boards meets the requirements of the Canadian Institute for Health Research's Guidelines for Health Research Involving Aboriginal People. Confidentiality was provided by changing interviewee names to pseudonyms prior to transcription of interview tapes, and by using quotations in a way that does not identify the location or position of the interviewee.

Interviewees were given a consent form to read and sign prior to participation in interviews. The consent form assured participants of confidentiality. The consent form clearly indicated that interviewees could decline to respond to any questions, or withdraw from the interview at any time.

As a non-Aboriginal person, I recognized the inherent challenges in developing relationships and trust in the Aboriginal communities I visited and with the Aboriginal women I interviewed, especially considering the short time frame of this project. I relied on the mentorship of others who have worked with Aboriginal women or done research in this field, and followed their advice on partnership building and respectful approaches. I encouraged the people I interviewed to describe their population's health challenges and priorities, so that my priorities as a researcher would not dominate the interview. I remain committed to full distribution of the results of this research in order to benefit the Aboriginal women whom the project was designed to serve.

#### Knowledge Exchange

Copies of this report were distributed to each of the 16 interviewees. Additional copies will be made and distributed by the CCSP as needed or desired. The results were presented to the CCSP, and a poster presentation

was held at Simon Fraser University. Additional venues for dissemination of the report will be sought.

#### QUALIFICATIONS OF THE RESEARCHER/STUDENT

The graduate student involved in this project and author of this report is a registered nurse with 12 years experience in women's health, including employment as a health care researcher performing interviews and leading focus groups. At the time of this research, she was completing her first year of a two-year Master of Public Health degree.

# Current Interventions to Increase Aboriginal Women's Participation in Cervical Cancer Screening

Several programs in BC are dedicated to improving the health of the Aboriginal women in the province. Most of these programs give some attention to cervical cancer screening. The programs are described below.

All health authorities in BC have Aboriginal health plans, programs, or teams, with staff dedicated to improving health in Aboriginal communities. Within the Provincial Health Services Authority (PHSA) there is an Aboriginal Health Program at BC Women's Hospital and Health Centre that provides outreach, health education, and cervical cancer screening in remote reserves. This program serves between 150–200 Aboriginal women per year.

Also included in PHSA is the BC Centre for Disease Control, which contains the Street Nurse Program. The nurses of the Street Nurse Program have been organizing "Papalooza" in Vancouver's downtown east side since 2002. The nurses perform between 50–100 Pap tests during this three-day event which is hosted once or twice per year. Participants in Papalooza have included up to 42% Aboriginal women. (D. Taylor, personal communication, June 11, 2008).

The Aboriginal Women's Wellness program was developed by the Vancouver Island Health Authority (VIHA). This program has a coordinator whose work includes women's health promotion and outreach; and a family nurse-practitioner whose work includes women's health promotion and outreach, as well as cervical cancer screening for the local Aboriginal population.

Vancouver Coastal Health has an Aboriginal Health Initiative Program that supports health promotion projects with Aboriginal and First Nations organizations within the Vancouver Coastal Health region. Fraser Health

Authority has an Aboriginal Health Initiatives program and has just hired a nurse-practitioner to serve Aboriginal clients at the Kla-how-eya Aboriginal Centre Health Clinic in Surrey. Interior Health Authority and Northern Health Authority each have an Aboriginal Health program or team.

Within the health regions there are individual efforts to increase cervical cancer screening rates among Aboriginal women. An example of this occurred recently in Port Hardy, where the public health nurses were funded by the health authority to organize, advertise, and host a "Pap Week" event, which included nurse-run clinics performing Pap tests in eight Aboriginal communities. In all, this week-long series of clinics served 300 women and performed 69 Pap tests (P. Rardon, personal communication, June 17, 2008).

There are federal health nurses in 19 communities across BC, employed by Health Canada, with a mandate to provide health services to the onreserve First Nations population in their communities. This has often included support for cervical cancer screening on local reserves.

