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Onion Lake First Nations Women: Knowledge, Attitudes and Health Beliefs of Cervical Cancer and Cervical Cancer Screening

By

Tina Marie Wilson ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfilment of the requirements for the degree of master of nursing

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ABSTRACT

Canadian First Nations women utilize cervical screening programs less often or not at all when compared to other Canadian women and due to this are at a greater risk for developing and dying from cervical cancer.

Factors that influence women's participation in screening programs include cultural health beliefs, feeling physically or psychologically uncomfortable, especially with male physicians, and feelings of embarrassment. Little research has been done that examines the possible reasons why First Nations women do or do not obtain cervical screening tests. The purpose of this study was to explore the knowledge, attitudes, and health beliefs of cervical cancer and cervical screening among First Nations women residing in Onion Lake Saskatchewan.

Eight First Nations women who had experience with cervical screening participated in the study. Open-ended interviews took place at each woman's convenience and occurred in their own chosen location. Each interview was taped recorded and transcribed verbatim. Data analysis occurred throughout the data collection process. Key concepts were identified and coded. Major themes and sub-themes were identified and coded within each interview as well as across the interviews.

The identification of cultural beliefs, values, and customs among First Nations women is vital for the development and implementation of effective screening programs and therefore the Health Belief Model was used to explain the health beliefs of First Nations women and to provide additional suggestions for increasing participation in screening programs.

The women shared their thoughts and feelings about cervical cancer and cervical screening. As well, the women shared their experiences with cervical cancer, abnormal cervical screening tests, and with cervical screening tests in general. Many of their reactions and behaviours were described by previous researchers such as feelings of being uncomfortable when the test was done by a male physician, and a desire for more information about cervical cancer.

This discussion includes the implications that the findings have for nurses. In addition, the Strong Model of Advanced Practice, which incorporates 5 domains of practice, including, direct comprehensive care, support of systems, education, research, and publication and professional leadership, was used to assess the role of the advanced practice nurse in improving the cervical screening rates among First Nations women.

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I would like to express my appreciation to the many people who supported me through this research study. First are the women who shared their personal experiences with me and who gave of their time. It was a privilege to hear all their stories. Without the participation of these women this study would not have been possible.

I would like to thank my thesis committee who supported and guided me through this study. I learned so much from all of you and greatly appreciate your patience and knowledge.

Lastly, I cannot thank my husband enough. His encouragement helped me reach my goal.

Dedication

This is dedicated with gratitude to the women who volunteered to participate in this study and share their thoughts, feelings, and knowledge with the hope that this information may help other First Nations women.

It is dedicated with great love to my husband who supported and encouraged me through all of my studies. Thank you.

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CHAPTER I: INTRODUCTION

Statement of the Problem

"Cervical cancer is one of the few readily preventable forms of cancer" (Noorani, 1997, p. Executive Summary). Deaths due to cervical cancer have decreased since the introduction of cervical screening for pre-cancerous lesions (Foulks, 1998). Nevertheless, women continue to be diagnosed with, and die from, this potentially preventable disease. In Canada, for the year 2001, an estimated 1450 new cases of cervical cancer were detected and 420 women died from cervical cancer (National Cancer Institute of Canada, 2001). Although cervical cancer and associated mortality are relatively uncommon compared with other types of cancer in Canada, it is the eleventh most common malignancy in women (Noorani, 1997).

The Papanicolaou Smear (Pap test) continues to be one of the most effective available tools for the early detection of cervical cancer. It has been estimated that 50 percent of women who have been diagnosed with cervical cancer have never had a Pap smear, or have not had one for 10 years or more (Beers and Berkow, 1999). Since its introduction in Canada in 1949, the Pap test has decreased the incidence of, and mortality due to, cervical cancer (Miller et al., 1991). Screening for cervical cancer is very effective for the early detection of preinvasive and invasive cancer (Beers and Berkow, 1999), and the impact of cervical cancer can be minimized if women who are at risk regularly participate in early detection programs.

It was reported in an editorial in the Canadian Medical Association Journal (Grunfeld, 1997) that despite the value of screening, many Canadian women particularly hard-to-reach groups such as native, elderly, poor and immigrant women are underscreened. For example, the incidence of cervical cancer was found to be 10 times higher in status Indians in a study conducted by Saskatchewan researchers who linked the health insurance system with the provincial cancer registry (Gillis et al., 1990). Authors of other studies have reported that First Nations women do not utilize cervical screening programs or utilize them less often than other cultural groups (Hislop et al., 1996; Strickland, Chrisman, Yallup, Powell, & Squeoch, 1996; Mahmoodian, 1997). Barriers to cervical screening may be identified by qualitatively exploring knowledge, attitudes and health beliefs associated with cervical cancer and cervical screening in First Nations women. A research priority includes the identification of barriers to screening, which will increase understanding of the reasons why women do, or do not participate in screening (Miller et al., 1991). Furthermore, it has been reported that understanding health behaviour in a cultural context is vital if the health status of high-risk groups is to be improved (Strickland et al., 1996; Weaver, 1999).

Research Question

The research question that guided this study was: "What are the knowledge, attitudes, and health beliefs of First Nations women, in Onion Lake SK, concerning cervical cancer and cervical screening?". A qualitative approach, using indepth and open-ended interviews was used for the study.

CHAPTER II: LITERATURE REVIEW

Cervical Screening in First Nations Women

It was reported that First Nations women in Canada and in the United States have a higher risk for developing and dying from cervical cancer when compared to the general population (Young & Choi, 1985). Canadian researchers (Young & Choi, 1985) performing a descriptive epidemiologic study of malignant neoplasmas among residents of Indian reserves in Manitoba reported that First Nations women had a greater risk of invasive cervical cancer than the provincial population. During a more recent study in Manitoba, researchers linking the provincial cancer registry, the population registry, and the registry of health insurance claims, reported that First Nations women had 3.6 times the age-standardized incidence rates of invasive cervical cancer and 1.8 times the rates of in situ cervical cancer compared to non-First Nations women (Young, Kliewer, Blanchard, & Mayer, 2000). Furthermore, only 43 percent of First Nations women had had 1 or more cervical screening tests compared to 60 percent of non-First Nations women between 1993 and 1996 (Young et al., 2000).

In a retrospective analysis of data from the British Columbia (BC) Division of Vital Statistics (BCDVS), it was reported that First Nations women had a mortality rate from cervical cancer that was 6 times higher than the rate among other BC women (Band et al., 1992). The BCDVS included data on all deaths in BC from 1953 to 1984, and these researchers concluded that the significantly higher death rates of First Nations women due to cervical cancer was related to the underutilization of the provincial Cervical Cytology Screening Program

(CCSP). In a study in BC, linking CCSP registry data and Band membership lists, it was reported that First Nations women, aged 13 to 59 years, had approximately 30 percent lower rates of participation in the CCSP (Hislop, Deschamps, Band, Smith, & Clarke, 1992).

Investigators in BC used a qualitative design, that included interviews and focus groups, to assess barriers to cervical screening in ‘under’ and ‘never screened’ First Nations women (Clarke et al., 1998). The participants reported embarrassment or feeling physically or psychologically uncomfortable, especially with male physicians. These feelings resulted in women being less likely to participate in the cervical screening program. There is a need for cancer control strategies that are sensitive to the culture of Canada’s First Nations women.

Following an analysis of the 1994 National Population Health Survey (NPHS), it was found that although the proportion of Canadian women who have never had a Pap smear remained constant from 1985 to1994, Pap screening continued to be underused by a large proportion of women, including young women, aged 18-24, and older women, aged 65 and over (Snider, Beauvais, Levy, Villeneuve and Pennock, 1996). In addition, these researchers noted that the NPHS survey excluded several groups of women, including First Nations women and concluded that the number of underscreened women may be underestimated due to this exclusion. Snider and associates (1996) reported that these statistics did not differ throughout Canadian provinces and that further research was needed to identify the reasons why women do not utilize the screening services, particularly women who are not included in traditional surveys.

The current study is of great importance for providing information specifically for women of Onion Lake which could support and guide screening program development and implementation. In addition, the information gathered from this study will be relevant for other women with the same and/or similar backgrounds.

Risk Factors for Cervical Cancer

First Nations women are vulnerable to the risk factors for cervical cancer experienced by Canadian women in general. Risks for developing cervical dysplasia include the following: young age at first intercourse, smoking, a high number of sexual partners, low socio-economic status (Miller et al., 1991) and immunosuppression, including HIV (Bouthillier & Noel, 1999). Additional risk factors include the use of oral contraceptives; lack of male condom use; increased parity; and low intake of vitamins A, E, C, beta-carotene and folic acid (Cox, 1995; Schiffman & Brinton, 1995). Furthermore, an association has been made between certain types of the Humanpapilloma Virus (HPV) and the development of cervical dysplasia. HPV is not thought to cause cervical cancer but in conjunction with various co-factors it is associated with cervical cancer (Cox, 1995). Women over 35 years and those who have a partner who has had multiple sex partners are at risk for the development of cervical cancer (Cox, 1995). The differences in incidence, of and mortality due to, cervical cancer among First Nations women maybe due to their health seeking behaviours and therefore, encouraging screening among this group is particularly important.

First Nations Health Beliefs

First Nations people comprise approximately 4 percent of the Canadian population and represent many diverse cultural groups (Newbold, 1998; Waldram, Herring, & Young, 1995). There are differences in their traditional social, spiritual and political beliefs, and thus findings from studies of one tribe cannot be applied or used to explain behaviours or practices in another. However, these groups have many similarities and therefore reviewing beliefs in a general sense may aid healthcare providers to begin to understand their health beliefs.

The degree in traditionality of a First Nations woman may influence whether or not she participates in cervical screening programs. The culture of North American First Nations people is based on a circular way of life which they have strived to preserve and maintain. Wright (1991) stated "Everything the power of the world does is in circles. The sky, earth, stars, sun and moon are round. The wind, in its greatest power, whirls. Bird's nests are in circles" (p. 132). The circular way of life represents a holistic view of life, including health that involves a balance between the mental, spiritual, emotional and physical aspects of an individual. When one is not well in one area the whole circle is affected and the individual is said to be in a state of unbalance (Wright, 1991). As well, First Nations people believe spiritual forces play a role in the development of well-being, both in the individual and the community. An imbalance in these forces is thought to cause illness in the individual and in the entire community.

Traditionally good health was dependent upon harmony, which must exist between the community, the environment, the people, and the spiritual world (Lee, 1996).

American researchers, Solomon and Gottlieb (1999) reported that the cultural beliefs of First Nations women cause them not to associate cancer with the pathogenesis of cancer, (e.g., smoking, high number of sexual partners), but associate cancer with other factors. Disease was traditionally believed to be related to the transgression of cultural taboos (Waldram et al., 1995) or loss of the soul (Calam, Bass, and Deagle, 1992). In addition, Brown (1990) reported that illness is believed to be a gift from the Creator and serves as a reminder of the work the individual must do to regain balance in his/her life. Thus traditional First Nations women may not perceive themselves to be at risk for cervical cancer if they believe that they are living a morally good life and therefore, may not see a need to participate in a cervical screening program.

Brown (1990) stated "we had ways of learning from illness and restoring balance, so that we had no major illnesses in North America. We did not have cancer or diabetes or heart disease or AIDS. But as life became more meaningless, as we exchanged our health for money and material things, as we moved away from living as though we believed life was sacred, we began to receive many illnesses. These illnesses are sent to remind us of the sacredness of all things that we have forgotten" (p. 5). Non-First Nations people, particularly healthcare providers, need to learn traditional beliefs of health so that serious illnesses, such as cancer, can be approached in a respectful manner and so that they may avoid, inadvertently, providing care that is in direct opposition to traditional ways.

It was reported in a study of First Nations women in the United States, that a woman's sense of self was threatened with respect to cervical cancer and caused fear in relation to changes in body image, attractiveness, relationships, sexual function and reproduction (Strickland et al., 1996). A First Nations woman is expected to be a strong and healthy person so that she can support the family and pass on the culture. Also, in traditional culture, the role of 'giver of life' was the highest honour (Strickland et al., 1996; Brant, Fallsdown, & Iverson, 1999) and thus reproductive function was highly valued. Although women are able to have children following treatment of cervical cancer, a diagnosis of cervical cancer could threaten her identity and role in the community. Thus, fear, particularly fear of loss of connection to the community, is a barrier to screening. As well, the Pap smear is an intimate screening tool and its use may be seen as extremely invasive, since its use involves the exposure of a sacred part of a First Nations women's body.

Lee (1996) states that not living a traditional way of life can lead to illness. In addition, Strickland and others (1996) found that traditional First Nations women were expected to live a healthy lifestyle and practice healthy behaviours since this contributed to the safety and support of the family. Thus participation in screening programs for cervical cancer would appear to be a benefit to First Nations women as screening is part of a healthy lifestyle, and living a healthy life was traditionally an important responsibility.

