



# Cancer of the Cervix in North American Indian Women: A literature review



First Nations Centre  
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National Aboriginal Health Organization (NAHO)  
Organisation nationale de la santé autochtone (ONSA)  
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# **Cancer of the Cervix in North American Indian Women**

A literature review for the First Nations Centre at the  
National Aboriginal Health Organization

October 2006

## **Introduction**

Cancer of the cervix in Aboriginal women presents an enormous challenge that begs for action now. As women are the safeguards of the physical and cultural survival of Aboriginal people, it would be most beneficial for them to become empowered in a way that they can take precautionary measures towards preventing cervical cancer. The Aboriginal population is young. Young women are especially susceptible to the human papilloma virus, a precursor to cancer of the cervix. The high incidence of cancer of the cervix in Aboriginal women, lower rates of screening in the first place and poor attendance at follow-up of abnormal findings of cervical screening leads to higher than average mortality rates from this preventable disease. These facts demonstrate the necessity of developing culturally appropriate methods of health promotion and prevention campaigns for Aboriginal women. This literature review illustrates that the reasons for lack of compliance with Papanicolaou tests among Aboriginal women are complex and have been the subject of many studies in Canada and the United States and Alaska dating back to the 1980's.

## **Methods**

A literature search for materials spanning the past ten years was conducted on Ovid Medline (R), Cumulative Index to Nursing, Allied Health Literature, E-Journals @ University of Toronto using the key words cervix neoplasm, First Nations Women, Aboriginal Women in Canada, North American Indian Women, screening for cervical cancer. Thirty articles were found and reviewed. This review builds on previous work on health promotion regarding cancer of the cervix in Aboriginal women.

Firstly, this literature review presents a general outline of cervical cancer. The main part of the paper, however, is comprised of three main themes that emerged during the review of the literature, namely:

- Rates of cervical cancer among Aboriginal women
- Correlates and Determinants (reasons for cervical cancer)
- Screening –effectiveness, barriers and strategies

Lastly, a summary of findings is articulated.

## **What is cancer of the cervix?**

Cancer of the cervix is diagnosed annually in about one million women worldwide. About half die from it. Canada has been in the forefront in reducing the incidence of cervical cancer through promotion of Pap smear screening programs. However, cancer of the cervix remains a challenge for the health care system because of the numbers of invasive cancer that are missed and the high cost of maintaining quality screening programs. Cancer of the cervix is particularly a problem among immigrant women and Aboriginal women in Canada. Two general histological varieties of cells, squamous cell carcinomas and adenoma-carcinomas are present in cervical cancer. Squamous cell carcinoma has decreased as a result of screening but the prevalence of adenocarcinoma has risen because Pap cytology is generally ineffective in detecting these adenocarcinomas and their precursor lesions (Eduarte-Franco and Franco, 2003).

The cervix is the tubular passageway that connects the lower end of the uterus (womb) and the upper end of the vagina (birth canal) in the female reproductive system. The cervix has 2 types of cells. The surface of the cervix at the vagina is lined with thin, flat cells called "squamous cells". The tubular part of the cervix has "epithelial cells" that secrete mucous.

Cells in the tissues of the body die and replace themselves continuously. Sometimes cells as in the cervix change and grow forming lumps or precancerous lesions called dysplasia. If lesions are left undetected and untreated cancer can result. Dysplasia can transform into a tumour or carcinoma in situ (non-invasive cervical cancer). On the other hand, invasive cancer of the cervix means cells may grow uncontrollably invading deeper tissues of the cervix or spreading to adjacent organs. Approximately 90% of the cancers of the cervix are squamous intra-epithelial lesions (SIL) or cervical intraepithelial neoplasia (CIN) in those cells lying next to the vagina or ectocervix. The other 10% of carcinomas (called adenocarcinoma) occur in the mucous-producing cells of the canal or endocervix. Cancer of the cervix may have characteristics of both types of cancer and is called "adenosquamous carcinoma" or "mixed" carcinoma (Cherath, M.A., 2002). Squamous cell carcinoma has decreased as a result of screening but the prevalence of adenocarcinoma has risen because Pap cytology is generally ineffective in detecting these adenocarcinomas and their precursor lesions.

George Papanicolaou, an American researcher invented the Papanicolaou (Pap) test in the 1950's. The Pap test detects cervical dysplasia and its precursors. It is the primary method of screening for cervical cancer. The Pap test is a screening test only, not a diagnostic test. Although mortality

rates have been reduced because of the Pap test, the reduction is the result of repeated tests over the lifetime of women who undergo screening. Investigators cite a number of studies to show that the Pap test has a sensitivity of only 51%. Moreover, the number of false negatives is too high for women who may be lesion free at the time of screening, but may still go on to develop invasive cervical cancer in the following years (Healy et al, 2001).

According to epidemiological studies, some risk factors for cancer of the cervix are strongly associated with sexual activity. These include: number of sexual partners, age at first intercourse and sexual behavior of women's sexual partners. Studies have also shown an association between penile cancer and cancer of the cervix. Other risks are: tobacco smoking (nicotine metabolites can be observed in the cervical mucous), number of live births, deficient diets, and long term use of oral birth control pills. The latter has also shown an association with adenocarcinomas (Franco, Duarte-Franco, Ferenczy, 2001).

### **Cervical cancer and Pap test participation rates among Aboriginal women**

The estimate of new cases of cancer of the cervix in Canada in 2002 was 1,450 and 420 deaths occurred. Women diagnosed with cancer of the cervix are on average twenty years younger than women with other female genital cancers. On the average 26 years of life are lost per female patient dying of cervical cancer. It is estimated that in Canada alone 11,000 person years of life are lost. Although Canada was a pioneer in adopting organized screening for cervical cancer, compliance by most provinces in following the national guidelines calling for the implementation of program-based cytology screening is lacking. Opportunistic screening is the norm for early detection in most provinces and relies on cytology tests done at the discretion of family physicians.