Many individual First Nations bands and tribal associations have health directors and staff dedicated to health promotion activities in their communities. In many cases, these health promotion activities include providing cervical cancer screening.

#### INTERVIEW RESULTS

The results of the 16 interviews are grouped into three categories: 1) background health challenges for Aboriginal women; 2) barriers to participation in cervical cancer screening; and 3) outlines of interventions that are currently working to increase Aboriginal women's participation in cervical cancer screening, or interventions that are suggested to increase participation.

The background challenges facing many of the Aboriginal women served by the people I interviewed include the effects of colonialism, which are perhaps most evident in the persistent poverty facing many Aboriginal people. While screening programs cannot eliminate the problems faced by those members of the population suffering the ill health effects of poverty, it is important to acknowledge these conditions as barriers to participation in cervical cancer screening. Interventions to increase Aboriginal women's participation in cervical cancer screening must take into account the challenges created by poor social conditions and tailor programs accordingly.

The results of my 16 interviews illustrate these health challenges and I discuss how they interfere with the participation of some Aboriginal women in cervical cancer screening.

#### BACKGROUND HEALTH CHALLENGES

When asked to describe the background challenges, or social determinants, of the health of the Aboriginal women served by themselves or their programs, interviewees gave a number of responses. The primary challenge, forming a backdrop to all other more specific concerns, is the issue of poverty and the health challenges that often accompany poverty. When questioned about health challenges of the women in her community, one interviewee hesitated, then said, "I think a lot of these women are worried about putting healthy food on the table for their kids."

Specific health conditions and social conditions affecting Aboriginal women's health named by interviewees included the following: mitigating factors such as poverty, isolation, stress, need for healthy relationships, high drop-out rates from secondary school, high unemployment rates, domestic violence and food insecurity; diseases such as alcoholism, drug abuse, arthritis and diabetes; and lack of consistent access to health care providers.

One interviewee explained,

I think the health concerns of women, like the health concerns of all our community, stem back to some of the problems of colonization and residential schools. So it's a lot of historical stuff that we're dealing with still today and we see that in the health issues that we deal with....

The responses I received in interviews made it clear that the social determinants of health, including poverty and the legacy of colonialism, are major influences on the health of Aboriginal women.

#### BARRIERS TO ABORIGINAL WOMEN PARTICIPATING IN CERVICAL CANCER SCREENING

1 asked interviewees to describe the barriers that prevent Aboriginal women from participating in cervical cancer screening. Interview responses are organized into the following themes: poverty, lack of cultural safety, legacy of paternalism, privacy and confidentiality concerns, Pap test not seen as a priority, history of sexual abuse, availability of health care providers, and fear of focusing on cancer.

#### **POVERTY**

Many of the women I interviewed mentioned persistent poverty, and the social challenges that coexist with poverty, as barriers to Aboriginal women's participation in cervical cancer screening. Chief among these social challenges are the daily struggles for quality childcare, adequate employment, and reliable transportation, all of which affect women's ability to participate in cervical cancer screening.

Lack of transportation to health care providers and facilities to participate in Pap tests was listed as a barrier by almost every person I interviewed, including one who named access as a "huge issue," especially for women living in rural areas or on remote reserves.

One interviewee stated, "A lot of women are leading very chaotic lives for a lot of reasons, and their self-care is not on their radar." Another interviewee mentioned that "The barriers are about actually having the support to take care of yourself and getting the support from other women and their families or the communities to help you do that."

#### LACK OF CULTURAL SAFETY

The term "cultural safety," and the issues of trust and respect that are embedded in the concept of cultural safety, were mentioned by several of the women I interviewed. Cultural safety is a concept that originated in New Zealand in response to the effects of colonization on both Aboriginal peoples and on healthcare professionals' treatment of Aboriginal clients. Maori nurse, Irihapeti Ramsden, is considered the originator of the concept, and she writes, "Cultural safety addresses quality in healthcare though issues of communication and access to the health service" (Papps and Ramsden, 1996). One interviewee expressed the barrier in this way: "just having people culturally sensitized and having cultural safety, for Aboriginal people to seek help when they suspect a problem ... can be an obstacle." Another interviewee noted that barriers include "the stereotypes, the discrimination, the racism. I think those are the major challenges we have to overcome with Aboriginal people."