Authors of a study comparing Cree Indian methods of treating disease and the treatment process of the Western healthcare system reported that Western practitioners are not informed about holistic health care practices (Morse, Young, & Swartz, 1991). These researchers observed a Cree healer from Northern Alberta for 2 years and collected ethnographic data on Cree healing. It was found that Cree healing practices were not dependent solely on the therapist, as is found in some medical models, but rather a participatory role was established between the Cree healer and the person that requested healing (Morse et al., 1991). The participatory role is symbolized by the purification practices of smudging with fungus, sage or sweetgrass, so that the individual seeking healing would be cleansed. The purification was found to symbolize "...the healer's sharing of spiritual power, which allows the patient some control as an active participant in the treatment process" (p. 1362). Healthcare providers of the Western care system display credentials on his/her wall, establishing "power and authority" (Morse et al., 1991, p. 1362). The traditional concepts of sharing and responsibility among the Cree demonstrate a fundamental difference in approach to health and healing.

Morse and associates (1991) found that First Nations people do not go to healers to find out if anything is wrong, but seek out healing when they want to be cured. An example, "a cough...is not considered a symptom...but a disease that can be cured" (Morse et al., 1991, p. 1362). Another study, describing HIV illness among First Nations women, found that some of the women would not seek treatment until they 'felt sick' (Mill, 2000). In comparison to the Western health system, which encourages patients to obtain regular check-ups to ensure normal health, traditional First Nations persons will seek out care when they feel sick. This belief has consequences for cervical cancer since it can be asymptomatic. Therefore, given that fairly advanced cancers are not 'felt', the severity of undetected cervical cancer should be expressed in traditional terms.

An in-depth review of the literature did not reveal any research studies that investigated Saskatchewan First Nations women's health beliefs, as they relate to cervical cancer. A study exploring this area has the potential to discover specific healing beliefs and practices of women in Onion Lake, Saskatchewan.

Guiding Theoretical Framework

The HBM has been used to develop interventions to promote specific health behaviours and health behaviour change programs. It is hypothesized in the HBM that individuals will engage in behaviours that guard against or suppress conditions of ill health if they consider themselves to be at risk for a certain disease, and if they believe it to be a serious one (Maiman and Becker, 1974). In addition, the individual must trust that actions he/she takes will be advantageous in decreasing the development of the disease or its severity. Moreover the individuals must believe that they are capable of taking these actions (Maiman and Becker, 1974) and the benefits of the actions must outweigh the risks. Lastly, a provoking event, or cues to action, may be needed before an individual adopts a health behaviour.

The unique health needs of Canadian First Nations women have received inadequate attention. Cultural beliefs, values, and customs have a direct influence on health behaviours, and therefore cultural consideration is essential if effective screening programs are to be developed and implemented. Models have been created to explain and predict behaviours based on the health beliefs of individuals. One such model, the Health Belief Model (HBM) has been used to explain health behaviours related to the utilization of screening programs (Burak & Meyer, 1996). The HBM is an appropriate framework for exploring attitudes toward cervical cancer screening. Also its use may provide a guide for nurses that will direct their approach when caring for First Nations women.

Purpose of the Study

Increasing the utilization of Pap screening is paramount for the prevention of cervical cancer in First Nations women. LeMaster and Connell (1994) suggest that, "prior to the implementation of health education interventions among Native Americans, the health beliefs and practices of the culture and of the health providers should be determined to address incongruities and assure cultural relevance" (p. 534). Therefore, the knowledge gained in the proposed research study will be used to provide nurses, other healthcare providers and policy makers with relevant information. First Nations women's health beliefs concerning cervical cancer and cervical screening will be identified, so that recommendations for an appropriate and culturally sensitive cervical screening program may be developed and implemented. Health education interventions are vital to health prevention efforts. More research is needed to provide First Nations women with effective health education interventions to influence health behaviours that will decrease the morbidity and mortality associated with cervical cancer and will contribute to models of care (e.g. health promotion programs that are acceptable to a variety of cultures). Findings will be used to add to the existing body of knowledge about health beliefs of First Nations women in Canada as they relate to cervical cancer and cervical screening

The purpose of this research project is to explore knowledge, attitudes and beliefs about cervical cancer and cervical screening in First Nations women in Onion Lake, SK. The significance of the proposed research is underscored by an Elder, who stated, "Cervical cancer robs a people of its childbearing women, its mothers, its elders...its hope for survival and the passing on of the culture" (Strickland et al., 1996, p. 141).

CHAPTER III: METHODOLOGY

The purpose of this study was to answer the question, "What are the knowledge, attitudes, and health beliefs of First Nations women, in Onion Lake SK, concerning cervical cancer and cervical screening?" A focused ethnography was chosen as the methodology to guide the study (Morse & Field, 1995). "Ethnography, in the broadest and simplest sense, can be defined as the systematic process of observing, detailing, describing, documenting, and analyzing the lifeways or particular patterns of a culture (or subculture) in order to grasp the lifeways or patterns of the people in their familiar environment" (Leininger, 1985, p. 35). A focused ethnography has similar objectives however, "nursing ethnographies today focus on a distinct problem within a specific context among a small group of people" (Roper & Shapira, 2000, p. 7). Morse (1994) stated that focused ethnography is an appropriate methodology to explore the knowledge, attitudes, and beliefs of a cultural group (Morse, 1994). The knowledge learned from focused ethnography is used primarily to improve practice and therefore the research question is formulated prior to going into the field (Muecke, 1994). Interviews are generally limited to the chosen topic. Focused ethnography allowed the researcher to specifically explore cultural values that influenced women's attitudes towards cervical cancer and cervical screening.

In-depth interviews are used as the method of data collection. A limited number of key participants who have knowledge and experience related to the study phenomenon are interviewed during focused ethnography research. Morse

(1994) states that focused ethnography is used for "time-limited exploratory studies" (p. 199). There is little information available to guide nurses who want to provide culturally sensitive and effective care to First Nations women who could benefit from cervical screening. This approach was appropriate for the proposed research question as it is often used to generate knowledge for nursing practice (Morse, 1994).

Setting

The community of Onion Lake is located along the western border of central Saskatchewan (SK). Onion Lake has a membership of approximately 3500 people and approximately 1500 First Nations persons live on reserve. "Reserves are parcels of land held by Canada on behalf of Indian bands" (Waldram, et al., 1995, p. 11). A health centre is located within the reserve and is open 5 days per week, from 8 am to 4 pm. The health services personnel include one physician, one pharmacist, three community health nurses (CHN), four community health representatives (CHR), two home care nurse, three home care aids, one clinical registered nurse, four community health workers with the Brighter Futures Program, one lab and x-ray technician and several administrative staff. Permission to conduct the study was granted following a meeting with the Onion Lake Health Board and is attached (Appendix A).

Since beginning my nursing training 12 years ago, and due to my aboriginal ancestry, I have had a strong concern and interest in First Nations health. The community of Onion Lake was chosen because the I had worked there for 4 years and had established a trusting professional relationship with community members.

As well, while employed with the tribal health board I learned that the First Nations women were concerned about their health, their children's health, and the health of their neighbors. The women of this community demonstrated their concern about various health issues by their attendance at community health events. First Nations women are eager to learn about disease prevention and health promotion for themselves, their children, and their community. The women that volunteered to be interviewed for this study were all interested in their health.

All interviews took place at a location and time specified by each woman and therefore varied throughout the study. The first interview took place at the Brighter Futures building and the remaining took place at the Health Centre, and the Rehabilitation Centre.

Participants

The target population for the study was First Nations women residing in Onion Lake. Many terms have been used to identify Indian people and include, Aboriginal, Native, and First Nations. "Status, or registered, Indian people are those who are defined as Indians by virtue of the Indian Act. More recently, the federal government has introduced a further distinction within the status Indian category: regular and Bill C-31" (Satzewich & Wotherspoon, 1993, p. 15). Thus, First Nations refers to people who are status and/or registered under the Indian Act including, regular and Bill C-31. Volunteers who were 'First Nations', had experience with cervical screening, residing in Onion Lake and/or had once lived in Onion Lake, and 18 years of age or older were eligible for inclusion in the study.

Recruitment

The participants for this study were recruited via the usual lines of communication used in First Nations communities. Firstly, a First Nations Community Health Representative (CHR) was contacted and the purpose of the study was explained to her. The CHR agreed to be a contact person so that women who were interested in participating in the project could call and leave their phone number and other contact information with her. The researcher provided the CHR with an information letter (Appendix B) that she could hand out to potential participants. Secondly, posters, both English and Cree, were placed in several areas of the health centre (Appendix C; Appendix D). The poster was translated from English to Cree by the Director of Education at the Onion Lake Learning Resource Centre. The director suggested what portion of the poster was most suitable for translation. Through consultation with the CHR's it was determined that the only appropriate area in the community to place the posters was at the health centre. The reason for using the health centre was that the topic is a sensitive one for First Nations women.

All participants were recruited through contact with the CHR who reported that two of the women had stated that they had seen the poster. The CHR was contacted several times throughout the study and all women who had responded were telephoned. During the telephone conversations, the women were screened to ensure they met the inclusion criteria and interview times were scheduled for a time convenient to them.

Sample

Eight First Nations women volunteered to share their thoughts and feelings about cervical cancer and cervical screening. Morse (1991) states that sample size is determined when no new data is identified during data collection. Therefore, the sample size was considered complete when no new information was being obtained (i.e. saturation was reached). Two additional women who indicated their interest in the study did not keep appointments on 3 occasions. The researcher felt that it would be inappropriate to continue calling the women to schedule other meeting times because on the third call they both seemed to hesitate about when they could meet.

Demographic data was collected prior to the beginning of each interview using the form in Appendix E. This information was collected so that the researcher could describe the research sample and explain the context of each woman's world.

Each woman had previous experience with cervical screening. Three women had never had cervical cancer and/or an abnormal pap smear, although one had had a relative that was diagnosed with cervical cancer. Three women had been diagnosed with cervical cancer. Of these, one had a hysterectomy 5 years ago, another had surgery 2 years ago, and the other woman could not recall what she had had done 12 years ago. One woman had recently had an abnormal pap smear that she was concerned about. The eighth participant stated that she had been told that the results of her pap smear were CIN III 1 year ago.

Participants were between the ages of 22 and 46 with an average age of 35.5 years. Two of the participants were in their twenty's, three were in their thirty's and the remaining three women were in their forty's. Seven of the participants had children, with a range 2 to 5 children and an average of 3.3 children. Six of the women were members of Onion Lake. Two of the participants who resided in Onion Lake were members with other reserves; one was from Saddle Lake, Alberta and the other was from Poundmaker, Saskatchewan. Two of the women were married. Six of the participants were in a relationship.

Data Collection

One semi-structured interview was done with each participant. The individual interviews were approximately 60 – 90 minutes in length. All interviews began with an open-ended question and prompts or trigger questions that related to components of the HBM were used when needed (Appendix F). This format of interviewing allowed the woman to share and describe relevant personal experiences (Field & Morse, 1985). Each participant choose where and when the interviews took place. This allowed for maximum comfort so the women could share their experiences with no distractions, in a relaxing environment.

Prior to beginning the interview, which were done in English at the request of each woman, the reason for the study was explained to each woman and written informed consent was obtained (Appendix G). Each interview was audio taped

and transcribed verbatim. All participants were interviewed face-to-face and chose to be interviewed in English. Purposive sampling was used during the data collection process. The first five women who were interviewed had experience with cervical cancer and/or an abnormal pap smear. Therefore, women with no experience with cervical cancer were
purposively sampled for the remaining interviews.

Data Analysis

Data analysis occurred concurrently with data collection. Morse and Field (1995) recommend that the researcher listen carefully to the taped interviews and that this should be done as soon as possible following the actual interviews. Thus, the researcher listened to the taped interviews on the same day that the interviews took place. Researcher bias was addressed through journal entries prior to, during and following interviews (LaBiondo-Wood & Haber, 1998). In addition to personal thoughts and feelings concerning the topic, the researcher included her perspectives in the journal as a First Nations woman.

The taped interviews were transcribed verbatim except that names were omitted and the relationship of the person was identified in brackets (e.g.,______[sister]) (Morse & Field, 1995). In addition, nonverbal communication occurring during the interviews was indicated during transcribing by using square brackets (e.g., [crying]). Pauses occurring during the interviews were indicated by the word 'pause'. The researchers' comments were transcribed with a different heading so that it was separate from the participants' comments.

The transcriptions were checked for accuracy by listening to the tape while reading the transcription. This check for accuracy was completed several times.

Following the transcription of the interview the researcher began coding the data for major themes. "Categories are initially kept as broad as possible without overlapping...as each unit of data is examined, certain words or phrases demand the researcher's attention" (Morse & Field, 1995, p. 132). The researcher wrote the major themes in the margins and highlighted relevant phrases that supported the choice of the theme during the next phase of analysis. Sub themes were sorted from the major themes as the data accumulated.

The data from the transcriptions was managed manually and then sorted by using Microsoft Word ®. Documents were created for each participant. Next, when analyzing the data, passages were cut from the interview and taped to a piece of paper and then filed to a folder labeled with the category. The researcher placed relevant data into the appropriate categories until no further relevant data occurred in the interviews.