A difficult challenge in any work targeted at prevention is getting a proper estimate of the rates of cancer of the cervix and screening patterns of Aboriginal women in Canada. Young et al, linked the data in the Manitoba Cancer Registry to the Manitoba Health Insurance Services population registry. The data contained payments to physicians for performing Papanicolaou tests between the years 1984-1997. The data contained information on women who had malignant cancer of the cervix. The criteria used for eligibility was taken from the 1989 National Workshop on Screening for Cancer of the cervix. The latter recommended that women be screened once every 3 years from the time of initiation of sexual intercourse to the age of 69 years. This method produced a cohort of local

women tested for a 3 year period and gave the number of Pap test for women during that time 1993-94 and 1995-96.

The results indicated that “Aboriginal women had 1.8 and 3.6 times the age-standardized incidence rates of in situ and invasive cervical cancer, respectively” (Young et al, 2002, p.1467). The incidence of cancer in Aboriginal women was higher in all age groups in all 3 regions (Winnipeg, south-rural and north-remote). “The age specific pattern differed between in situ and invasive cancer. There was a peak incidence of in situ cancer in the 20-34 age group. For invasive cancer, there was a linear relationship between age and incidence” (Ibid). Fewer Aboriginal women had at least one Pap test in the 3 previous years, except for females in the ages 15-19, than non-Aboriginal women. After age standardization 43% of Aboriginal women had at least one or more tests compared with 60% of non-Aboriginal women. In all 3 regions the rates of Pap tests were lower for Aboriginal women.

Cervical cancer rates are high in Native North American and Native Alaskan women. During the period of 1991-1996 the cervical cancer rate was the most common form of cancer among women in the Northwest Territories. The rate accounted for 35% of all cancers diagnosed and affected more Aboriginal women. The rate was higher in the NWT than the rest of Canada.

Among the most common sites for cancer in First Nations Status Indians (SI) women in Ontario are breast, cervix, lung and colon and rectum. In the non-Aboriginal female population the most frequent cancers are breast, colon and rectum, and lung. Cervical cancer ranks 6<sup>th</sup>. Formerly, the rate of cancer in First Nations was lower than the general population however the rates of cancer in First Nations communities are escalating and approaching that found in the general population. Cancer of the cervix occurs 73% more often in SI women than among all other Ontario females. Although the rate of cancer of the cervix is declining among the general population in Ontario it remains higher among SI women (Marrett, 1998).

### **Participation rates in Papanicolaou testing among Aboriginal women**

In a study by Hislop et al, cervical cancer mortality rates were linked to computerized personal Cervical Cancer Screening Program history files and band membership lists to determine participation in cervical cytology screening by Native women from 28 bands in British Columbia. Seventy-two percent (72%) of the women were located; over half of these returned for a recent Pap test. Results indicated that as women got older cervical

cytology screening decreased and leveled off between ages 40-59. Native women participated 30% less in cervical cytology screening than other women in British Columbia. (Hislop et al, 1992).

In British Columbia Haida women over 60 had fewer cervical screenings compared to non-native women. One method to improve the cervical screening rates of Aboriginal women would be improved computer information and recall systems and qualitative research to enlighten health providers with information about why participation rates in cervical screening among native women are low (Calam et al, 1992).

Aboriginal women in Manitoba were less likely to have had one Pap test in the previous 3 years. Only 43% of Aboriginal women compared to 60% of non-Aboriginal had received more than one test (Young et al, 2002). Only 50% of First Nations women compared to 85% of all other BC women had a Pap smear at least once in the previous 3 years.

Gupta et al (2003) note that preventive care using the rates of childhood immunizations by physicians and public health, mammography screening programs, and cervical cancer screening can be used as measures. The method used was longitudinal data, an immunization monitoring system and Canadian census data bases. The results showed that the childhood immunization program is well established across most socioeconomic strata with very little variation. Even with the positive results of a preventative care study, the rates for cervical cancer screening remained unchanged (low rates) and indicated a strong association in socioeconomic status with women of low socioeconomic status being lowest.

### **The Human Papilloma Virus (HPV)**

Unlike most cancers, cervical cancer has a central causal factor the human papilloma virus (HPV). HPV is an infection which may be a necessary cause of this disease and of its precursor lesions. Among the risks factors for cancer of the cervix are specific sexual behaviours, smoking, parity, oral contraceptive use, diet and HIV infection. Since HPV is so important to the development of cervical cancer (being a determinant factor), this section of the literature review focuses on HPV. It also outlines the debate over cervical cancer testing methodologies, namely HPV gene testing versus the more traditional Pap test.

Cervical cancer can be prevented through prevention of the Human Papilloma Virus (HPV). Health promotion aimed at sexual behaviour change and treatment of STDs can help. Of late, there has been much

talk about vaccination against HPV. Franco et al (2001) state that vaccination may have value in developing countries where 80% of the incidence of cervical cancer occurs every year and where Pap screening is not very effective.

The medical response to the high numbers of false-negatives, persistence of cervical cancer and fear of missing lesions has resulted in annual Pap tests and colposcopies for minor grade cervical lesions. The latter response renders the Pap test inefficient. Additionally, such practice has been known to traumatize women psycho-socially. For Aboriginal women located in remote areas, the cost can be prohibitive considering that a flight from a remote area to a hospital for a colposcopy can cost up to 2200 Canadian dollars (Franco, Duarte Franco, Ferenczy, 2000).