A health professional spoke of the lack of trust that often interferes with Aboriginal women seeking health care:

A lot of people have experienced some really negative interactions with non-First Nations people, and that brings ... a certain level of lack of trust and caution in dealing with people, so that also makes them reluctant to just go out there and keep trying. If they have a bad encounter with one physician or one clinic, they're not going to just keep doing it.... So they just stop. What happens is that they wind up using 'emerg' or walk-in clinics as their primary care, but they fall through the cracks because neither of those places do primary care.

## LEGACY OF PATERNALISM

One of the health professionals I interviewed spoke of the health effects from what she called "the legacy of paternalism." She described the ways in which her Aboriginal clients had been encouraged by health professionals in their communities to allow others to make health care decisions for them:

In order to encourage people to use the health care services provided by the government through the last century, they have undermined the individual's decision-making and ownership of their health.... So, many people from a First Nations community ... may have experienced a lack of independence in their own health care.

This interviewee went on to state that many of her female clients wait to be told that they need a Pap test, and in the absence of reminders, don't participate in cervical cancer screening.

#### PRIVACY AND CONFIDENTIALITY CONCERNS

Several of the women I interviewed noted that "shyness" and privacy were barriers for Aboriginal women participating in Pap tests. One interviewee stated that Pap tests are considered private because they are related to sexual activity; therefore there is some hesitance to discuss or undergo the Pap test.

In one interview, the respondent noted that women living on reserve have told her they don't want to go for a Pap test when the health professional visits the reserve, because "everyone will know my business" if they see her showing up for an appointment with the health professional. In another interview, concerns about confidentiality arose when discussing the training of local nurses to perform Pap tests:

... when we ask them [women in community] about whether or not they would support their own community health nurse providing the services [Pap tests], they say no.... They want that confidentiality.

Regarding confidentiality in smaller communities, one interviewee said, "It's like any community, it's not just Aboriginal communities. It's all small communities. 'Oh I seen so and so go down to the doctor, what's goin' on?'" Another interviewee stated, "I know a lot of First Nations communities who are interested in anonymity and privacy, and they don't feel they get it with the on-reserve nurse."

An issue related to confidentiality was described in this way by an interviewee:

... there are practitioner issues. The nurse in the community can be seen, for instance, as similar to Child Services.... They may be involved in taking a child into custody, and then you're supposed to go to this same nurse to do your Well Woman exam?

This issue was countered by another interviewee, who stated that in her community the local nurse "developed a trusting relationship with the client, and so they were quite happy with that [the local nurse performing their Pap]."

#### PAP TEST NOT SEEN AS A PRIORITY

"Paps are not on the radar, really, as a priority," stated one interviewee when asked to describe barriers. Others explained that many Aboriginal women have other, more pressing, concerns: "For women to say that they're important, that they're a priority, they would say 'no, my children are my priority, and my elders are my priority, my youth are my priority.""

Some interviewees also noted a lack of awareness of the importance of cervical cancer screening, and knowledge about what the Pap test is: "I don't think they all know what a Pap test does anymore."

#### HISTORY OF ABUSE

The majority of interviewees mentioned sexual or physical abuse as a barrier to Pap screening among some Aboriginal women, sometimes noting that this abuse occurred in residential schools. The option of having the Pap test performed by a female provider may overcome this barrier for some women, but as one interviewee commented, "For any woman who has experienced sexual abuse ... a pelvic examination is a no-go zone, regardless of who's doing it."

#### Accessibility of Health Care Providers

Accessibility of health care providers was described as a barrier in those areas where there are not enough physicians or nurses. One interviewee described this situation:

So we actually just got invited to ... do a clinic and it was with the support of the physicians because the physicians are so overworked right now they can't do just the routine [Pap] screening. They can't get enough ... office time.