The researcher wrote descriptive paragraphs about the categories and sought out relationships among the categories. Analysis of ethnographic research involves identifying relationships among the categories and relationships among all parts to the whole. Field notes were examined for key words or phrases. Relationships among these words and phrases were identified. Repeated words in the data were identified. For example, 'support', 'fear', and 'responsibility' were noted. The data were studied so that the researcher was able to identify similarities between the relationships among the coded key words and this identified the categories.

The researcher cut out important quotes using the computer program Microsoft Word and then pasted them in the selected categories. These codes changed as the data accumulated from further interviews.

Rigor

"Rigor is required in any research to prevent error of either a constant and intermittent nature" (Morse & Field, 1995, p. 143). Empirical researchers, who believe that there is little control over interpretation of the findings, have criticized the reliability and validity of qualitative research (Morse & Field, 1995). Thus there has been concern among users of research about the trustworthiness and relevance of findings reported in qualitative research. Sandelowski (1986) stated that "qualitative methods are frequently viewed as failing to achieve or to make explicit rules for achieving reliability, validity, and objectivity-criteria of adequacy or rigor in scientific research" (p. 27). Rigor may be demonstrated in qualitative research by ensuring the criteria of credibility, fittingness, auditability and confirmability are addressed (Sandelowski, 1986).

"A qualitative study is credible when it presents such faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognize it [as their own] from those descriptions or interpretations" (Sandelowski, 1986, p. 30). The researcher offset this threat by journal entries acknowledging how the researcher influenced and was influenced by the participant (Sandelowski, 1986). Fittingness refers to the findings being viewed by the audience as "...meaningful and applicable in terms of their own experiences" (Sandelowski, 1986, p. 32). Auditability is demonstrated when another researcher can clearly follow the 'decision trail' used by the researcher in the study (Sandelowski, 1986). The researcher kept an audit trail by noting events throughout the interviews that were not on the tape recording (e.g., crying) and by keeping a journal throughout the research process. As well, both co-supervisors read the transcripts and followed the reasoning process. Confirmability is required once the criteria listed above are met (Sandelowski, 1986).

Ethical Considerations

The study received ethical review by the Ethical Review Board at the University of Alberta (Letter of Approval Appendix H). Informed consent was obtained from all the participants (Appendix G). Informed consent was accomplished by providing detailed information about the study, the role of the participant in the study, and the time commitment of the participant. Thus the researcher identified the purpose of the research and investigators responsible for the research prior to having the participant sign the written informed consent. In addition no undue pressure was applied for individuals to participate and they were informed that they could refuse to answer any questions, that they could stop the interview at anytime, or withdraw from the study at anytime. The participants were informed that their healthcare would not be affected in any way if they refused to participate or if they dropped out after signing the consent.

Participants were informed that the interview would be approximately 60 to 90 minutes in length and that it was possible that the researcher might request a second interview. Participants were informed that they may not actually benefit from participating in the study, but that their participation may help healthcare providers provide better care to First Nations women. The setting of qualitative research takes place in the field, thus the data were collected at sites selected by participants. Interviews were conducted at a time that was most convenient for the participants.

The anonymity of the participants was assured and participants were informed that the information they provided might be published but that their names would not be connected with the information. In addition, the findings were presented in a way so participants could not be identified. Only the researcher knows the identity of the participants. Fictitious names were given to the participants and used in the text of the reported findings. The supervisory committee, transcriber, and researcher are the only individuals who have access to the tapes and transcribed interviews. One participant expressed an interest in receiving a copy of her interview so the researcher provided her with one. The participant did not change any of her comments.

The data, including the audiotapes and the transcribed conversations were kept in a locked cupboard, which only the researcher had access. The informed consents were stored separately from the written material, audiotapes, and transcripts. The data will be kept for a minimum of seven years. The participants were informed that if the data were to be used for secondary analysis, ethical approval would be obtained.

CHAPTER IV: FINDINGS

Three major themes were identified in the data, which provided a description of the knowledge, attitudes and health beliefs among First Nations women as they relate to cervical cancer and cervical screening. All the women had personal experiences to share, whether the experiences were with a diagnosis of cervical cancer and/or with their experiences related to cervical screening. Although the shared experiences were highly personal, common themes emerged. It is the shared experiences and attitudes that generated the themes. During the interviews the women expressed that what they were sharing were their own feelings about cervical cancer and cervical screening. The women emphasized that they wanted to speak for themselves and did not want to speak for other First Nations women. Therefore the findings have been written up in first person singular.

One major theme identified in the data was 'these are my feelings'. In relation to the women's feelings the following sub-themes emerged: vivid recollection of healthcare encounter, healthcare providers' role, encouragement and support, fear, barriers to cervical screening, and responsibility for health. Women's experiences with healthcare providers caused many feelings and memories. For example, one woman remembered the physical pain she experienced during her encounter. Another recalls feeling supported and respected during her encounter. These memories led the women to express their concerns about the role of healthcare providers and to make suggestions that would have improved their experiences. The women also expressed their desire for support and encouragement during their related experiences with cervical screening. All of the women expressed feelings of fear about cervical cancer. The fear that the women experienced motivated them to actively seek out and avoid preventive health services such as cervical screening. For example, one woman reported feeling paralyzed by fear. The women also identified some barriers to cervical screening, which were caused by many different feelings, such as feelings of embarrassment and/or shame during the cervical screening test. In general, because of their own personal experiences, the women reported feeling responsible for their health.

The next major theme that emerged in the data was ‘this is what I know’. Many of the women stated at the beginning of their interview that they knew very little about cervical cancer. Although some knew more than others, all women knew several things about cervical cancer and cervical screening. In relation to this major theme, several sub-themes were identified, which included: level of understanding of cervical cancer, the importance of follow-up, quest for information, and strategies for prevention and education.

The final major theme identified was ‘this is my culture’. This theme included the effects that traditional and cultural beliefs had on the women’s health beliefs about cervical cancer and cervical screening. It is recognized that the traditional culture of Canadian First Nations people has been changed due to contact with non-First Nations people (Berry, 1999) and therefore ‘traditional’ culture in this study refers to the beliefs of long ago. Choney, Berryhill-Paapke, and Robins (1995) reported that “a Christian Indian who was asked to tell what traditions, customs, and values exemplify Indianness might give a very different answer from that of one who followed the old ways" (pg. 76). All the women, except one, identified with First Nations traditional culture and reported that it was important for their health and influenced their healthcare decisions. The one woman that reported she did not follow First Nations traditional culture stated that she knew many First Nations women did and that because of this their choices for healthcare would be different. The themes identified within this category included: combining traditional and biomedical healing, you've lost your soul, it's taboo talking about sex, and tension between cultures.

The following text includes verbatim quotes from the women, which allows for their perspectives to be fully described. Fictitious names were given to each woman and they are: Ann, Betty, Cathy, Dawn, Erica, Fran, Gail, and Harriet.

These Are My Feelings

All of the women had personal experiences to share. Their shared experiences included their own diagnosis of cervical cancer, their own abnormal cervical screening test results, and/or their experiences with the cervical screening test. For example, one woman shares her experience of the physical pain she felt during a cervical biopsy. Another woman discusses the pain she felt during surgery because it was done without an anesthetic. Another women shared her feelings of disbelief when she was given her diagnosis of cervical cancer and told that she needed a hysterectomy. Some of the women described feelings of anxiety and confusion when receiving care from the western healthcare system.

Some of the women identified several characteristics that they felt healthcare providers should possess. For example, the women felt validated and appreciated when the care providers took time to explain to them what was about to happen and/or to explain what was happening to their bodies. As well the women felt less anxiety and more comfortable when their healthcare providers listened to them and answered their questions. The women also reported that not only family and friends could provide support, but that healthcare providers' support and encouragement was important too. The participants suggested that encouragement and support enabled them to seek out health services

Although all of the women expressed feelings of fear related to cancer, their reasons for feeling the fear were different. For example, some of the women were fearful of cancer because other members of their family had had cancer. Other women were fearful of cancer because they felt that it was a "death sentence" and believed that once a person was diagnosed that they would die.

Vivid Recollection of Healthcare Encounter

All the women began the interview by immediately sharing their personal experiences. These experiences were recollected in very vivid detail. They reveal in detail, not only their experiences with cervical cancer and cervical screening, but also their impressions of the healthcare providers and the care that they received. For example one woman reported that she felt comfortable with her healthcare providers approach and appreciated the way that she received her diagnosis. She reported that her care provider was very good because he provided her with information about cervical cancer and because of this she felt that he was being open and honest. The respect that she then felt from the physician made it easier for her to hear that she needed to have a hysterectomy. The participant added that her physician gave her a choice to have a second opinion which allowed her to feel comfortable with his advice and more able to trust his advice. In addition, the care provider took the time to schedule an appointment for a second opinion. This allowed her to relax and not worry about having to do this on her own and perhaps feeling awkward that she wanted too. The approach from the doctor seemed to help the woman get through this difficult experience. This experience proved to be a very positive and powerful experience for the participant as it eased her apprehension and allowed her to return for follow-up and continue with treatment. Erica said,

> The doctor handled it really well. My appointment was scheduled when the offices are closed so I knew he was going to be giving me some fairly bad news. The office was empty, and the lights were all turned down. He said, "You know, you've got cervical cancer and it's already well advanced. I will give you the option of getting a second opinion" and he referred me to another surgeon and my appointment was for the next day. It was a real comfortable surrounding but the way he handled it really helped a lot. He gave me a lot of information, pamphlets and people to phone for support. I'd gotten my diagnosis, and I had no choice but to have a hysterectomy. And that was a tough time for me, but I got through it.

The experiences that the women shared proved to be very powerful experiences. For example, one woman recalled the steps that were taken during her biopsy and the words that were spoken. Although she was told that she would feel a "pinch" she stated that she felt intense pain during her biopsy. She recalled wishing that she was not alone, and that her partner could be with her for support. She concluded that it would have been a less painful experience with that support. As well, once the procedure was completed and she was able to see her family, she allowed her self to express this pain in an emotional way by crying. Ann said,

> They needed to do swabs and then they sprayed the solution on and they said, “Okay, we need to take a biopsy from you, and there’s going to be a pinch”. That was painful. *Really* painful, because I remember afterward being very emotional and crying because of being there by myself and walking out towards my in-laws and my partner and my child.

Another woman felt respected and heard during her procedure because she had her questions answered. For example, she recalls asking whether she could have the procedure during her menstrual flow and the nurse telling her that she could. Also, when she became worried about the increase in her flow the nurse relieved her fears by saying that that was expected. This positive encounter with healthcare providers was followed by a negative encounter, as she hemorrhaged the next day and needed to have surgery. The experience was a negative one because the surgery was done without an anesthetic. The facility was unable to locate an anesthesiologist because it was a holiday and therefore the participant described feeling a lot of pain. Betty said,

> I went in in the morning and I was out of there by after noon. They performed the procedure while I was menstruating and they said that was okay. I noticed the flow had increased and I told the nurse that the flow was heavy. She said “that’s okay it’s the procedure. That’s fine, it will stop”. Sure enough it did slow down. It went like my normal period and they said I could return to normal work duties. So I came back to work the next day and I hemorrhaged. So I had to be rushed back by ambulance. It wasn’t a very pretty experience. They were able to locate the doctor but they couldn’t get anybody to freeze me...so they had to re-stitch without the freezing. And I *felt* that. It was *awful.* So that’s what I didn’t like about the experience.

Healthcare Providers’ Role

In relation to healthcare providers roles, the personal experiences of five of the women with their care providers highlight potential areas for improvement and areas that they felt satisfied and comfortable with.

He Was Really Good Four of the women felt that they were more likely to be motivated to seek out healthcare, specifically a cervical screening test, if they had a good caring doctor. The women defined the 'good caring doctor' several different ways. One woman reported that her doctor explained 'everything' and that made her feel comfortable. Another woman felt much the same way and reported that adequate explanations lessened her apprehension about receiving care. Harriet and Betty said,

> This doctor I was seeing in Saskatoon, he was very good. He explained *everything*, all the tests that he did and he was really good.
>
> The doctor that would do my Paps, he was really good. He would say, "This is what level we're at now and it's increasing". He'd say, "I'm getting concerned. We'll send you into Saskatoon where they do these biopsies".

Another woman reported that her anxiety about the cervical screening test was lowered when her care provider explained the test. She felt that adequate communication skills were important for care providers to possess so that she could relax during the procedure. Fran said,

> Talking with the doctor, learning more about what's going on and things like that. It's good to be able to talk to your doctor. At least knowing a little bit of what was going to happen and having somebody.

Having a doctor that she could trust and communicate with was also important to another woman. This participant reported an experience where the communication style she encountered caused her fear. Erica said,

> The second doctor, I found his bedside manner was really bad. He said, "Yup, you've got it, you've got to have surgery immediately".