Primary methods for prevention include health education (sexual behavior modification) and vaccination to prevent HPV infection. Two types of vaccines for HPV are being developed: prophylactic vaccines to prevent HPV in the first place and therapeutic vaccines to induce regression of precancerous lesions or remission of advanced cancer of the cervix. The vaccines are being evaluated in different populations and appear to be promising however, wide scale use of the vaccines for use as a preventive strategy is more than a decade away.

Cases of progressive cancer of the cervix occur because of a false-negative Pap test result, or because a woman did not get a test at all, or was not tested enough. Many Canadian women do not have access to organized, centralized cervical screening despite well-developed recommendations and guidelines for the implementation and maintenance of cytology-based screening (Eduarte-Franco and Franco, 2003).

“Primary Screening of Cervical Cancer with Human Papillomavirus Tests” (Franco, 2003) presents comparative scientific studies of the HPV DNA testing and the Pap tests from various countries. The debate is, simply, since HPV is a *determinant* of cervical cancer, whether or not the HPV should replace the Pap smear in *detecting* cervical cancer. Although this technology would be more expensive to use, the HPV test in combination with the Pap smear would save the lives of more women. HPV is found in just about all cervical cancers.

A cross-sectional study (Healy et al 2001) conducted in the Baffin and Keewatin regions, where 80% of the Nunavut population resides, invited all women who had a Pap test between May 1 to December 31, 1999 to participate in the study. All signed consent and filled out a questionnaire in English or Inuktitut. The study was under the auspices of Queen’s



University Health Sciences and Affiliated Teaching Hospitals and licensed by the Nunavut Research Institute.

Seventy percent of all 1855 (n=1290) women who had a Pap test participated in the study and all age groups were represented. The ages ranged from 13 – 79 years with the mean age of 31 and the median of 28 years. Aboriginal Inuit comprised 86% of participants. The mean level of education was 11 years. Only 13% of the women reported never ever smoking, and 70% were current smokers and 17% were former smokers.

The overall prevalence of cancer producing HPV types was 25.8% and that of squamous intraepithelial lesions (SIL) was 6.9%. The prevalence of HPV was highest among the younger women under 30 and tended to decrease with age. The SIL among the Inuit women was found in 36% of women younger than 30. More than 90% of women with SIL had oncogenic HPV in their cervical specimens. Twenty-one percent of women with a negative Pap test also harbored oncogenic HPV. Infection rates were highest in the very young women under 20 years.

Studies have demonstrated that 99% of invasive cervical cancer is positive for the HPV DNA, which has intensified interest in the use of HPV testing in place of the Pap test. Persistent infection with specific oncogenic (cancer causing) HPV types has proven to be an independent risk factor for the development of cervical cancer and its precursors. Many epidemiological studies have shown that more than 90% of HPV tests reveal the presence of high- grade squamous cell intra-epithelial lesions. At the same time, the predictive value of a negative HPV and negative Pap test is greater than 96%. (Healy et al, 2001).

### **The debate over HPV DNA testing versus the Pap test**

Given the strong correlation between the HPV virus and the presence of cervical cancer, new testing methodologies which focus more on HPV are being developed.

A conference news release on the CBC (“Specialists weigh the value of new cervical cancer test”, CBC, 2003) cited that a new technology called HPV-DNA testing is currently in use to detect the human Papilloma virus the causative factor for just about all cervical cancers. Right now research is looking at combined Pap Smears and HPV–DNA testing. Such testing, although more expensive means those women would have the test once per year. The test is promising and Dr. Gavin Stuart (head of the Cervical Cancer Prevention Network in Vancouver) cautions that the largest barrier

contributing to death in cervical cancer lies in the fact that women are not screened at appropriate intervals after abnormal cervical cells are found following Pap smears.

According to Dr. Robert Lotoki, the fact that only 55% of women in Canada have a regular Pap test and that the HPV-DNA test is less invasive, suggests that the newer HPV-DNA tests could encourage more women to go for testing. In the future an HPV-DNA test may only require a self-administered test using a swab or tampon that can be assessed in the lab.

The most frequent sexually transmitted diseases are HPV infections. For women of reproductive age 5%-40% can have asymptomatic HPV. This infection can be transient or intermittent. There are many types of HPV and the chance of a woman having the same type at another time is small. The condition of persistent infections results in the risk of cervical intraepithelial neoplasia (CIN) and is proportional to the number of positive findings for HPV (CBC 2003).

There are limitations to cytology screening. For instance, as many as half yield false-positive results. Up to one third of false positives are attributed to errors in interpreting slides and two thirds to poor sample collection and slide preparation. The Cervical Cancer Prevention Network, a coalition of federal and provincial representatives, is focused in identifying barriers, needs and new directions in the development of organized cytology screening. A category for classifying borderline low grade lesions called atypical squamous cells of undetermined significance (ASCUS) has resulted in finding low grade lesions. Some women have hidden high grade squamous intraepithelial lesions (HSIL) and low grade intraepithelial lesions (LSIL). Much debate is made over the management of LSIL as to whether it should be conservative or interventionist. Studies are underway to assess whether HPV testing could improve the detection of missed HSIL among women with an initial diagnosis of ASCUS or LSIL.

Should HPV testing be just an adjunct to the overall screening method? Some experts say cytology screening alone is enough. Those for HPV testing say that it is a sound approach for secondary prevention in developing countries where it is difficult to implement high quality cytology. The International Agency for Research on Cancer (IARC) and the World Health Organization (WHO) state that HPV testing and screening is a justifiable strategy.