Access was not always seen as an issue, and in one smaller city a health provider stated, "If they don't mind seeing the new doctor in town, they can have a Pap today."

#### FEAR OF FOCUSING ON CANCER

One interviewee stated that some of the Aboriginal women she works with are hesitant to discuss cancer or cancer risks because of a belief that "what you focus on, you get." Another interviewee noted, "I know a lot of them [Aboriginal women] are really intimidated, because they're frightened about what they'll find.... The word 'cancer' just terrifies everyone."

In summary, the barriers preventing many Aboriginal women from participating in cervical cancer screening are primarily those related to poverty, lack of accessibility to health care providers, and lack of culturally safe relationships with health professionals and the health care system.

### Suggestions to Improve Numbers of ABORIGINAL WOMEN PARTICIPATING IN CERVICAL CANCER SCREENING.

When I discussed suggestions for interventions to increase Aboriginal women's participation in cervical cancer screening, the answers I received in interviews fell into several categories: 1) build partnerships in the communities of the women you're trying to reach; 2) educate women from a young age about the importance of cervical cancer screening and the importance of the HPV vaccine in preventing cervical cancer; 3) create brochures or other educational material that reflect Aboriginal women's lives; 4) organize a day or week dedicated to Pap screening; 5) bring services to the women who live in remote communities; 6) offer drop-in appointments, and 7) use of creative technology for hard-to-reach populations.

Below are details on each of these suggestions, followed by notes on which barriers could be overcome by each of the suggested interventions. Table 1 shows a comparison of barriers and corresponding interventions.

#### Build Partnerships in Aboriginal Communities with Individuals, CHRs, Agencies, and Health Authority Staff Working with this Population

Many of the health authority staff whose work currently includes a focus on Aboriginal women's health indicated in interviews that they would like to strengthen their connection to provincial health programs. These staff people organize health conferences, visits to reserves, and Pap events, all focused on Aboriginal women's health. Participating in some of these events

Barrier Intervention • Bring services to the women who live in re-Poverty, including reduced access to transportation and mote communities. childcare Offer drop-in appointments. • Build partnerships in communities of Aboriginal women. Lack of cultural safety Create brochures or other educational material that reflect the lives of Aboriginal women. • Educate women from a young age about the importance of cervical cancer screening and the Legacy of paternalism importance of the HPV vaccine. • Create brochures or other educational material that reflect the lives of Aboriginal women. • Bring services to the women who live in remote Privacy and confidentiality communities. • Educate women from a young age about the importance of cervical cancer screening and the Pap test not seen as priority importance of the HPV vaccine. Create brochures or other educational material that reflect the lives of Aboriginal women. • Use of creative technology for hard-to-reach History of sexual abuse populations, e.g. self-collection. • Organize a day or week dedicated to cervical Availability of health care cancer screening. • Bring services to the women who live in remote providers communities. • Educate women from a young age about the importance of cervical cancer screening and the Fear of focusing on cancer

Table 1: Barriers and Interventions

would provide networking opportunities that would benefit both provincial health programs and the event organizers. Provincial health programs could also provide materials to enhance the training in cervical cancer screening currently received by CHRs.

importance of the HPV vaccine.

Several interviewees who had previously participated in Pap outreach efforts stressed the importance of time invested in building relationships with communities. One interviewee stated,

I'll come back a year later and they'll remember me ... so maybe in a small town that relationship is more than knowing them, it's also about trust and a reputation of things that get passed on ... what I notice is that our numbers will go up over time. You get that, 'Oh, they came and they weren't so bad.'

In Port Hardy, the nurses who organized a Pap Week event this year were told by the local band nurses that more women have stated they will attend the Pap Week event next time because "now they know the nurses."