> And that was the scariest part, the way he said it. "You've got to have it *immediately*".

I Didn't Really Know What was Happening Four women reported not knowing what was happening to them. They felt that the healthcare system was lacking when it came to making woman feel comfortable and informed about their health. There was a general sense of not having adequate explanations. One woman reported that she still doesn't know what her diagnosis of cervical cancer meant or if she even had it, and if she did, she was not sure if a part of her cervix was removed or all of it. She reported that she didn't understand anything that was happening to her. Her feelings of frustration and confusion were clear during our conversation. Dawn said,

> I still don't know, to this *day*, whether they found anything or what portion they removed, if they even removed anything I don't know! Nobody explained anything to me because, maybe because I didn't ask. Maybe they thought that I understood everything that was going on, but I *didn't*.

More confusion was felt as one participant reported that she was not sure how her health would be affected for the rest of her life. She expressed concern about the process she went through, and felt that it was very impersonal and uncaring. This lack of support and explanation caused not only confusion but also frustration. Ann said,

> When you're in Saskatoon and Lloyd sometimes you just get pushed along as if you're just a file. "Here you go, this is what's wrong, this is what we're going to do, see you later". I don't understand where I go from there, how's my health going to be affected by it now.

Another participant experienced similar impersonal feelings when receiving care. This caused feelings of frustration, confusion, and uncertainty for her.

Betty said,

> I didn't understand when I went through the procedure. I was told I had cervical cancer. It was rushed like, "this is what's going to happen, we're going to fix it, blah, blah, blah". That was it. It would have been nice if they had given [an explanation], and tell me, "Okay this is the cervix and this is where the cancer formed and this is what the cancer looks like at different stages". I don't know which part of the cervix it affected. What could have happened? It was almost like, "Here we'll fix you, you're done, goodbye. Next.".
>
> It was scary. I didn't know what was going on or what was going to happen there.

<u>More Time Explaining</u> Two women found that they did not receive enough information and/or explanations about their condition when they received care. Furthermore, one of these women reported that it is important for healthcare professionals to express cultural sensitivity by stating that the test he/she is about to do is for the woman's health and that it is not intended to offend her in any way. Furthermore, she reported feeling calm about having the cervical screening test when healthcare providers took the time to explain the test. Gail said,

> I think it's important that the healthcare providers have an understanding of where these women are coming from and how they might perceive what's happening. Let the woman know that, okay, "I know that you have certain beliefs. You have a tradition that you follow as a First Nations lady, however, in this day and age, there are a lot of diseases and a lot of things happening today and in order for us to prevent we need to do these examinations. We're not going against your beliefs, we're only doing it for your health" I think that would really calm the person down. It would really calm me down. Also explaining the procedure and letting them know what's going to happen instead of just all of a sudden, get you on the bed there. So more time explaining.

The other woman also reported that she wished her care provider spent more time explaining things to her. Not only did she wish to be informed about the procedures she underwent, she also wanted to know about all aspects of her health, but did not ask. The feeling of disappointment with her care was noted during our conversation. Ann said,

> They gave me a letter stating the aftercare…what to do, what not to do. They just hand it to you. But I wish they would have sat with me and read it with me or explained it to me. I still don't understand because I was so busy being a mother, being a partner, with all these other things I do plus work. I still don't know what caused it for me. Nothing was ever explained of why or how it got to that point.

Encouragement and Support

Four women reported that support was extremely important to them. The women identified family, friends, and spouses as important people to provide support. The women reported that being able to talk with someone provided them with the emotional support that they needed. Also they felt social support when someone was physically with them. One woman stated that she needed the support to make sure that she actually went in for her pap smear. Fran said,

> I had to bring somebody with me just to make sure that I went in. (laughs). I brought my younger cousin. She's 2 years younger than I am and that was her first Pap smear. My appointment was first so I went in and she made sure I went in and then I came out...and I made sure she went for her appointment. We tag teamed it.

Two of the women did not have support, at times, and they both found this difficult. One participants' husband left her following her diagnosis. She felt fortunate that her parents and her sister were there for her. Erica said,

> You have to be able to discuss something like this [cervical cancer] with your spouse and they have to be able to understand it and be able to support you. My first marriage broke apart...that was the end of it when I got diagnosed with cancer. He just wasn't there. So I was fortunate that I had the support from one of my sisters and my parents.

The other woman reported that she wanted support during her biopsy. She needed support so that her fears of the unknown could be tolerated. She felt that her feelings of uncertainty would have been more manageable if she had had someone with her. Ann said,

> I went in by myself, which I really wish I shouldn't have done because it was really nerve-wrecking for me because I had no idea what they were going to do.

One participant stated that her sister is refusing to go back for another pap test following an abnormal reading. She understands that for many women it can be frightening to return for follow-up, as it was for her, because of the possibility of being diagnosed with cervical cancer. She reports that constant encouragement and support is needed. Cathy said,

> I would try and keep encouraging her. To tell her "if they find it early they can do something about it". I try and set examples for my clients. I tell people, "Did you know this lady had this kind of cancer because she never got tested and they could have done something about it right away and she would still be here".

One woman reported that her friends urged her to seek other treatment options instead of the recommended hysterectomy. They told her that she would no longer be a woman if she had the procedure done. The women also told her that if a body is opened up during surgery the cancer will grow faster and the person will die right away. The participant felt that this belief was supported by the fact that many people in the community who had had cancer and then surgery had indeed died. She reported that in order to resist the advice of her friends she took the time to mentally prepare herself and support herself spiritually. Even so, she reported feelings of relief when she discovered that her body cavity would not be opened during surgery. Erica said,

> I don't feel like I've lost my soul. I think I took the time to get myself there emotionally, spiritually. Women urged me "Don't have the surgery. Do whatever you can to [not have it]. You're not going to be a whole woman if you have your uterus removed, because if you have your uterus removed you're not going to have children" I actually had one woman tell me that "if they open up your body it gives the cancer a chance to grow faster" I was so happy when I found out that they did the surgery vaginally now and in my mind if they didn't open my body cavity, I'd be O.K. (laughs).

Believe in yourself

Two women reported that prior to their diagnose of cervical cancer they knew something was wrong. Both women had several appointments with their doctors. They described their feelings of strength, as they had to believe in themselves, and continue to seek health services for check-ups. They expressed feelings of determination to believe in themselves when something was wrong, even when a problem could not be found. Erica and Betty said,

> My whole life I'd experienced menstrual problems like heavy bleeding. It really got bad after I had my last child and I knew there was something wrong and I was experiencing some pain. I kept going to the doctor and I kept telling him "there's something wrong. I know there's something wrong".
>
> I would have pains to the stomach and yeast infections. I had yeast infections that you couldn't believe. They became so normal in my life. And when my sister started to get yeast infections I kept telling her, "Go see the doctor. I had those. It's something to worry about." Later when she went to a larger centre that's when they did more tests and they found that she had cervical cancer and by then it was too late and she had to have a hysterectomy. So, I'd *push* to go for Pap smears. "Go for your Paps, go for your Paps, go for your regular checks".

Fear

All the women described being fearful of cervical cancer. For some this fear was a result of their abnormal test results. For others the fear resulted from family members having cervical cancer.

Recognition of Genetic Component Three women reported that they were fearful about cervical cancer as other family members had been affected by cervical cancer and other types of cancer. Ann, Gail, and Betty said,

> When I was diagnosed with CIN I, I had a huge fear because I thought it was hereditary then, that if your Mom had it you would have it.
>
> One of my cousins passed away with this type of cancer, and she had a lot of fears. She didn't want to go for surgery. She was told that if she went for surgery that it [the cancer] would move into other areas. The surgery was for her uterus to be removed, the whole uterus. She didn't want that done. She died from it. And those are my fears. It's in our side of the family.
>
> I was scared of cancer. Because of the cancer in my family.

Fatalistic View of Cancer Four women commented that cancer causes fear because it is often thought of as a fatal illness. These women reported they themselves and/or their loved ones believe cancer to be a fatal disease. One woman reported that her father began 'cutting off the emotional ties' with her because he wanted to prepare himself for her death. This shared experience demonstrated the potential impact that a diagnosis of cervical cancer could have on a First Nations woman. Another woman experienced a big scare because she thought that she was going to die from the cancer as many people she knew had died from cancer. Her fear was exacerbated when she reported not receiving any information that let her know what was going on and therefore it caused even more anxiety for her as no one told her she wasn't going to die and that it was at a stage that was treatable. One participant reported that her sister was not returning for follow-up of an abnormal pap smear because she believed it to be 'downhill'. Another participant describes being in a lot of fear because she too believed that cervical cancer was fatal but once her mother was treated and survived she realized that some of her fear was related to lack of knowledge and understanding. Cathy, Ann, Erica, and Dawn said,

> People are scared. I'm thinking of my sister. She hasn't gone back to get retested. She did have an abnormal result the first time and I'm still having a hard time trying to get her to go. I think she's afraid. Some people are afraid that if they do find cancer, it's downhill from there.
>
> My Mom has gone through the process. She told me that she had cancer in her cervix and that she had to go for surgery. So it was a very big fear for me because as soon as you hear 'cancer' you think of the ultimate. There's nothing more than, but for this person to die. So I never understood and that really put me in a lot of fear.
>
> My Dad had a really difficult time with it, because he was already in his early 60's at the time and as soon as he heard cancer [he thought] I was going to die. He started cutting off the emotional ties with me then.
>
> I thought I was going to *die*...and that was a big scare for me because I didn't understand and didn't know what it [cervical cancer] was all about. No one told me anything or what to expect.

Motivation for Cervical Screening

The fear associated with cervical cancer affected the women's motivation to seek screening. Two women reported that their fear of cancer was the reason why they obtain regular pap smears. Gail and Betty said,

> My fear is of having it [cervical cancer]...motivates me. I want to have good health. I don't want that kind of a disease.
>
> I was scared of cancer.

Another woman's fear of being unhealthy recently motivated her to obtain a pap smear. This woman reported that she was not concerned about her health until recently when her arm went numb. She then reported that she then decided to have a full exam to check everything. Although she expressed that she wanted to have a full exam she only agreed to have a pap smear because the person doing it was a female nurse. Harriet said,

> I feel it's [cervical screening] very important. I'm really concerned about my health now, because I got a little sick and I was scared about my health. That's why I changed my mind, like last month, I didn't care, but something happened. My whole arm went numb. And the numbness was just going up to my neck. I agreed to go for a Pap smear because she was female and I was really concerned about my health too.

However, this same woman reported that fear of having cervical cancer would prevent her from wanting to have a cervical screening test. She felt that if she knew that she had cancer she would change as a person and shut down. Harriet said,

> To find out that I have some kind of illness...like to know you're sick you just want to block it out and you don't really want to know. If I knew I had a sickness or an illness I would probably just shut down from everything, like family and I would probably totally change, and not for the better either.

Another participant stated that her motivation for screening comes from her upbringing. She stated that her mother taught her how important it is to have cervical smears, especially after she began to be sexually active. In addition, her mother had survived cervical cancer and therefore she had learned that if the changes were found early something could be done. Ann said,

> Almost every year I've had one. My Mom stressed it to me when I was small. Like when I started menstruating and once you become

> physical with a man you need to have this test done every year.

Barriers to Cervical Screening

Through their own experiences and knowledge the women were able to describe barriers and/or potential barriers to cervical screening. The barriers identified by the women included; lack of privacy, male care provider and issues of modesty, and feelings of embarrassment.

Lack of privacy Two women felt that the physical location of the screening room lacked privacy and they felt that this would influence how women felt about getting the testing done there. At the Onion Lake Health Centre the waiting area is located outside the door and one participant felt that could cause anxiety for the women. The participant suggested that women may feel that the door isn't locked and someone could walk in during the exam. Both participants felt that women leaving the room may feel that the people in the waiting area would assume that they were there because they had an STD or they were pregnant. Cathy and Betty said,

> People are scared to go in there. I know that the door probably gets locked. There's a lot of people sitting out there, as soon as you leave that room they automatically know what you've been going in there for. They might say STD or something like that.
>
> If I go to the doctor they'll think I'm here because of a pregnancy test. I've heard that young girls who come to see the doctor, for whatever reason, are stereotyped as *pregnant, pregnant, pregnant*. Some will probably be scared or would prefer to go to a larger centre.