## **Screening –effectiveness, barriers and strategies**

An inquiry into the literature indicates that getting Aboriginal women to screen for cervical cancer is problematic. This is by far the most important issue that the literature review revealed. A 2006 study among Native American women in the US reported that only 60.76% of the women in the study had a Pap smear in the previous 24 months and 39.3% reported having a mammogram in the previous 2 years. These rates fall far below screening rates for Non-Indian women in the US where 72% have a mammogram and 78% have a cervical cancer test (Becker et al).

As with other health problems among Aboriginal people, the health care system presents barriers to cervical screening. There are lengthy delays between screening and referrals for follow-up, high staff turnover and it can be difficult to get timely clinic appointments.

Jurisdictional issues related to the delivery of services for off-reserve natives affect participation in mainstream services. Treaty Indians may have to deal with band, municipal, provincial and federal levels of government in order to secure medical services (Aboriginal Nurses Association of Canada, 1999). Other factors that interfere with recruitment are geographical location, and location of treatment based on physicians' influence (Adams et al).

Non-participation in Pap Smear Tests was related to a lack of awareness, shyness and discomfort in discussing and undergoing the procedure (Clarke et al, 1998). First Nations women are reluctant to go for cervical screening due to the lack of culturally suitable services. Moreover, better communication about Pap smear testing is needed, as is a greater awareness of cervical cancer. Women need affordable access to services such as transportation and childcare (Clarke et al, 1992).

On the other hand, health care providers need an increased awareness and understanding of cultural concepts of cancer and its prevention and sensitivity to cultural behaviors (Young et al, 2001; Fernandez et al, 2000; Adams-Cameron et al,1999). The shortage of primary care providers means that a woman does not get consistency or continuity of care. Moreover, their preference for female providers may be denied. In communities other health care priorities take precedence over women's health. Transportation and distance from care are factors in accessing screening programs, as is lack of knowledge of the benefits of screening and fear of cancer (not wanting to know about cancer or results of tests). Some communities lack telephones thus communication is a barrier to

participation in breast and cervical screening programs (Salmon and Kaur, 1996).

Research and interview questions are often perceived by native people 'as being too personal, intrusive and an invasion of privacy'. Such questions come to light in the following quotation: "Like which kinds of groups that I belong to and details of my sexual life". This form of inquiry resulted in refusals to participate in one project. Another barrier to Pap testing is that screening is a preventive behavior that conflicts with the cultural belief that one does not go to the doctor unless one is ill.

Other factors negatively affecting participation rates are local/seasonal economy activities. Indian Health Services is the only health care available to the Native American Indians and they can harbor negative feelings about certain practices. For instance, participants referred to difficulties in obtaining medical appointments (having to wait for hours despite previous appointments, the 9-5 office hours, etc.). Record keeping practices and policies are not understood. Moreover, there was a feeling that information given to health care providers was not confidential. Urban natives complained that the mainstream health care providers treated them badly thus preventing women from attending a systematic service that is fundamentally "discriminatory" (Michielutte et al, 1995).

Grunfeld (1997) indicates that since the introduction of the Pap test rates of cervical cancer have declined dramatically. However, some groups of women continue to die from this form of cancer. In 1997, Aboriginal women had 6 times the rate of cancer of the cervix in Canada compared to women. Fifty percent (50%) of women who develop invasive cervical cancer had never had a cervical screen and women at low risk are over-screened. Interviews and focus groups with immigrant and Aboriginal women revealed that some reasons for non-attendance at screening were lack of knowledge about the importance of screening, staff turnover, embarrassment, and discomfort— especially with male physicians

Grunfeld also notes that the physicians in the recognized Buehler and Parsons study actively promoted screening to their female patients and as such provide a role to be emulated by other health care practitioners. The latter can promote both opportunistic and regular cervical screening to their clients. Lack of a consistent primary care physician is also cited for not having a Pap test. Women in some ethnic groups have access to a regular nurse practitioner and this increases their participation in screening programs.

The following summarized literature explores themes of culture, ethical considerations, health promotion and recruitment, and education, thus indicating barriers and effectiveness of strategies.

### **Finding the cultural meaning for cancer**

Fitch et al (2004) examines the influence of knowledge, attitudes, beliefs, and practices in participation in breast and cervical screening among ethnic groups in Northwestern Ontario. The data showed that Ojibwa and Oji-Cree women were less likely than other women to perform BSE, to refuse CBE or mammogram, to not have been told how to do a BSE, to not have been given written information on how to perform BSE, and to be uncomfortable and fearful about cervical screening procedures. As compared to 0-8% of the other ethnic groups in the study, 33% of native women refused an internal examination.

The conclusion was that cultural beliefs, attitudes and practices of marginal populations such as native women are a necessary part of planning strategies to address barriers to effective breast and cervical screening. This study validates the need for educating nurses about cultural sensitivity and participants of screening programs.

Efforts have been made to develop and implement culturally sensitive cervical cancer screening methodologies (Smith et al 2004). For instance, The Apsaalooke (Crow) are located in Southeastern Montana. Tradition is important and permeates all aspects of life. Language retention is high. The Northern Plains tribes have the highest rates of mortality due to cervical cancer and low participation in Pap tests screenings related to cultural, social and economic reasons. One example of positive intervention is the "Messengers of Health" program which aims to increase participation rates in Pap tests through teaching native women about cervical cancer.