Building respectful partnerships in Aboriginal communities with individuals, CHRs, agencies, and health authority staff working with this population would help overcome the barriers presented by lack of cultural safety. This can best be accomplished by actively listening to the community and their expression of health care priorities, then working with leaders and women's health champions in the community to set health improvement goals that are mutually agreeable. It is important that researchers approaching Aboriginal communities be aware of the history of colonialism and the far-reaching impacts of colonialism on Aboriginal people's health today.

#### EDUCATE WOMEN FROM A YOUNG AGE ABOUT THE IMPORTANCE OF CERVICAL CANCER SCREENING, AND THE IMPORTANCE OF THE HPV Vaccine to Prevent Cervical Cancer

Several interviewees suggested that young women should be educated about the importance of cervical cancer screening and prevention, including a focus on the HPV vaccine and the Pap test. "Normalize the Pap test," stated one health provider.

One interviewee suggested that many communities seem more accepting of educational interventions that target young people: "It gets accepted in the community easier if it's under the rubric of 'our youth need this."

Another interviewee suggested that the promotion of the HPV vaccine should be a primary goal for cervical cancer prevention efforts:

If I were to focus my efforts in cervical cancer prevention for Aboriginal communities, I would focus it right now on the HPV vaccine. Because I still think that we have monstrous health inequities due to isolation, due to access to care.... When we look at who shoulders the burden of cervical cancer in Canada, there's the socioeconomic disparity, there's Aboriginal women, and immigrants. And for two out of three of those groups with a vaccine program that's publicly funded and available through school-based programs, we're going to take a big bite out of that.

Educating women from a young age about the importance of cervical cancer screening, and the importance of the HPV vaccine to prevent cervical cancer would help to overcome the barrier of the legacy of paternalism and empower young Aboriginal women to take control of their own health. This education would also work to overcome the barriers of nonprioritization of Pap tests and fear of focusing on cancer, by combating misinformation about cervical cancer and stressing the benefits of prevention and screening.

# CREATE BROCHURES AND OTHER EDUCATIONAL MATERIALS THAT REFLECT ABORIGINAL WOMEN'S LIVES

One interviewee stated that educational material must be "reflective of the women that you're trying to promote this screening to ... not just the young women. It's got to be older women as well." Another interviewee suggested that educational materials about cervical cancer screening should focus on the benefits to women and their families of being healthy:

...one thing I always begin with, with the group is that if you're healthy then you can ... continue to care for your children. And we know it as mothers, right? We start with the women's health, because if she has healthy children then you'll have a healthy community.... If every woman was healthy then she would have healthy children.

I was told that educational material and programs should include Aboriginal role models:

To get women doing it [participating in Pap tests], you need to have First Nations role models involved. They need campaigns. They need advertisements, and explaining why it's important for their beliefs.... I would suggest finding some role models.

Another interviewee suggested that we "tell success stories" of Aboriginal women who have been screened for cervical cancer and treated successfully for cervical cancer or cervical dysplasia.

One suggestion was that brochures and other educational material should include other women's faces along with Aboriginal women's faces:

Paps are low among three groups. It's not just Aboriginal women. Aboriginals, young women, and immigrant women, and I kind of think it'd be nice if somehow a resource could be developed with all three in mind.... One of the reasons is I don't like the targeting like, right away you think okay yeah here we are, we are targeted with this again, like we're the ones who don't get Pap tests....

Education about cervical cancer screening should be placed in the context of overall health and wellbeing, suggested one interviewee. She said health providers should make the Pap clinic be,

the place in the community ... where you do the wellness, and then encompassing it [the Pap test] in wellness, it's not just come in and have a few cells taken from your cervix, but we care about your whole health and wellbeing.

Creating brochures and other educational material that show the faces of Aboriginal women and include text that is relevant to and appropriate for Aboriginal women, with a focus on overall wellbeing, would assist in overcoming the barriers of cultural safety (by demonstrating respect for culture); the barrier of paternalism (by encouraging the empowerment of Aboriginal women to take control of their own health care needs); and non-prioritization of Pap test (by combating misinformation about cervical cancer and stressing the benefits of prevention and screening).