Male care provider and issues of modesty Four women reported that they feel more comfortable having the test with a female care provider rather than a male. Even when a doctor explains what he is doing one woman felt better with a female. More recently a female clinical nurse has been hired to provide weekly health clinics for woman at the Onion Lake Health Centre. One woman reported that women are now sent there if they need to have a pap smear. This participant felt that this has improved the comfort level for many women. She continues to share that the physician working in Onion Lake is like a family member because he has been providing care for more than 20 years. She felt that First Nations women are more comfortable having the test with someone who is not from the community. One woman reported that it was part of her traditional beliefs that only her partner see her genital area and therefore she preferred a female care provider. Harriet, Cathy, Gail, and Fran said,

> My first Pap smear was done by a male and I was very nervous. He did explain...but I was still nervous and I just didn't want it done but I had it done because he was my doctor. Maybe that's why I didn't have another one [Pap smear]...because of that [male gender].
>
> I was talking to one woman who went to see the doctor for a concern and wouldn't allow the doctor to check her, she told the doctor, "I know you, and I don't want you to see me there" and so he referred her to the nurse, which is really good now. They don't want to show their private areas to a family member but she's not a family member, she's from another community. I think people feel better about seeing someone like that. I feel uncomfortable that it's a male doctor. I feel better to see a female.
>
> I want to go to a female doctor and have a female do the test. I noticed with a male it was more rough and painful. With a female it wasn't that painful and the roughness wasn't there.
>
> I had it done by a male doctor and I was uncomfortable...because of the way I was raised. My [traditional] grandmother always told me that the only man that should know you like that is your husband.

One participant felt that a barrier to seeking treatment following an abnormal pap smear is that First Nations women find the health services rushed and confusing. As well, the women often have to travel and this does not always allow for the support that they need. Erica said,

> The process is so fast. They're being rushed here and there and they're like, "What's going on?". And a lot of these women have to leave the community too which creates other hardships. A lot of families aren't in the position to go and support this person while they're over there in Edmonton or Saskatoon, and that's really sad.

This participant further reported that some First Nations women she knows are fearful of western health services and that they become frightened and confused when accessing them. The women then seek out traditional health practitioners and stop visiting mainstream physicians because they don't understand the terminology. This participant felt that women basically feel more comfortable using traditional medicine because it's something that they understand. Erica said,

> I find a lot of women don't know the terminology. And a lot of them are going alone to these doctors and these procedures...and they're not getting a good understanding. So a lot of them start off going that route and then they don't know what's going on. They don't have a full understanding and they're withdrawing and trying to go this other route [traditional] that they understand, the language, the terminology, the customs.

Feelings of Embarrassment The women stated that a major barrier to cervical screening for First Nations women is embarrassment or uncomfortable feelings about someone looking at their private parts. Betty, Cathy, Gail, Erica, and Ann said,

> When I started, I hated them. I was so ashamed because somebody else was looking at my privates. I didn't know any better.
>
> Nobody likes to show that area, it's private. I think everybody feels that way. You have to go and do this once a year and people don't

> really like to have it done even though they have to. Some people I think are shy to go and have something like this done.
>
> It's like exposing your private areas to strangers. And that's showing disrespect for yourself.
>
> It's like opening yourself up. It's almost like you're opening your soul, you're baring yourself physically but also emotionally, psychologically, spiritually. So the act of baring yourself, not only physically, is what a lot of women have to come to terms with.
>
> They don't want to have that image of having to lay down and have someone put something inside of you and take something from you. That's probably the scariest part I think a lot of women go through. The feeling of someone putting something inside of you, it creates so much anxiety for women. Like it did for me.

A participant reported that embarrassment may result with a diagnosis of cervical cancer because it could mean that the woman has shared her body with too many sexual partners. She felt that First Nations woman focus on this issue and therefore they are uncomfortable and/or unwilling to talk about it. Ann said,

> When they're told that it [cervical cancer] could be caused by multiple partners, right away their sexual being is being looked upon. Too many people have been a part of your body. It's something they wouldn't want to share, "Tina I have cervical cancer now because I had too many sexual partners". That's something a lot of women here are not willing to admit or even willing to talk about.

Responsibility for Health

Although all the women stated that they were uncomfortable with the cervical screening test for different reasons, all had obtained screening for various reasons. Four women reported a strong feeling of responsibility for their own health. These women did not like to have the pap smear done, but because they knew what it was for they felt that having it done was an important responsibility. Even when the women had had negative experiences with the tests, for example, pain during the procedure, they returned year after year because they knew it was important. Dawn, Ann, Fran, and Betty said,

> I go through the motions...of doing what I have to do and it's just something I know I have to do and it *gets done and that's it*!
>
> I think it's very different for me because my Mom has been open with me about healthcare and women's bodies...and what we need to do for ourselves and taking care.
>
> They've [experiences with cervical screening] been O.K., except for the one with the male doctor. Because of that, it was kind of eerie to go back the next year but I felt I had to. The responsibility to myself.
>
> I haven't had a bad experience. My womb is tiled and my Paps are painful because of that. All my Paps have been kind of semi-uncomfortable. *I still go*! (smile). But sometimes I think, "I hope they got it, I hope they got it, I hope they didn't miss it" because it's painful.

Another woman reported that she was brought up to believe that exposing your private areas to strangers shows disrespect for yourself and therefore she experienced various thoughts when getting her cervical screening. However, she felt that this experience could be thought of as positive because she was doing it for her own health. Gail said,

> A lot of thoughts go through my mind when I get my Pap smear done and I try to look at the positive side where I'm doing it for my own health.

Another participant reported that First Nations women feel a responsibility for their health. She described her experience with cervical cancer as a fight. She said that a woman must be balanced so that they have the ability to fight. This participant reported that she not only had a lot of responsibility for preparing herself for treatment but the follow-up care was a tremendous amount of responsibility. She stated that following treatment she then had to go for pap smears every 6 months for 3 years and than every year after that. She concluded that after 5 years she has a clean bill of health. This demonstrates the strength that she had to have to fight this disease and that she had an active role not only in her treatment but also in her cure. When this participant spoke of her survival, she reported on the actions that she took, she did not focus on the ability of the physicians and specialists. She healed herself by having the strength to go for surgery. She felt that the decisions she made accounted for why she is alive. She reported that she was responsible for her health and that she needed to, and wanted to, stay alive for her daughters. Erica said,

> You have to be balanced in order to overcome any type of illness. You really have to force yourself and remind yourself, "Hey I have to go for that" even though the fear's still there. You have to force yourself. For me I had to decide to live. I have 4 daughters and I chose to fight this disease because I wanted to be around for a long time yet. I could have sat back and, "Oh jeez I've got cancer" and let it overcome me but...I *didn't*. (laughs). So consequently I'm sitting here today. (laughs).

The same participant continued to report feelings of responsibility in terms of the role she played in the development of her cancer. She said she was shocked when she realized that she may have had something to do with her diagnosis. Erica said,

> To find out that I had it and that I possibly had a lot to do with why I got it, the things that I did...and things that my husband did…was a shock to me. I did get STD's from him and the doctor told me that

> one of the STD's he gave me contributed to the cervical cancer.

This is What I Know

All of the women stated at the beginning of their interview that they knew very little about cervical cancer and cervical screening. However as the interviews progressed it became clear that many of the women had some knowledge about cervical cancer and cervical screening. As well, it became evident that there was a deficit in the women's knowledge. This lack of knowledge affected the women in different ways. All of the women reported that they felt learning about cervical cancer and cervical screening was extremely important for First Nations women. The participants in this study suggested various education strategies that could be implemented to help First Nations women learn about this important topic.

Level of Understanding of Cervical Cancer

Four women openly discussed the possible causes of cervical cancer. Two of the women reported that having multiple sexual partners put a woman at risk for developing cervical cancer. Gail and Ann said,

> I know it could be untreated STD's. Also, where women have more than one partner, when they're living an unhealthy lifestyle, that's a high risk for diseases like that [cervical cancer].
>
> I think a lot of women focus on multiple partners.

Another participant reported that a woman whose partner had multiple partners puts her at an increased risk for cervical cancer. Cathy said,

> I know that it could be from your partner having many sexual relations before you met. The hormonal changes after birth and the sexual activity of your partner. I know sometimes you can't find the cause of cancer.

Another woman reported that she believed that there was a connection between the development of cervical cancer and heredity, having sex at an early age, and birth control. Betty said,

> If you had sexual relations at an early age. Also, it's from heredity. And my younger sister and myself, who were on birth control, developed cervical cancer, so I think there's some kind of connection there too.

Check to See if Anything is Wrong

Three women reported that the pap smear is a test that it is used to see if anything is wrong. One of the woman reported that during her first pap smear she did not know what it was for or how it was done. She remembered that the doctor told her he was using it to check for STD's and cancer cells. Harriet said,

> That's where they check for cancer cells. That's all I know about Pap smears. The first Pap smear I'd ever taken was in 1994 and the doctor was telling me that he wanted to check for diseases...like for an STD and cancer cells.

Two of the women described the test in detail. Ann and Betty said,

> I know that it's for testing to find out if there's anything wrong with that part of your body. I know they take a swab of tissue and analyze it. I know you have to get it every year, especially when you become sexually active.
>
> That's when they open the inside and then they scrape the cervical area...and then they look at the cells, to see if you are a carrier of the cervical cancer cells. For mine the doctor will always check the vaginal walls just to make sure that everything's okay and no lumps are there.

Importance of Follow-up

Because the women understood what the test was used for, they knew that the follow-up was important for them. For example, one of the woman referred to the time following the test as a "waiting period". She reported feeling happy once she learned that the her test was okay and that she was healthy. Gail said,

> I would prefer the healthcare provider to call...and explain that everything is okay "We didn't find abnormalities" Because I feel after the test and in the waiting period you don't know what to think, how is it going to turn out, are they going to find something? Right until you get your test results in paper and you read it and you see there's no abnormalities then there's that sense of relief. Everything is okay. You're healthy and I feel happy after that knowing that there's nothing wrong.

The other women described similar feelings and further reported that she felt like she was left "hanging" when there was no follow-up. She stated that not only abnormal results should be followed up but normal results as well. She reported feeling anxious and nervous when waiting for the call because she thought that she might have missed it. Ann said,

> They said "this is what we're going to do with your biopsy and if there is a need for us to do surgery we'll contact you. If there isn't a need we won't call you". So to me, that's okay that they're going to call me if something was going to happen but regardless if there is anything or there isn't I think there should be someone to call you and say, "Your tests are okay" or give some sort of an explanation. Like you're just left hanging, waiting for the phone to ring or nervous because you're thinking you missed the call.

Quest for Information

Three women reported doing their own research once they were either diagnosed with cervical cancer and/or had an abnormal pap smear. These women felt frustrated when they discovered there was a lack of information for them to find. One woman reported that being able to do her own research gave her something that she could control, as she had no control over what was happening to her body. Erica said,

> There was very little information out there. When you go into the doctor's office, you see this rack, you know the sheets on flu's and stuff like that. There's nothing on cervical cancer. You really have

> to hunt and look for it. I think most of my frustration was not being able to find as much information as I could on my own, for my own benefit. I had to have control over that you know (laughs).

Another woman's quest for information not only created frustration but some anxiety as well. She reported that she didn't know how her tests progressed from CIN I to CIN II. She reported asking her care provider about this and remembers being told that if it had advanced to the next level it would have been considered to be cervical cancer. The participant than reported that she wasn't ready to hear any more information, and that the information she received was enough for her because she didn't want to know how far it could have gone. Ann said,

> When I was there last week my gynecologist said "I'm really glad you had surgery done because when we analyzed your Pap test you had developed to CIN 3" So I asked her to explain to me and she said that after CIN 3 it would be considered cancer. And that was good enough for me. I didn't want to hear anymore of how bad it would have gotten.

A woman diagnosed with cervical cancer was told that she would have to wait for 9 months to have her hysterectomy, and she reported that this really shocked her. The fact that she had done her own research increased her anxiety because she had read that it was very important to have the cancer removed immediately. Erica said,

> I remember when they phoned me about my surgery date was 9 months down the road. *Nine months*. I remember my sister was in the living room when I got the phone call and I was like "9 months, that's a long ways away. I could be dead by then" (laughs) I know I can laugh about it now but it seemed like such a long ways away to me at the time...and by that time I had already done all my research into cervical cancer…it just seemed like such a long ways away.

One participant sought out information from her family members only to be told that she would have to find out about the cervical screening test by herself.

She noticed that she was able to gain more information from some younger relatives. Fran said,

> The younger they got the more open they were. My older aunts that I was asking didn't feel comfortable sharing. One of them just told me, "you have to be there. I can't tell you". And the other one didn't answer me and just walked away.