Thirty percent (n=305) of the women did not know about a test to check for cervical cancer. Of the participants, 35% had not had a Pap test in the past year. Fourteen (14%) had not had a Pap test in the past 3 years. The responses to risk factors indicated that 54% of the women did not know that sex at an early age was a risk. As well, 29% did not know that multiple sexual partners is a risk factor and 14% did not know that a woman can do something to prevent cervical cancer.

The work of this study provides guidance for cervical health education of the Apsaalooke women through increased understanding and knowledge

of cervical health and the areas that need to be addressed. Further, the information about risk factors and recommendations for Pap tests provides the “Messengers” with information to educate women in a culturally sensitive way. Moreover, implications emerged about their role to act as liaisons between women and health care professionals in making appointments and reducing barriers by providing childcare and transportation. Information also helped to create outreach. “Messengers” are women whom other women can talk to about cervical health.

When a gentle, well-trained interviewer administered the survey, items that were not viewed as culturally sensitive became “acceptable” to the respondents and therefore the information collected was more accurate” (p.82). Cultural nuances can also be inadvertently ignored or not understood even though input from a community is sought. In this study researchers were white and the native researchers were not Apsaalooke and their values and attitudes were different from the participants. Thus shared meaning and shared values may be absent regarding items chosen for the questionnaire (Plas and Bellet 1983).

Hodge et al (1996) indicate that the use of the talking circle along with traditional Indian stories that emphasized positive roles and values in Indian culture proved positive because the preferred form of communication in hard to reach populations is the talking circle. When sharing, participants have the chance to talk about their fears, concerns or needs. In the circle, a participant has centre stage and can talk without interference from others. While the talking circle in this project provided support for women it also was accompanied by story telling which related to health behavior in general.

Anthropological field concepts were used to explore data in this study. The focus groups (talking circles) exposed health care beliefs and attendant behaviors as well as the barriers to cervical cancer screening. Modesty, taboos and use of traditional healing practices are important elements among American Indians. “Witching, evil spirits and elements beyond one’s control were identified as possible etiological causes of cancer.” (p. 1595) Women’s level of education, concepts of disease, communication styles and health beliefs, fear of cancer and its consequences prevent women from attending follow up Pap smear sessions. As well, poverty, substandard housing and unemployment often take priority over preventive health practices.

“The use of traditional healers indicated that women seek native healers for female problems and for issues surrounding pregnancy and child birth” (p.1595). Women revealed that consulting a traditional healer does not

interfere with western medical practices. Women did not like to report their use of traditional healing practices or beliefs in great detail. They considered these were private matters not to be discussed. The cultural healing practices of these northern Californian Indians include use of native language, consulting native healers and reliance on traditional ceremonies.

Emphasizing aspects of traditional health and/or healing cause one to become aware of possible differences in perception in a patient/physician encounter. The patient physician relationship is complicated by issues of communication problems and health care system policies and procedures. When women are encouraged return for screening they find that the health system puts up barriers so that women do not comply with the physician's orders. Long delays between screening and referrals for follow up, high staff turnover and the inability to get timely clinic appointments contribute to poor attendance for pap screening and follow up. Expectations on a doctor may be unrealistic and ways of communication may prove an impediment to true understanding in the provider-user encounter. Issues of modesty are often misunderstood or ignored by physicians. Native women are not direct in their communication thereby requiring more time and more prompting during a medical appointment.

The result of this project was the development of a tool based on information gathered which was utilized in a replicate study. The tool (survey) consists of data on demographics, cancer history, knowledge, attitudes and beliefs, quality of life issues and acculturation patterns.

"Talking Circles: Northern Plains Tribes American Indian Women's Views of Cancer as a Health Issue" (Becker et al) also indicates the benefits of utilizing a talking circle to increase comfort levels for American Indian women during screening for cervical cancer. In this project, the effect of using a cultural healing practice and using community workers as researchers in populations at risk was documented. In order to understand the low attendance at breast and cervical cancer screening, researchers believed it necessary to find out negative thoughts and feelings about cancer found within the context of the Talking Circle. In keeping with cultural tradition a respected female spiritual leader who was an expert on intra-group communication patterns and traditional symbolism was chosen to lead the groups.

The following were some of the themes that emerged during the talking circles:

*Native Indian languages have no name for cancer.* “The word cancer is threatening and damaging as well as final” in the way that it works. Moreover, cancer can impoverish one because of the cost of treatments and drugs and supportive services. This is true especially if you do not have insurance, or the Indian Health Services doesn't pay.

*Life with Mother Earth is only part of the continuum.* There is the belief that one must take what comes to you in life as well as perspective that cancer is beyond one's control and that you have to eventually die of something. Other ideas were living in the present, not dwelling on illness or negative events and not visiting a health provider unless one is ill or pregnant.

There is *Non ownership of the cancer disease.* Women do not get biomedical information on how cancer occurs. Women explained a non-acceptance of cancer through their beliefs that early detection and or preventive measures are not understood or valued.

*Others take priority.* Women felt that they should take better care of themselves for their families sake and if women had cancer they have a hard time deciding who to look after; themselves, or their family. Respect for the needs of others and care for the extended family is a strong factor distracting women from self-care.

*Pap smears mean sexuality, trauma.* Pap tests were often depicted as events associated with intense psychological barriers —rather than breast exams or mammography. Women did not feel comfortable talking about personal experiences such as incest or rape, and when they did it included experiences about Pap tests. The trauma associated with Pap tests were difficult to talk about and is not a priority for activism. Shame and humiliation were associated with Pap tests. Testing by male providers presents a problem, as well as having to go to a new health care provider each time.

*Lack of trust* was a prevalent theme with regard to existing injustices within the health care system. This refers to scheduling, tests, and rules about having mammograms and breasts exams and pap tests at the same time. There was a need for flexibility because these routines/regulations are barriers to screening.