#### Organize a Day or Week Dedicated to Pap Screening

Several of the interviewees for this project had previously participated in organizing events like "Pap Week" or "Papalooza," well-publicized events with Pap tests available on a drop-in basis, and sometimes door prizes, flowers, or other incentive gifts to encourage participation and contribute to the positive atmosphere of the event. One interviewee explained to me that Papalooza is successful because "it's a celebratory thing. It's available in the women's neighbourhood, and we fuss over them..." Several interviewees told me that the Community Health Representatives (CHRs) in their community or reserve can assist with advertising and recruiting women to participate in a Pap Day or Pap Week event.

While most interviewees were enthusiastic about dedicated Pap days or Pap weeks, there were two cautionary notes expressed. One is the difficulty for providers in deferring all other client concerns in order to focus on the Pap test in a short appointment time. One provider expressed her caution this way,

I think, how can you ask a question and then when they tell you the answer go, 'Thank you!' and carry on? 'Have you ever been abused?' or those invasive things, and they say 'yes.' They tell you their health issues and you go, 'That was really nice. I've noted that. Now we're moving on to talk about your depression,' or something. I actually find it hard ... to speed up.

The second caution was about confidentiality at well-publicized Pap events. One nurse stated that CHRs have told her that some Aboriginal women won't show up at a dedicated Pap Week event because they fear that other members of their community will see them at the event and their privacy will be compromised.

Having dedicated "Pap Days" or "Pap Weeks" would help overcome the barrier of lack of availability of health care providers, especially in remote reserves.

# Bring Pap Tests to Aboriginal Women Living in Remote

Several interviewees stated that the best approach to improving cervical cancer screening rates in Aboriginal communities would be to deliver Pap tests in the community, performed by female providers who have established a relationship with the community, and have gained the trust of the women in the community.

One interviewee cautioned that Pap Day or Pap Week events should become a regular feature, rather than a one-time event: "One-offs are not a good idea, because the women feel like they're being researched, then forgotten." Another interviewee emphasized that "consistency makes a big difference.... People start relying on it and knowing it's there so ... it has to be consistent." Bringing cervical cancer screening to Aboriginal women living in remote communities would help to overcome the barriers presented by poverty, such as lack of transportation and lack of childcare.

Some interviewees expressed caution about using the nurse who is from the community they're serving. One interviewee commented, "So there may be an issue of, a little bit of distance is a good thing, that it's a trusted provider but not a provider who lives right in the community." Other interviewees told me that in their communities the local nurse was a trusted provider and they had heard no concerns about privacy.

One interviewee expressed her experience with the difficulty of retaining nurses who have been trained to perform Paps in the reserve where they reside:

So there's the barrier of actually having practitioners. A lot of real issues, particularly on reserve, is this cycling through of nurses. We looked over the past ... 8 to 10 years, and we had trained 90 nurses to do STI testing.... Five were still practicing.... There's no ability to retain nurses. It's very tough work ... the reserves are very isolated.

Her concern was echoed by another interviewee who expressed concern about the cost to the individual band of training nurses to perform Paps:

And so there was a lot of time and effort put into ... training them ... and also too those that were trained soon left the community. So the communities didn't benefit from their ... professionals taking this training. So it was costly for them, they'd have to pay for their nurses to leave the community, accommodations, travel, everything, their wage....

Another concern was expressed regarding these nurses having the support of local physicians to whom they can refer clients when the Pap test is abnormal, or when there are other issues beyond the nurses' scope of practice:

One of the things we asked each nurse before they came down [for the Pap training] is whether or not they had the support of the community, and the support of a local physician because when you see something and it needs to be referred on to a physician so you need to have that good working relationship with the physician. We found over the years that some physicians, said 'No, we offer this service. Why should we support the nurses to offer this in their community? People can come in to see us.'