Strategies for Prevention and Education

All the women thought that it was important for First Nations women to learn about cervical cancer and cervical screening. In addition, the women had various ideas of how this information could be presented to First Nations women. The women felt that the health centre was an appropriate place to learn about cervical cancer and cervical screening. The women understood the challenges of educating First Nations women. For example, some wanted one-on-one teaching, while others wanted to learn about this topic in a workshop format. The women felt that the teaching could begin in the schools, for example, during health classes. Furthermore, the women reported that both healing practices, traditional and western, needed to be combined when teaching First Nations women about cervical cancer and cervical screening. They also reported that if First Nations women were more open to discussing this topic, there would be less challenges in educating them about cervical cancer and cervical screening. One participant felt that education was very important as many women may only have screening when something is wrong. She felt that women need to be educated about cervical cancer and told that if it is discovered early it can be treated. In addition, women may also make some changes to their lifestyle, such as quitting smoking, if they were educated about the risks for cervical cancer. Another woman reported that it was important for women to know that the test is okay, as millions of women go through it everyday. Erica, Gail, Harriet, Fran, and Betty said,

> I think it should be in a school setting for young women, starting at age 12 or 13. It's sad to put the onus on somebody else to give this information to the kids, but the parents at home are reluctant or unwilling to change. So if you start providing information in the schools these kids are going to get that information then they're going to be able to provide that information to their kids. Or to their younger siblings...so hopefully in a generation or so, things will change and they'll be able to provide this information in the home setting eventually.
>
> I was stuck in my own world and my own way of seeing and understanding things and when I did make that step to go out from my community and go get some education I understood. I learned that there are a lot of things that we need to re-educate ourselves. And, coming back to my community I see a lot of women don't have that awareness...or the education that they need...to understand that we need to have prevention. Also, I think it would take First Nations and non-First Nations to combine their theories and educate the ladies.
>
> The health centre is open for everyone but not everyone has the opportunity to just pop in and ask questions. I would prefer to be invited personally to learn about cervical cancer in a workshop. [Also] I'm really close to elderly women. They like nurses coming to their home to talk to them. They really enjoy that.
>
> Cervical cancer…it's personal. [Women] could do more to learn about it. Be more open. The people we thought that we could ask about it, they don't [feel comfortable]…we're [young women] are left dangling. They put up a wall and send me back to the doctor to ask him.
>
> Most women, the only time they'll get a Pap is when something's wrong. By that time it's too late, then you've got to go to the extreme and get a hysterectomy. If they were getting screening, they could have caught it and monitored it and maybe they could have changed a little bit of lifestyle here, and there, cut down on smoking. Also to let women know that it's okay, millions of women go through this.

Although education was viewed as extremely important the women acknowledged that there would be challenges. For example, one participant felt that handouts about cervical cancer and cervical screening would be useful. She noted that they may need to be provided in a private viewing area. Erica said,

> I would pick up information on it but I don't know how other women would feel, if they would be comfortable enough to pick it up in the waiting room. Maybe off in another little room, you can just sit and read there. Just for one or two people, not very big. More private.

This is My Culture

All of the women reported that culture is important when discussing the health of First Nations people. Although one woman stated that she does not use traditional healing methods, she knew that this would be important for other First Nations women. Cervical cancer and cervical screening is a health issue that is not talked about among First Nations women. It's a personal issue that many First Nations women feel uncomfortable discussing as it involves mentioning the most private areas of a woman. Although, at times, it would seem that the described cultural beliefs could be barriers to care such as not talking about sex, or believing that cervical surgery causes a women to lose her soul, the women seemed to be simply reporting their cultural beliefs. The women felt it was important for non-First Nations care providers to learn about their culture.

Combining Traditional and Biomedical Healing

Three of the women felt that combining the two healing systems, both the traditional and the modern, was extremely important in their own care, as well as in the care of First Nations women. They reported that some of the diseases of today, such as cervical cancer, did not exist before contact with European people and therefore the traditional healers would not have knowledge of the medicines needed to heal these new illnesses. The benefits of traditional medicine are highlighted when a participant reported that she needed to get herself spiritually ready before treatment. Furthermore, this participant stated that by preparing the mind emotionally she prepared the body physically for healing. Erica, Gail, and Fran said,

> We still follow the traditional culture and beliefs in our family. I think we've moved along with technology and are trying to blend our culture and beliefs with the scientific and medical world. Combining the two. When I got my diagnosis...I needed to get myself spiritually set for this long hard task, with this long road that I had to go on. I sought spiritual guidance. I went to the ceremonies and stuff but I [also] combined that with drugs, medical tests and anything like that. I tried to combine the two. I find that a lot of people when they're diagnosed with any type of cancer they don't want to go through the medical route. They're trying to heal their illness through ceremony, sweat lodge, herbal medicines. But the way our family has come to, a solution I guess, is that these types of cancers that we're experiencing now weren't here before contact. Before Europeans got here. So consequently we would not have the knowledge on how to heal those types of cancers or illnesses...we have to combine the two. We have to be able to work along with science and medicine.
>
> I think it's important to combine the traditional and the western, for the health and well being of First Nations women. They need to understand that a lot of the diseases that we have today, we did not have. Then slowly, these diseases started coming. They had medicines to treat these diseases. Today it's different again with all these chemicals with the plants. They're not as strong as they were back then. They don't have that much power or strength, like they did back then, when there was no chemicals in the air or in the soil.
>
> We need to bring these issues out because we didn't have these diseases before. And these are new to our people. We have to take another route to heal, and develop another way of doing things or dealing with it. To try and overcome it. To help them [women] understand that they can still go through the traditional route, but for their spiritual well being, not their physical. To get their consciousness there to help them fight the disease. I was going to sweats and stuff, but I was combining the two. The sweats help to

> get rid of the impurities of any drugs or chemicals that they're giving you.
>
> I was told that a lot of things that are wrong with us now we don't have the traditional medical care for because new things are happening to us...new to traditional medicine.

You've Lost Your Soul

Two of the women reported that the soul of a woman resides in the cervix. Thus, if a woman were to have her cervix removed she would no longer have a soul or she would lose her power and strength as a woman.. Erica and Gail said,

> It is a sacred area and it is an area where a woman gets her strength. In our culture a woman is considered to have a lot of power and a lot of sacredness and it comes from our monthly menstruation. There's teachings behind that, my cousin, she had that strong traditional belief where you can't have your uterus taken out even though there's a disease or something. Life comes from there and that's a woman's sense of power. I don't know how else I can explain it but that's where we get our source of energy, our source of power, our source of strength.
>
> I went and spoke to Elders [women] about their beliefs and I found that (pause) traditionally or culturally, a woman's soul resides in the cervix. Early in my diagnosis I was really reluctant to have my uterus removed and the cervix, and I didn't know why. It was just like a feeling there. But speaking with these women, telling me that your soul resides there and if you have that removed then basically you've lost your soul. I was *really* astounded by that. That was part of the reason I started going to sweats to get a good grasp on that concept and I was getting myself in a spiritual place and a mental place, could I not transfer that soul elsewhere? After my surgery I was really at a loss. My soul was gone and then I was thinking, "No, I think I've been able to get myself to a place where I, transferred my soul. I still have it." So, that may be another reason that they're [First Nations women] reluctant to go through the surgeries and stuff like that and just live with it. They may not understand *why* it is that they're reluctant.

It's Taboo Talking about Sex

Three of the women commented that in First Nations culture it is not appropriate to discuss intimate issues such as, relationships and/or sex. They felt that this would have an influence on the women's choices of whether or not they would obtain a cervical screening test. In addition, young women who tried to discuss the test with relatives where told that it was something that they would have to learn about on their own. Betty, Erica, Fran, and Ann said,

> With our culture, everything's taboo, we don't talk about sex. So that's another issue within Native communities.
>
> Your sexual, your genital parts, your relationships and stuff like that are just a taboo topic to talk about and women generally don't talk about it. So now that we're moving into an era where you're supposed to be going for these Pap smears, once or twice a year, a lot of Aboriginal women just don't feel comfortable going for that test. A lot of women just avoid the issue I guess.
>
> When I first went in I wasn't sure what was going to happen. I tried to ask older women in my family but they didn't feel comfortable sharing that experience. So I was left on my own to experience it for myself.
>
> To me, you know, I'm open, but people around here are not open to talking about stuff like that. They want to keep it to themselves. Just be hush-hush about surgery or anything to do with the sexual part of themselves.

One participant further reported that this taboo existed between men and women. The woman reported that discussing these matters causes uncomfortable feelings. Erica said,

> It's another taboo area. You don't discuss that with men. Sometimes it's very difficult to talk about it and that's just the way you were raised. My family is different. We talk about anything amongst ourselves. But still there are limits to what we can discuss in front of our Dad or our brother. But for the most part we try to include them so that they can participate in our little talks.

Tension Between Cultures

One participant stated that she needed to accept that there are different diseases today. Western medicine is needed to treat them as the traditional healers would not have any experience treating them. However, Erica also stated that women will need to attend to all aspects of an illness and the self, spiritual and emotional. In addition, Erica felt that women cannot concentrate on the physical, 'get rid of it' only. This could, for many First Nations women, create tension or difficulties when trying to take care of themselves. Erica demonstrated this by stating that she has had to go through many things following her diagnosis with cervical cancer and her hysterectomy. She has since had many cervical screening tests and that this has occurred over 5 years, and now she has been given a 'clean bill of health'. She felt that her clean bill of health was possible because of the work that she knew she needed to do. She combined traditional ceremonies with modern healing methods and admits that she needed to bring herself to this understanding. Erica said,

> I had to come to the understanding that we don't have the knowledge to heal cancer. You can still use, our culture, our beliefs and rituals to help you spiritually, to get you into that place before you can get totally healed. So if you're just focussing on 'get rid of it, cut it out, get rid of it, get rid of it now' you know, in the end you're going to feel, 'hey, I should have sat back and thought about it'. Maybe that's where some of the women are, why they're feeling that way. The medicine wheel is so important. I find that now, and that's really sad that I had to get sick in order to get a good grasp of how it pertains to you personally. You have to be really balanced in order to overcome any type of illness.

One participant stated that she puts aside her cultural beliefs and prays before she has a pap smear. She does this so that she can tell the Creator that she does this for her health and that she does not disrespect herself as a First Nations woman. Gail said, Today I have to look at it in a different way. I understand our traditional beliefs, our traditional background for being a First Nation's woman, and having our sacredness. However, in this day and age there's a lot of diseases now that have come, and in order for us to prevent and to stay healthy, we have to look at the modern way of preventing. With the Pap smears I have to try and put these cultural beliefs aside in order for my own well being. I put it aside and I do it for my own health. At the same time I will acknowledge in a prayer and ask the Creator that "I don't do this intentionally. I do it for my own health and well being".

CHAPTER V: DISCUSSION

The purpose of this study was to explore the knowledge, attitudes, and health beliefs about cervical cancer and cervical screening among First Nations women residing in Onion Lake. A qualitative research design, using focused ethnography was used for the study. The eight interviews provided an opportunity to gain insights into the area of study. Findings from this study can be used to provide healthcare providers with an understanding of the challenges facing women contemplating cervical screening tests. Potential areas of, what does and does not work, when addressing the issue of cervical cancer among First Nations women is demonstrated. In addition, it is clearly emphasized in the findings that culturally appropriate interventions are important when providing health services to First Nations women.

The study findings lend credibility to the guiding theoretical framework, the HBM. For example, the components of the HBM became evident throughout the conversations with the women. Therefore, the discussion will include the findings as they relate to the components of the HBM.

Several of the women expressed feeling susceptible to cervical cancer. This in fact encouraged many to obtain cervical screening tests. Some women stated that this feeling of susceptibility was related to the fact that they knew of family members who had been affected by cervical cancer and by other types of cancer. The women stated that although they were afraid of cancer they knew that they had to continue with screening as this was a responsibility that they had for themselves and their own health. In addition, the women recognized that their own actions and/or that of the husbands could increase their susceptibility to cervical cancer. Having multiple partners was recognized as a cultural taboo, as traditionally, it was respectful to have only one life-long partner. The belief among First Nations people that breaking taboos can result in disharmony and illness has been identified by others (Calam et al., 1992; Lee, 1996; Mill, 1997, 2000; Plawecki, Sanchez, & Plawecki, 1994). All the women felt that it was important to learn about cervical cancer. They felt that young women should be taught about cervical cancer and the ways to prevent it. The women suggested that the teaching could be done in the schools during sexual education and/or other health classes.

All of the women believed that cervical cancer was a very serious health issue. Cervical cancer was viewed as a 'death sentence' by most of the women. Wilkes, Freeman, and Prout (1994) reported that Native Americans have a fatalistic view of cancer and that this is because of the fact that many diagnosed with cancer have died from cancer. This belief encouraged some of the women to obtain cervical screening tests and to return for follow-up and obtain treatment when they needed it.

The study participants reported that health services could be enhanced if they were integrated with traditional medicine. The First Nations women in this study sought traditional health services when they became dissatisfied with western services or when they did not have their questions answered. Also, the women may became scared or confused when they did not understand the process of western health services and the speed at which they tend to occur. Researchers, Broad and Allison (2002) found similar results when they examined the integration of western and traditional Hawaiian values. These authors reported that personal responsibility for health could be enhanced when individuals select pathways of treatments that were specific to their needs. In addition, Strickland and others (1996) found similar findings during their qualitative study and reported that First Nations women were unhappy with the communications that they had experienced with their healthcare providers. The women reported that the providers often appeared to be in a hurry, did not seem to be familiar with their health histories, and didn't have the time provide explanations about the care they were giving (Strickland et al., 1996). These findings were similar to the current study. The memories reported by the participants in this study demonstrate the need for healthcare providers to be aware of the impressions they, and the procedures, leave on their patients. They also need to consider the influence they have in making the experiences positive or negative. Its clear that these First Nations women will indeed remember their experiences for a long time, perhaps forever.