*Significant others play an important role* in the process. The women who had received a mammogram in the previous 2 years were motivated through the encouragement from significant others especially family, friends, elders and health providers who reminded them to attend scheduled women's health exams and/or advised them to keep healthy.



Women's health perspectives took the lead in this study which shed light on how the health care system's approach to scheduling cancer screening procedures places barriers on more robust participation levels. Screening services are perceived as prescribed procedures leaving no choices or preferences for women. Services are often arbitrarily assigned to suit the health system— such as a woman must get a breast exam before having a mammogram. A Pap smear may be scheduled on the same day as a breast examination as part of “women's health day” and this arrangement may be perceived as personally traumatic for some women. In this way, the Pap smear can be a psychosocial barrier to a mammogram or vice versa.

With respect to an academic research methodology, qualitative research is the one that often addresses issues of cultural relevance. Strickland (1999) emphasizes this fact in his study: “The Importance of Qualitative Research in Addressing Cultural Relevance: Experiences from Research with Pacific Northwest Women”. Two participatory research studies were conducted with two different tribes to investigate the influence of culture on health related behavior, one (the Yakama) on cervical screening participation and the other on pain management (the Nooksack).

This qualitative inquiry was able to illustrate that the women wanted: (a) a holistic education covering needs across the life span, (b) positive messages about cancer like informing women how to take care of themselves and (c) information to benefit the whole community. The women were looking for a “wellness approach” rather than a disease oriented model. Additionally, educational activities should integrate cultural activities appropriate to Yamaka traditions.

### **Health promotion and recruitment**

Strickland et al (1999) conducted a health promotion study amongst Yamaka women in Washington concerning health promotion and the influence of religion on community values and health beliefs. The purpose of this research was to design a community-based cervical cancer prevention screening program utilizing concepts and practices of Wa'Shat Longhouse religion and ultimately provide relevant concrete examples for the practice of trans-cultural nursing.

The Yakama people have retained some of their traditions in the transition to the present. Many people speak the original mother tongue and follow the old spiritual practices. The latter is the Longhouse or Wa'Shat religion

also known as the Drummer and Dreamer religion and the Indian Shaker Church. Today, the Longhouse is where the Yamaka people hold traditional celebrations, meetings, recreational and educational activities, religious ceremonies and funeral services. The Wa'Shat is a sacred dance introduced by Prophet Smohalla as a means to restore the country to the native people. Today the Wa'Shat religion is tribal or indigenous religion of the Yamaka people. This cultural knowledge was operationalized to meet the project goals.

The program planning goals of a community-based health promotion for a cervical cancer prevention program focused on women and health providers. These were holistic and wellness oriented as opposed to disease centered. For instance, ones that addressed women across life-span. The women's wellness program was framed to honor self care for the good of the community, promote healthy lifestyles, diet, exercise, healthy relationships, respect, and protection of the land; and regular Pap tests and mammograms within the context of the people's religious beliefs. According to Longhouse beliefs disease is the result of a personal imbalance (loss of a sense of identity) and nature (environment). Prevention strategies then would be directed to restoring balance. "A holistic approach is a return to traditional ways, eating traditional foods, exercising, having good relations with others, drinking water, learning from nature, and protecting the gifts of nature" (p. 193).

Cancer prevention aimed at health providers urged that failure in communication meant that women missed Pap tests. The health provider must work on facilitating communication with the elders and traditional women about Pap tests. The providers also had to understand the Longhouse beliefs about the body, keeping healthy, prevention and illness and death.

Education of health providers must include facilitation of the acceptance of a Yakama woman's spiritual beliefs such as not wanting to give up any part of the body. So a nurse will not say "I'm going to take away a few cells" while explaining the Pap test as a woman might just leave. Another example is that "fear of death" is not a good prevention motivator for Indian people as it is seen as a natural part of life.

The Northwest Portland Area Indian Health Board (2001) created a program to increase the number of native women attending breast and cervical cancer screening. The purpose of the project is to reduce mortality rates from breast and cervical cancers through the recruitment of women for screening programs to enable early detection and treatment. The women's health promotion program was formed through partnering of

nine federally recognized tribes and two Indian Health boards who developed a four year strategic plan. In 1999, its 4th year of operation, the goals were to: gather what works for outreach programs, create education and screening targets among the tribal groups and make these programs known through publication media. Additionally, the project sought to identify successful strategies for designing an outreach plan honoring traditional ways and values for Indian women so that they may benefit from early breast and cervical cancer detection. Other health promotion goals included the planning of an Elders conference, promoting routine screening and developing ways of measuring progress toward screening goals.

Health promotion often goes hand in hand with recruitment. The Breast and Cervical Cancer Mortality Prevention Act (1990) authorized the Centers for Disease Control and Prevention to set up the National Breast and Cervical Cancer Early Detection Program (hereafter referred to as national early detection program; Henson, Wyatt & Lee, 1996) to promote cancer screening among low-income and minority women in the United States. Through this initiative, low income uninsured and under-insured women have improved access to screening and diagnostic services for breast and cervical cancer (Lantz et al, n.d.).

Subsequent to this act, in 1993 Congress extended the legislation to include tribes, tribal organizations, and urban health centers that serve American Indians and Alaskan Natives. As a result 15 tribes were able to implement breast and cervical cancer early detection programs from 1995-99. Data from the tribal programs to the year 2000 indicated that 30,547 mammograms to 16,859 women, and 56,995 Pap tests to 25,333 women. One hundred and forty-eight (148) cases of breast cancer, 168 cases of cervical intraepithelial neoplasia III or in situ cervical cancer and 5 cases of invasive cervical cancer were found (Orians et al., 2002).