By bringing in health care professionals from outside the reserve community, the concern about confidentiality can be addressed, as well as the concerns about retention of on-reserve nurses and costs to individual bands to train nurses. Health professionals coming to reserves to offer cervical cancer screening should work to establish collegial relationships with local health care providers and others working locally on Aboriginal women's health issues, so they are seen as helpful and not adversarial.

#### OFFER Drop-in Appointments

Several of the health professionals I interviewed noted that having drop-in appointments available seemed to work well for their Aboriginal clients, especially those clients for whom lack of transportation and lack of child-care were barriers to participation in cervical cancer screening. Offering dropin appointments would address the barriers of lack of transportation and childcare, as women can access health provider services on their own schedule, when transportation and childcare are available to them.

#### Use Creative Technology for Hard-to-reach Populations

One interviewee noted a recent research study done in Vancouver that enlisted women at high risk for HPV infection (and thus cervical cancer) to participate in cervical cancer screening by performing "self-collection" of cervical cells. (Ogilvie et al., 2007). The study addressed the need for creative approaches for women who do not participate in cervical cancer screening at recommended intervals. This intervention would help with overcoming the barrier of sexual abuse, as there is no pelvic examination to undergo, and the woman herself is in control of the specimen collection.

#### Discussion

Previous research has demonstrated that Aboriginal women suffer a disproportionately high rate of cervical cancer, and Aboriginal women access cervical cancer screening less often than recommended and less often than non-Aboriginal women. While previous research examined reasons for these disparities, this project sought to evaluate current interventions to overcome barriers to Aboriginal women's participation in cervical cancer screening, and propose solutions to increase this participation.

"Health promotion in Aboriginal communities is less about transfer of knowledge than about transfer of respect and power," stated one of the women I interviewed. Through the twelve weeks of this project, one of the most significant lessons I learned was the importance of building partnerships in Aboriginal communities and with Aboriginal agencies and programs prior to entering the community with a health promotion agenda or program. These partnerships must involve a relationship of mutual respect and power-sharing, and building relationships should precede any other intervention efforts.

Following relationship building, suggestions from this research project include these activities to promote Aboriginal women's participation in cervical cancer screening: educate women from a young age about the importance of cervical cancer screening and the importance of the HPV vaccine in preventing cervical cancer; create brochures and other educational material that reflect the lives of Aboriginal women; organize a day or week dedicated to Pap screening; bring services to the women who live in remote communities; offer drop-in appointments; and use creative technology for hard-to-reach populations.

The social determinants of health have an enormous impact on the health of Aboriginal women in BC. The legacy of colonialism, the impact of residential schools, and the economic hardships resulting from these issues all play a role in producing poor health outcomes for this population. It is important to acknowledge that many Aboriginal women face the challenges of poverty daily. Outreach projects should be designed in ways that both recognize and attempt to overcome these barriers whenever possible.

Results from this project indicate that individuals and agencies serving Aboriginal women are very receptive to the idea of working together with provincial health programs to design and carry out projects of mutual concern and benefit.

This project demonstrates that qualitative research can play a role in informing and supporting the work of provincial health programs. Future collaborations between qualitative researchers and provincial health programs should be encouraged.

A report summarizing the project was distributed to the 16 individuals who participated in the interviews. Additionally, presentations of the report's finding and recommendations were done for the CCSP and a poster session was held at Simon Fraser University. Presentations will be held at other venues as they become available. These activities help to return the information and suggestions contained in the report to the community they are intended to benefit.

While this project employed a sample size of only 16 interviewees, the opinions offered in interviews demonstrate broad insight into the array of work currently being done to encourage Aboriginal women's participation in cervical cancer screening. Interviewees offered suggestions that will be useful to health programs seeking to improve cervical cancer screening rates among their Aboriginal clients. Future research might expand on this work by exploring the elements of a therapeutic relationship between Aboriginal women and their healthcare providers, or describing the most appropriate learning styles for young women of all ethnicities to educate young women about the importance of cervical cancer screening.

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