Six of the women stated that they obtained cervical screening tests because they believed that they are a benefit to their health. Cervical screening was viewed as a part of a healthy lifestyle and an instrument that protects health and well-being. The women expressed feelings of happiness following an exam, when the test showed no abnormalities. The women believed that the benefit of screening was that the abnormal cells could be treated if found early. Kegeles and others (1965) found that women's intents to obtain screening increased when they perceived that they could survive cervical cancer with early detection. Although this reference is older it demonstrates the usefulness of the HBM.

The women reported several barriers to cervical screening and/or to seeking treatment for an abnormal test which included; feeling embarrassed, feeling psychologically uncomfortable particularly with a male physician, the physical location of the examining room, feeling that the doctor has a cold abrupt manner, anxiety of having something put in you and having something taken away, lack of privacy, lack of understanding of the western healthcare system, and feelings of being rushed. Similar barriers have been reported in other studies (Moore et al., 1997; Brant et al., 1999; Calam, Norgrove, Brown, & Wilson, 1999; Clark et al., 1998; Fallsdown et al., 1991; Grunfeld, 1997; Katz, 1998). This study found that some of women felt embarrassed because they had to expose their "private parts" for the cervical screening test. First Nations psychological framework and holistic worldview would make them less likely able to think of their body parts as discreet parts, that is , isolated from the rest of the body, as women from western society. Calam and associates (1999) noted additional barriers to cervical screening for native women and these included; insufficient information on reasons for pap tests, inadequate follow-up and recall systems, feelings of embarrassment and lack of continuity in care. In addition, a seemingly uncaring manner and lack of communication were additional barriers to regular screening (Moore et al., 1997). These researchers concluded that an approach that includes a focus on staying healthy, providing clear information, and building trusting relationships with First Nations women is a crucial role for physicians and other healthcare providers.

Katz (1998) noted that the procedure and purpose of the test needed to be revealed through effective communication and simple language so that underscreened women will return for follow-up when results are abnormal. Explanations need to be provided before the test so that the woman can be prepared for possible outcomes of the test.

Moore and others (1997) argue that women who perceive that their provider cares about patients and who trust their provider will access preventive health services, including pap smears. The First Nations women in the current study felt the same way. They reported that healthcare providers can support them in their screening decisions. When the women felt listened to, they were more likely to trust and act on the healthcare providers' advice to 'get screened regularly'. Another cue to action for First Nations women in this study was the education that they received from their families. For example, one mother informed her daughter that screening was important especially when she became sexually active.

Almost all deaths due to cervical cancer could be prevented if women received regular screening and immediate treatment for abnormalities. These women identified friends, partners, spouses, family, and healthcare professionals as people who supported them. Crane (1996) found that informational support impacted adherence rates for cervical screening only when it was given by a professional. In addition, adherence rates for cervical screening were greater when the emotional support was provided by an immediate family member. The women in this study identified support and encouragement as a very important part of their healthcare decisions.

Implications for Nursing Practice

Nurses, especially in First Nations communities, are often the first point of entry into the healthcare system and as such have the opportunity to make this entry a smooth experience for the First Nations person. In addition, nurses need to be prepared to meet extraordinary situations in both a sensitive and competent manner (Canadian Nurses Association (CNA), 2000). Nurses who are aware of First Nations health beliefs will be able to make health visits as meaningful, respectful and effective as possible. To have effective working relationships with First Nations individuals, an understanding of the "tribal healthcare delivery system" is essential (Brant et al., 1999, p. 732). Brant and associates (1999) reported that nurses need to be aware of the fact that First Nations people have "suffered years of oppression by non-[First Nations]" and that this "oppression results in the lack of trust of non-[First Nations]" (p. 737). Therefore, the first goal of nurses working with First Nations women must be to establish a trusting relationship between themselves and their clients. In addition, these nurses must be willing to learn about the culture of First Nations people. Buehler (1992) reported that nurses may begin this process by asking women which tribe they are from and by asking what they need to know about their culture before providing health services.

The women in this study felt validated and appreciated when the care providers took time to explain to them what was about to happen, for example, what to expect with the Pap smear. In addition, nurses need to recognize that some First Nations women may equate removal of the cervix with a loss of the soul and because of this follow-up is important for these individuals to determine how they are coping. This study also demonstrated the effects that culture may have on the communication patterns between the practitioner and the patient. For example, a behavioural norm of First Nations people is the ethic of non-interference. Brant (1990) stated that "the advisor is perceived to be an interferer. His attempt to show that he knows more about a particular subject than the advisee would be seen as an attempt to establish dominance, however trivial, and he would be fastidiously avoided in the future. The ethic of non-interference, then, is an important social principle" (pg. 535). Nurses and other healthcare professionals should remind their First Nations clients that it is appropriate and expected, when accessing 'western' or biomedical' health services for clients to ask questions when they are unsure or require more information.

The findings from this study provide nurses with relevant information concerning the beliefs among First Nations women related to cervical cancer and cervical screening. Nurses may use this knowledge to promote regular cervical screening among First Nations women. As well, nurses can promote an understanding of cervical cancer among First Nations women by ensuring that culturally sensitive material is available for these women and located in appropriate, private areas. A system that incorporates culturally diverse practices can be developed and encouraged by nurses. Nurses can contribute to the development of education programs and resources based on the identified learning needs. A health education program providing the basic knowledge of cervical cancer would help decrease the fears among the women. For example, primary messages for a cervical cancer educational programs should include: the risk factors for the development of cervical cancer, the message that cervical cancer can be cured, the importance of early screening with the Pap smear, the need for annual Pap smears and the rationale for having Pap smears. However, this study found that the women had a fatalistic view of cervical cancer, and therefore nurses need to recognize the challenges that exist regarding cervical screening programs.

Several studies have found that First Nations people seek out health services when they notice that something is ‘wrong’ with their body or when they notice physical symptoms (Medicine, 1988; Mill, 1999, 2000; Morse et al., 1991). Because of this, a health message informing First Nations women that cervical cancer is generally a “quiet” disease and that women do not “feel” it is important. Furthermore, some studies have found that First Nations women suffer from a higher mortality rate due to cervical cancer because the cancer is found in late, untreatable stages (Hislop et al., 1992; Strickland et al., 1996). This health message, coupled with the knowledge that explains that this type of cancer is curable when found early, will allow the women to make an informed and knowledgeable choice for screening.

Nurses have always played an important role in terms of health education and disease prevention. They educate their client about their health and advise them on preventive measures. “In the past, nursing in Canada developed the necessary knowledge and skills to meet the needs of individuals, their families and communities and has been motivated by at least three currently cited principles of primary care – accessibility, public participation and health promotion” (Patterson, 2000, p. 1). Nurses practitioners in rural and/or isolated communities have been providing advanced care to their clients and to the communities for many years in Canada, and some may say the first nurses were actually doing this 300 years ago when Jeanne Mance and the Grey Nuns visited the sick in their homes (Patterson, 2000). The women in this study suggested that healthcare services would be improved if First Nations and non-First Nations care providers were providing care. For example, healthcare providers should utilize and support links between ‘western’ health systems and traditional health systems and healers (Gregory, 1989). It seems that this need could be met by the education of First Nations nurses. Care then would be maximized, as these nurses would have a greater understanding of the needs of community members. The movement for nurse practitioners was strong in the Canada in the 1970’s and this movement has been reawakened in recent years. Some models could meet these needs to educate First Nations nurses working in advanced nursing practice roles working on reserves.

The Role of the Advanced Practice Nurse

The use of an advanced nursing model may highlight potential competencies of the advanced practice nurse (APN) needed to improve the cervical screening rates among First Nations women. The Strong Model was chosen to identify the potential role of the APN in increasing screening rates among First Nations women.

The Strong Model of Advanced Practice: The Strong Model of Advanced Practice was developed by academic faculty members and a group of advanced practice nurses at Strong Memorial Hospital, University of Rochester Medical Centre in 1994 (Mick & Ackerman, 2000). The Strong Model incorporates 5 domains, which include, direct comprehensive care, support of systems, education, research, and publication and professional leadership. In addition, the Strong Model includes the conceptual strands of collaboration, scholarship, and empowerment (Ackerman, Norsen, Martin, Wiedrich, & Kitzman, 1996). The HBM model was used in this discussion to explain the health seeking behaviours of First Nations women based on their health beliefs as they relate to cervical cancer and cervical screening.

In the literature, the APN may be designated by many titles and this has caused great confusion when attempting to define advanced nursing practice (Kohr, 1998). As well, there is debate among nurses about whether or not the APN should be graduate prepared (Kohr, 1998). Although the intent of this report is not to present a definition of advanced nursing practice, it will be defined, for the purpose of this discussion, as a registered nurse who functions in an extended practice role and fulfills the domains identified in the Strong Model. The Strong Model was chosen because the identified domains are similar to others that are identified in the literature as areas of competence that are essential for advanced nursing practice (CNA, 1997; Davies & Hughes, 1995; Kohr, 1998).

Direct comprehensive care. According to the Strong Model activities that are patient-focused, such as assessments, procedures, patient counseling and interpretation of data, comprise the domain of direct comprehensive care (Ackerman et al., 1996).

To promote screening and understanding of cervical cancer in First Nations women, Clarke et al. (1998) reported the following recommendations from First Nations women. Informational aids that are culturally sensitive, simple to understand, non-threatening, are readily available and visible. First Nations women desired healthcare facilities to have a focus on women's health and to provide holistic healthcare that included both traditional and Western medicine and practices (Clarke et al., 1998; Strickland et al., 1996). Other authors have found that healthcare for First Nations people is holistic and involves a balance among all the parts of the person, mental, emotional, spiritual, and physical (Plawecki et al., 1994). Berger (1999) stated "there is no need to take an either-or-approach: the challenges of balancing life in 2 worlds, Native [First Nations] and non-Native [First Nations], are familiar to Native American people" (p. 15). The APN can ensure that culturally sensitive material is available for First Nations women. In addition, anxiety about the results of the test can be reduced when information about the test is provided before screening (Foxwell & Alder, 1993). The APN conducts and documents patient history and physical examinations that also includes an assessment of the psychosocial, cultural, and religious factors affecting the patient needs. A system that incorporates culturally diverse practices can be developed and encouraged by the APN.

Support of systems The domain, support of systems, is demonstrated by activities that nurses do to contribute to the promotion of "innovative patient care and facilitate the optimal progression of patients through the healthcare system" (Ackerman et al., 1996, p. 70).

Advanced practice nurses can prepare women for Pap testing and decrease their anxiety by explaining that the test is used to detect changes to the cervix not to detect cancer (Clarke et al., 1998; Ibbotson & Wyke, 1995; Strickland et al., 1996). As well, women need to know that abnormal results do not necessarily mean cancer is present (Ibbotson & Wyke, 1995). First Nations women need to know that they are welcome to bring a friend and/or family member for support during testing. Open and honest communication between the healthcare provider and the First Nations woman allows for feelings of relaxation and control. Also, First Nations women need to feel that they may ask questions about the test. In addition, the APN acts as a spokesperson for First Nations patients when interacting with other professionals, families, and the public.

Education The Strong Model supports the enhancement of student, public or caregiver knowledge related to health and illness (Ackerman et al., 1996). Nurses working in advanced practice can educate their First Nations clients about their risks for cervical cancer and the clinical usefulness of cervical screening. More specifically, education should be provided in a culturally sensitive manner. For example, preventative health messages need to be framed in terms of how screening contributes to the health of the community, not only to the health of the individual (Strickland et al., 1996). As well, the APN needs to emphasize that the Pap test contributes to wellness, rather than to the prevention of cancer. The APN identifies the learning needs of various populations and can contribute to the development of educational programs and resources. In addition, professional development of nursing staff through education is facilitated by the APN.

Research Ackerman and associates (1996) stated that the domain of research includes activities that "...support the generation of knowledge and the integration of research findings into clinical practice...this domain supports a culture of practice that challenges the norm and strives to find better ways to provide care, based on research" (p. 70). This domain strives to go beyond the status quo and search for more efficient ways to provide excellent patient care.

The knowledge imparted by research will provide nurses, other healthcare providers and policy makers, with relevant information. First Nations women's health beliefs concerning cervical cancer and cervical screening need to be identified, so that recommendations for an appropriate and culturally sensitive cervical screening program may be developed and implemented. Health education interventions are vital to health prevention efforts. More research is needed to provide First Nations women with effective health education interventions to influence health behaviours that will decrease the morbidity and mortality associated with cervical cancer and will contribute to models of care (e.g. health promotion programs that are acceptable to a variety of cultures). APN's conduct clinical investigations and participate in investigations to monitor and improve the quality of patient care services.

Publication and professional leadership. Leadership activities in this domain aid in the promotion of the nursing profession and require a commitment to the profession and the profession's public (Ackerman et al., 1996). As well, APN's are committed to the sharing and dissemination of findings relevant to their area of practice (Ackerman et al., 1996). Knowledge gained through experience in working with First Nations women and/or through research activities may be shared and disseminated through presentations or publication at local, regional, National, and international levels. The APN may also serve as a consultant to individuals and groups within the professional or lay communities (Ackerman et al., 1996).