Lance et al conducted a study in partnership with the first 15 tribal programs that were funded to determine how tribal programs adapted the national program for the women in their communities (1999). The research focused on two specific questions “(a) How have tribal programs in the National Breast and Cervical Cancer Early Detection Program organized and implemented the service delivery component of the programs and (b) What strategies were used by tribal programs to address challenges in the start-up and maintenance of clinical services?” (p.677). The audience for the study is an international one for those targeting indigenous women or marginalized groups owing to culture, geographic isolation and/ socio-economic factors.

The 6 challenges identified were:

(1) Designing/implementing a screening service delivery model to fit the population being served and the health care system in which the program would operate. The two models that emerged were a screening clinic model and an integrated model. The screening clinic model offers cervical and breast screening and educational services during special clinic or specific times in existing clinical settings.

(2) Increasing access to mammography screening. There are limited resources, and Travel and long waits are involved so the challenge is to bring mammography to places where women feel comfortable. Some programs combine Pap tests and breast screens at the same time or use mobile mammography units.

(3) Securing the support and cooperation of providers and other staff in busy clinical settings involves a change in mind-set. Staff are oriented to acute care and not prevention so they need to be educated. Support includes referring appropriate women to the program, getting appointments scheduled at appropriate times, having an allocated space for screening and educational activities, and gathering data from records for tracking and follow-up activities.

(4) The need to provide culturally sensitive care (language included) emerged from all sites. One respondent stated “Many Indians believe they get second-class care and they expect it, you have to build trust with the people you serve”. Thus, culturally appropriate care was defined as services settings where women feel comfortable and respected.

(5) Providing Diagnostic Services varies across programs and types of service. The waiting times can be lengthy and can involve traveling long distances. Some programs have purchased equipment such as colposcopes and ultrasound machines for clinic sites thus allowing for greater capacity in diagnostic follow-up. Case management is an essential strategy used for women requiring follow-up diagnostic tests for coordination of care outside local delivery system.

(6) Providing treatment services is a challenge as the National Breast and Cervical Cancer Early Detection Program does not cover any component of treatment. Travel can be more expensive than surgery, radiation, and oncology services. Secondly, treatment may require review, prioritization and approval through tribal contract health systems before any money is committed.

## Education

The Lumbee are the largest tribe east of the Mississippi River and are recognized by the state and not the federal government. The study by Dignan et al (1998) concentrated on the integrated Lumbee tribe residing in Robeson County, NC. Medical care is provided by local private health care providers, the county public health department and from a non-profit health care corporation.

The value of lay educators in cancer education was indicated by this study in evidence of slightly higher levels of change in knowledge and intent to get the Pap smear than mass media-based and group-based education programs. Although intensive individualized intervention affected behavior change, it was minimal. Other factors that played a role in the success of the program included education, income, ethnic identification and access to health care. Notably, those at highest risk did not respond positively. This project confirmed the need for health education among women with low educational levels, limited income and limited access to health care.

The program consisted of an in home individualized education session from a local Lumbee lay educator regarding the Pap smear, the importance of follow-up when indicated and access to health care.

Native Women Enjoying the Benefit (WEB) is a program that trains nurses employed by Indian Health Services (IHS), tribal clinics and other underserved populations to conduct breast exams and cervical screening. The program also teaches Community Health Representatives to carry out outreach and education. A study by W.O Petersen et al (2002) illustrates how the WEB program overcomes barriers to screening for AI/AM women by reducing intercultural and intracultural obstacles as well as barriers for RNs and LPNs in performing screening exams. Further research will validate perceptions that more women are being tested through electronic tracking.

The barriers to participation in breast and cervical cancer screening are numerous for American Indian women. First, there is funding. Over one-hundred tribes are not federally recognized and do not get receive subsidized health services. Their members may not have health insurance. IHS covers only 60% of health services for tribes-people, and the 50% who live off reserve only receive about 2% of IHS budget. Other barriers to cancer screening are found in the under utilization of clinic staff, shortages of trained female and Alaskan Indian and American Indian staff. High staff turnover, scheduling difficulties, and lack of mammogram equipment exacerbate the problem. Insufficient attention is paid to patient

education and the development of culturally appropriate materials. There is pervasive misperception of the risks for breast and cervical cancer among AI/A women. Additional barriers to participation in screening programs relate to socio-economic and socio-cultural factors as well as perceptions of nurses' roles.

Screening programs were threatened based on failure to recognize and make concessions to accommodate language, verbal and non-verbal communication, traditional beliefs, values, and practices that differentiate tribal perspectives from more mainstream ones. Other factors included distance, transportation, communication difficulties, and literacy.

The role of nursing is changing to meet current trends in health care from a traditional, subordinate service orientation into one that also includes health promotion and, more recently, to fill critical roles left vacant by physicians and nurse practitioners. Indeed, the nurse's role changed as a result of the training. Women preferred to come to a female for screening examinations. Women understand and respond to other women and women tended to indicate that the WEB trainees were more thorough than other providers. Encouraging women to take care of themselves is one thing women like to hear.

It was found that Native women are more willing to be screened for cervical cancer as a result of WEB. Indicators of this include: women requesting a female examiner; women expressing comfort, security, and satisfaction with the service as well as women's word of mouth promoting the importance of screening to friends (p.73). An enhanced awareness was found in the following indicators: knowing screening was available and useful, recognizing the value of early detection, Tribal Elders awareness of cancer risks, knowing about breast cancer, less fear of the unknown, seeking out self-care and prevention activities, being comfortable in talking about breast and cervix cancer and accepting that it is all right for them (women) to initiate screening appointments" (p. 75). One nurse cited that at a health fair one young boy stopped by the breast exam booth and commented "that's how my mom found out she had cancer" (ibid) so the news was out in the community.

In another study by Petersen et al (2004), the training of community health representatives (CHRs) is similar to the WEB nurse training previously discussed. For the CHRs, a five part curriculum is covered including: didactic lectures, discussions, demonstrations, simulations, practice sessions and provides print materials. While proficiency in screening is the focus of nurse training, the emphasis for CHRs is content teaching/promotional skills.

The CHRs in the study were resident tribal members, females, and community employees. CHRs know the cultural ways and communication styles of the communities they work in. They are skilled in how to communicate with fellow residents and can bridge communication barriers between various Native and non-Native concepts. They can deal with sensitive information and help women adopt screening behaviors that are more Western than traditional. CHRs provide information in a variety of settings and to diverse audiences which is necessary in rural locations. They encounter language and literacy issues and a myriad of obstacles all of which lead the development of creative strategies and adaptability to get the message out about cancer. CHRs meet women individually, in homes, in groups, in churches, automobiles, classrooms and libraries.

Following training CHRs increased their monthly health promotion sessions and interactions with women. Prior to the training they met with an average of 64-84 women per month (3-4 per CHR) and post-training they met with 211-235 women (11-12 per CHR).

The CHRs reported an increase in women's screening participation and interest in breast and cervical cancer. At the same time, they held perceptions that many women were still not being reached. However, they believed they were more effective in reaching and influencing women.

Tribal facility expectations for breast and cervix cancer education activities and screening increased after the WEB training. The CHRs viewed their facilities as slightly more supportive of their efforts by providing sufficient time for health promotion but insufficient resources and funding to meet facility expectations.

The CHRs were American Indian women who had the longest length of employment among health care providers with Indian Health Services and tribal health clinics. They shared common identities with the women they served which positioned them to broach sensitive topics that fit into culturally acceptable modes for AI/AM women. CHRs are adept and creative in meeting educational needs on an individual, or group basis. These are characteristics cited in many studies for successful health promotion (the use of volunteer lay health educators and lay health advisors and community health educators or workers who work with diverse cultural and ethnic groups). CHRs' perceptions are positive and associated with desired changes in their role, facilities' activities and in women's screening related behaviors.

CHRs can play a complementary role “not only of convincing women of the importance of being screened, but they can also work to create a demand that ensures women use the screening capacity available when trained nurses conduct the screening exams” (p.242).

## **Summary**

The cervix is the tubular passage connecting the bottom of the uterus to the top of the vagina in the female reproductive system. Two types of cells are found in the cervix, thin flat cells (squamous cells) and epithelial cells that secrete mucous (adenosquamous). Most cancers are of the squamous cell type (in situ) and 10% are of the adenosquamous (invasive cancer). Cancer of the cervix represents 10% of all cancers affecting women worldwide, and is prominent in developing countries. One third of the women diagnosed with this cancer died in Canada in the year 2000.

The burden of disease is significantly greater for Aboriginal women whose incidence of cancer of the cervix and mortality rates related to it are high compared to mainstream statistics. Aboriginal women are often diagnosed in the later stages of cervical cancer which is unfortunate because cervical cancer is preventable. Access is a major problem for Aboriginal women not participating in cervical cancer screening. Jurisdictional issues where one has to traverse many levels of government in order to secure medical services presents barriers as do geographical location and availability of transportation.

The risk factors for cancer of the cervix are strongly correlated to sexual activity. These facts may stigmatize women and cause shame that may prevent women from seeking appropriate information and help. The risks include number of sexual partners, age at first intercourse and the sexual behavior of women’s sexual partners. Smoking, number of live births, deficient diets, and long term use of oral birth control pills also are risk factors for cervical cancer.

New research has found that the human papilloma virus is a primary causal factor and, thus, a determinant of cervical cancer. HPV is higher among women under 30. This has implications for large numbers of young Aboriginal women. While the United States approved the use of the HPV vaccine for 12 year old females as a preventive strategy to combat cancer of the cervix, Health Canada has not followed suit.

The challenge in the battle against cervical cancer lies in the recruitment of Aboriginal women to participate in cervical cancer screening programs and this will linger for a long time. Barriers to cervical screening are



numerous and range from not having a primary care physician, lengthy delays between screening and referrals for follow-up, high staff turnover, and the inability to get timely clinic appointments. Negative encounters with health care providers result in major communication problems related to cultural differences. Modesty is an Aboriginal value that is often ignored by physicians and other health care providers.

Psycho-social obstacles include: shyness in discussing and undergoing the Pap test procedure, lack of child care, no female examiners, no telephone, lack of information/knowledge of the benefits of screening, no privacy, intrusive questions with concomitant fear of disclosure of information to others, fear of cancer and 'not wanting to know about cancer or results of tests prevent women from attending screening programs.

Some researchers have focused on finding the cultural meaning of cancer and developing strategies to conduct culturally appropriate research tools. For example, some have looked at the use of talking circles and native religious and spirituality practices.

Promising new approaches for the recruitment of women to cervical screening involved training programs for nurses to perform Pap tests and for community health representative (CHR) to carry out health promotion activities. The use of lay health educators showed great potential as well.

Low rates of participation among Aboriginal women are clearly related to a lack of awareness among health planners of community and cultural variables. It is clear that above all else community members, leaders and health workers must be involved in efforts aimed at increasing the effectiveness of screening programs for cervical cancer.

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