Conceptual Strands. Collaboration represents the belief that the unique skills and expertise of various healthcare providers contributes to excellent patient care (Ackerman et al., 1996). Scholarship represents the on-going curiosity and constant inquiry that support the APN's actions and decisions (Ackerman et al., 1996). The final conceptual strand, empowerment, is essential and provides APN's with the authority to analyze and identify relevant problems and to develop, implement, and evaluate actions for the problems (Ackerman et al., 1996). These conceptual strands are intertwined throughout the five domains of the Strong Model and support indirect and direct care activities.

These interventions would also begin to increase access to health services. For example, a qualitative study in British Columbia (Browne, Fiske, & Thomas, 2000) reported that "...participants reported being affirmed as [First Nations] women by practitioners who either validated their pride in their culture and history or affirmed culturally defined body images. Validation of self-identity and cultural pride signaled a willingness to listen to the patient and to understand her health within the social and cultural dimensions that she defined as most important to her" (p. 24).

In conclusion, the above recommendations for APN's does not provide a complete list of all possible nursing activities for increasing cervical screening among First Nations women. These recommendations perhaps represent a beginning for APN's in Canada. Canada is a country with increasing cultural diversity and nurses have an ethical responsibility for providing culturally competent care (CNA, 2000).

Indications for Future Research

The knowledge, attitudes, and beliefs of eight First Nations women were explored in the current study. Further research is needed to target specific information concerning First Nations women choices of obtaining cervical screening tests. For example, development of culturally appropriate survey tools would aid in increasing knowledge for healthcare providers who provide care to Canadian First Nations women. LaBiondo-Wood and Haber (1998) reported that information gained through qualitative research could be used to develop research instruments. These instruments can be used to assess the efficacy of interventions that would increase access to screening. Some interventions could include the use of First Nations nurses providing care and informing the women that they may bring a friend for support during screening.

Researchers, Browne and Fiske (2001) suggested further research is needed about this topic and reported the following:

> Analyses are needed that recognize that high rates of cervical cancer (among other illnesses) can no longer be blamed on women's high-risk status, nor can low rates of participation in screening programs be attributed to cultural issues. Rather, these rates are perhaps equally indicative of women's avoidance of a health system that is not culturally safe and that does little to acknowledge or counter patterns of individual or institutional discrimination (p. 129).

Further research studies need to focus on these issues. For example, "Is there indeed a concern with access to appropriate health services for First Nations women?" If so, research needs to be done that documents these concerns so that they may be addressed in mainstream health services. Further examples of research questions could include: "What are the experiences of First Nations women obtaining health services in the Western healthcare system?" "What is the relationship between support and First Nations women's choice to obtain a cervical screening or return for follow-up?" "What is the lived experience of a First Nations woman diagnosed with cervical cancer?" "What is the lived experience of a First Nations woman undergoing a hysterectomy?"

Strengths and Limitations

The purpose of this research was to explore the knowledge, attitudes, and health beliefs of cervical cancer and cervical screening among First Nations women. In this study the qualitative design of focused ethnography was used.

The use of a purposive sampling method was a strength in this study in that it allowed for data to be collected from women who had experience with the topic. Therefore, the women who volunteered to be in this study were able to provide information that was pertinent to the research question. Once women informed the CHR of their interest to participate in the study, the researcher contacted them by telephone. The women who participated in the study had a telephone, spoke English, and had experience with cervical screening. This may represent a limitation of the study as women who were unable to read the posters, spoke only Cree or did not have a telephone may have been less likely to participate. These women may have provided different insights about cervical cancer and/or cervical screening.

Another strength found in this study was the fact that all the women were given a choice as to where they would like to meet for the interview. As this is a sensitive topic for First Nations women it was felt that if they were able to chose the meeting place it would allow for greater comfort. I feel that this allowed for the greatest amount of information to be collected.

Having worked in the community as a nurse for 4 years allowed the women to have a discussion about this sensitive topic with someone that they knew and trusted. I believe that this was a strength for this study. As well, being a First Nations woman, I think, allowed me to understand where the women were coming from when they told their stories and experiences. For example, I could relate to the feelings of shyness and embarrassment that some of the women felt during cervical screening tests, and therefore my ancestry was a strength in the study.

Summary

The information provided by these women will guide nurses in promoting cervical screening among First Nations woman. In addition, the information will provide nurses with knowledge required to support First Nations women's efforts in attending cervical screening programs. First Nations women are desperate for knowledge that they can use to support their health choices and decisions for themselves as well as for their families. There needs to be a collaborative effort among healthcare providers and traditional health providers. Many of the women discussed the importance of both belief systems to maintain and promote health among First Nations people. Culturally sensitive healthcare is paramount to health promotion efforts. First Nations women need trusting and understanding healthcare providers to provide the healthcare that they need.

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Appendix A: ONION LAKE HEALTH BOARD RESEARCH STUDY APPROAVAL

ONION LAKE HEALTH BOARD INC.
ONION LAKE HEALTH CENTRE
P.O. BOX 70, ONION LAKE, SK S0M 2E0
Phone: (306) 344-2330 Fax: (306) 344-4762

June 25, 2001

Faculty of Nursing
University of Alberta
EDMONTON, Ab.

<u>RE: PROPOSED STUDY – TINA WILSON</u>

Dear Dr. Mills:

On behalf of the Onion Lake Health Board, we are very excited and pleased to confirm that the OLHB Inc. agrees and supports the study composed by Tina Wilson from the University of Alberta Campus.

We understand the study will commence during the summer months, most likely July and August.

I trust this information is satisfactory, and if you require additional information, do not hesitate to call the Onion Lake Health Centre at 1-306-344-2330, ext #238.

Again, we look forward in working with Tina; she really is a pleasure to have around our work environment.

Sincerely,

Doreen Masson
Executive Assistant
Onion Lake Health Board Inc.

/drm.

APPENDIX B: INFORMATION LETTER FOR POTENTIAL RESEARCH PARTICIPANTS

Principle Investigator:	**Co-Supervisor(s):**
Tina Wilson Master of Nursing Student University of Alberta Edmonton, Alberta	Dr. Beverley O'Brien Dr. Judy Mill Faculty of Nursing University of Alberta Edmonton, Alberta

Project Title: Onion Lake First Nations Women: Knowledge, Attitudes and Health Beliefs of Cervical Cancer and Cervical Screening.

Purpose:

The purpose of this study is to learn what Cree women in Onion Lake think about cervical cancer and tests that can detect this type of cancer.

Procedure:

I will ask you what you know about this type of cancer and about tests that can tell if you have this type of cancer. You can choose when and where we can have this talk. The talks will be tape recorded. The talks will last 60 to 90 minutes. If you wish to do the talk in Cree you may use a translator of your choice. What you tell me could be used in a study in the future. If this happens, the ethics committee will need to approve.

Benefits and Risks:

There is no harm that can come to you if you take part in this study. If you become worried about cervical cancer I will help you find a healthcare provider to speak to if you wish. There is no direct benefit from being in the study. What you say may help nurses to give better care to Cree women in the future.

Confidentiality:

Your name and anything that could say who you are will not appear in any report about this study. You will be given a code name if you agree to take part in this study and only the code name will appear with what you say. I will keep your consent form in a locked cabinet separate from the tapes and typed copy of what you told me. Only me and whoever types what is said on the tapes will listen to the tapes. Only me and members of my research committee read the typed talks. I will keep the tapes and typed talks in a safe spot for at least seven years. Then I will destroy both the tapes and the typed materials.

I may publish or present some of what you tell me. If I do, I will not use your name or any information that may identify you. All information will be kept private except when codes of ethics or the law requires reporting.

Freedom to withdraw:

You do not have to take part in this study unless you want too. You can drop out at any time just by telling me. You may ask any questions that you have about the study. Your medical or nursing care will not be affected if you decide that you do not want to be in the study.

Right to refuse to answer a question:

You do not have to answer any question that you do not want to answer.

Questions about the study:

If you have any questions about the study you may call Tina Wilson at (780)492-7556 or my supervisors, Dr. Judy Mill at (780)492-7556 or Dr. Beverley O'Brien at (780)492-8232. If you have any concerns about any part of this study, you may call the Associate Dean at the Faculty of Nursing at the University of Alberta, Dr. Phyllis Giovannetti at (780)492-6251.

APPENDIX C: ENGLISH ADVERTISMENT FOR PARTICIPANTS

Cervical Cancer among First Nations women

Would you like to be a part of a research project being done that is exploring the thoughts and feelings of First Nations women about cervical screening and cervical cancer?

I'm a graduate nursing student from the University of Alberta, who used to be a community health nurse in Onion Lake, and I would like to hear from you.

If you are interested, please contact the Onion Lake Health Centre at 344-2330 and ask for a CHR. Tell her your name and number and the nursing student will call you and let you know all the details about the project.

APPENDIX D: CREE ADVERTISMENT FOR PARTICIPANTS

Cervical Cancer among First Nations women

Ki-nohtē wīcīhitān cī, Ōma ē-nitōskamihk? Tānisi e-itēyitahk āpōw ē-itamācīhot awa Nēhīyaw iskwēw. Ōma ōci manicōs ahkisōwin ēkwa pap test.

I'm a graduate nursing student from the University of Alberta, who used to be a community health nurse in Onion Lake, and I would like to hear from you.

If you are interested, please contact the Onion Lake Health Centre at 344-2330 and ask for a CHR. Tell her your name and number and the nursing student will call you and let you know all the details about the project.

APPENDIX E: DEMOGRAPHIC DATA

Tribal status
Number of children
Age
Relationship Status (is the participant in a relationship)

APPENDIX F: OPEN-ENDED QUESTION AND TRIGGER QUESTIONS TO GUIDE INTERVIEW

Open-ended question: Tell me what you know about cervical cancer?

Trigger questions will include:

1. What do you think is the cause of cervical cancer?
2. Do you think it is important for you to know about cervical cancer?
3. Can you describe strategies to prevent cervical cancer?
4. How would you protect yourself or those close to you from getting cervical cancer?
5. Can you tell me what a Pap smear is?
6. What do you think the Pap smear is for?
7. What would motivate you to have a Pap smear?
8. Why would you not have a Pap smear?
9. What are your experiences with the Pap smear?

APPENDIX G: INFORMED CONSENT FORM

Project Title: Onion Lake First Nations Women: Knowledge, Attitudes and Health Beliefs of Cervical Cancer and Cervical Screening.

Principle Investigator:	**Co-Supervisor(s):**
Tina Wilson Master of Nursing Student University of Alberta Edmonton, Alberta (780)492-7556	Dr. Beverley O'Brien (780)492-8232 Dr. Judy Mill (780)492-7556 Faculty of Nursing University of Alberta Edmonton, Alberta

Do you understand that have been asked to be in a research study?

___Yes ___No

Have you read and received a copy of the Information Letter?

___Yes ___No

Do you understand the benefits and risks involved in taking part of this study?

___Yes ___No

Have you had a chance to ask questions about this study?

___Yes ___No

Do you understand that you are free to withdraw from the study at any time? You do not have to give a reason and it will not affect your care?

___Yes ___No

Has the issue of confidentiality been explained to you?

___Yes ___No

May Tina Wilson keep typed talks for use in the future?

___Yes ___No

This study was explained to me by:____________________Date:___________

I agree to take part in this study.

______________________________ ______________________________

Signature of Participant Date

______________________________ ______________________________

Printed Name of Participant Date

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate. (May be signed by the translator if one is used, has explained all areas of the information and consent forms to the participant in the Cree language)

____________________________________ _____________________
Signature of Investigator Date

APPENDIX H: HEALTH RESEARCH ETHICS APPROAVAL

Health Research Ethics Board

biomedical research
2J2.27 Walter Mackenzie Centre
University of Alberta, Edmonton, Alberta T6C 2R7
p.780.492.9724 f.780.492.7303
ethics@med.ualberta.ca

health research
3-48 Corbett Hall, University of Alberta
Edmonton, Alberta T6C 2G4
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ethics@www.rehabmed.ualberta.ca

UNIVERSITY OF ALBERTA HEALTH SCIENCES FACULTIES,
CAPITAL HEALTH AUTHORITY, AND CARITAS HEALTH GROUP

HEALTH RESEARCH ETHICS APPROVAL

August 2001

Name of Applicant:	Ms. Tina Wilson
Organization:	University of Alberta
Department:	Graduate Studies; Nursing
Name of Co-applicants:	Dr. Bev O'Brien & Dr. Judy Mill
Organization:	University of Alberta
Department:	Nursing
Project Title:	Onion Lake First Nation Women: Knowledge, Attitudes and Health Beliefs of Cervical Cancer and Cervical Screening

The Health Research Ethics Board has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the subject information material and consent form (if applicable).

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval.

Sharon Warren

Dr. Sharon Warren
Chair of the Health Research Ethics Board (B: Health Research)

File number: B-130701-NSG