

EXPLORING CERVICAL CANCER SCREENING
BEHAVIOUR: AN INTERPRETIVE DESCRIPTION
OF ABORIGINAL WOMEN'S EXPERIENCES

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By

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ABSTRACT

Background: In Canada, the prevalence of cervical cancer in Aboriginal women continues to increase with a significantly higher mortality rate than women of non-Aboriginal ancestry. Despite that invasive cervical cancer is highly preventable with regular cervical cancer screening, participation in screening remains lower among Aboriginal women. Since limited information exists on the way cervical cancer screening is perceived and experienced, the purpose of this study was to gain an understanding of Saskatchewan Aboriginal women's perceptions related to and experiences with cervical cancer screening.

Methodology: This qualitative exploratory study used an interpretive descriptive approach. Perceptions related to and experiences with cervical cancer screening were elicited through individual interviews with eleven Dakota First Nation women. Women were recruited through purposive sampling techniques. Initially direct quotes from individual transcripts were coded, and then organized with other participant quotes that reflected thematic similarities.

Findings: Shared insights reflected a main theme that described perceptions of, experiences with, and factors influencing cervical cancer screening participation among Saskatchewan Aboriginal women. This theme, transitioning from experiencing the negatives of cervical cancer screening participation to living healthier, consisted of the women's mind-set (attitudes and cultural beliefs), knowledge, encounters with the health care system, and sharing information across the generations, which included patterns of communication and a community oriented approach.

Discussion: Findings of this study suggest that improving knowledge about cervical cancer screening and cervical cancer may increase screening utilization. Emphasis on health promotion and prevention should be considered when designing education programs. Interventions designed to improve screening rates are more effective when community members are involved in each phase, ensuring cultural relevance. Improving knowledge about, experiences with, and stories shared regarding cervical cancer screening among Aboriginal women may increase screening rates.

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DEDICATION

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TABLE OF CONTENTS

PERMISSION TO USE	i
ABSTRACT	ii
ACKNOWLEDGMENTS	iii
DEDICATION	iv
TABLE OF CONTENTS	v
LIST OF FIGURES	viii
GLOSSARY	ix
1 INTRODUCTION	1
1.1 Introduction to the Problem	1
1.2 Statement of the Problem	2
1.3 Purpose of the Study	2
1.4 Relevance and Significance of the Study	3
2 BACKGROUND	4
2.1 Theoretical Framework	4
2.1.1 Philosophical Assumptions of Interpretive Description	6
2.2 Review of Literature	7
2.2.1 Cervical Cancer	8
2.2.2 Knowledge and Attitudes	9
2.2.3 Cervical Cancer Screening	10
2.2.4 Cultural Factors	12
2.2.5 Cervical Cancer Screening Programs	15
2.2.5.1 Saskatchewan's Cervical Cancer Screening Program	16
2.2.6 Gaps in the Research	18
2.2.7 Summary	20
2.3 Research Questions	21
3 METHODOLOGY	21
3.1 Research Design	21
3.2 Setting	22
3.3 Sampling Strategy and Sample	23
3.4 Ethical Considerations	25

3.5	Data Collection	28
3.5.1	Data Trustworthiness	30
3.6	Data Analysis	32
4	FINDINGS	33
4.1	The Sample	33
4.2	Shared Insights.....	34
4.3	Context.....	37
4.3.1	Accessing Services.....	37
4.3.2	Developing Trusting Relationships.....	38
4.4	Point of Entry	41
4.5	Experiencing the Negatives	42
4.5.1	Fearing Disease	43
4.5.2	Hanging on to Privacy and Traditional Ways.....	45
4.5.3	Needing Direction and Support	47
4.5.4	Not Understanding and Needing Information.....	48
4.5.5	Putting Myself through It.....	50
4.5.6	Avoiding and Reacting	50
4.6	Receiving Information and Gaining Understanding	51
4.6.1	Receiving Reminders	52
4.7	Changing Perspective: Living Healthier	53
4.7.1	Living Healthier for Self	53
4.7.2	Living Healthier and Being a Role Model for Their Children.....	54
4.8	Across the Generations	55
4.8.1	Shared Vision – Informing Youth in the Community	57
5	DISCUSSION.....	59
5.1	Reflections on Findings	59
5.1.1	Transitioning from Experiencing the Negatives of Cervical Cancer Screening Participation to Living Healthier	60
5.1.1.1	Mind-Set	60
5.1.1.2	Knowledge	66
5.1.1.3	Encounters with the Health Care System.....	68

5.1.1.4	Sharing Information Across the Generations.....	71
5.1.1.4.1	Patterns of Communication	71
5.1.1.4.2	A Community Oriented Approach	72
5.1.2	Summary	73
5.2	Reflections on Methodology.....	74
5.2.1	Strengths of Qualitative Methodology.....	74
5.2.2	Limitations of Qualitative Methodology	74
5.3	Implications for Practice and Research.....	76
5.3.1	Nursing Implications.....	76
5.3.2	Research Implications	78
5.4	Conclusion	79
REFERENCES	81
APPENDICES	86
Appendix A:	Literature Review Charts.....	86
Appendix B:	Information-Consent Letter	96
Appendix C:	Demographic Form.....	99
Appendix D:	Interview Guide	100
Appendix E:	Reflexive Journaling.....	101
Appendix F:	From Codes to Themes.....	102
Appendix G:	Demographic Characteristics of Participants	103

LIST OF FIGURES

Figure 1: Dream Catcher Model – Transitioning from Experiencing the Negatives of Cervical Cancer Screening Participation to Living Healthier	36
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GLOSSARY

Aboriginal Peoples – defined as including Indians, Inuit, and Métis peoples under Section 35(2) of The Constitution Act, 1982 (Department of Justice Canada, 2006).

Indian – used in legislation such as the Royal Proclamation, The BNA Act, and The Indian Act to describe the original inhabitants of Canada (Saskatchewan Association of Health Organizations [SAHO], 2004).

First Nations – According to the Department of Indian and Northern Affairs Canada (2001), no legal definition exists of this widely used term. First Nations refers to the Indian people in Canada, with whom treaties were signed (SAHO, 2004).

1 INTRODUCTION

1.1 Introduction to the Problem

Even though rates for cervical cancer have been declining over the past twenty years, there are an estimated 1,300 new cases and 370 deaths in Canada in 2010, 35 of these new cases and 10 deaths occur in Saskatchewan (Canadian Cancer Society, 2010). Invasive cervical cancer is highly preventable. With regular cervical cancer screening (CCS), early detection of precancerous conditions can lead to treatment and may ultimately avert cervical cancer from developing. The procedures associated with CCS include a Papanicolaou (Pap) test and a pelvic examination. A Pap test can identify changes in the cells of the cervix; if these changes are detected and treated early, cervical cancer can be prevented. All women between the ages of 18 and 69 and women under 18 years of age who have been sexually active should have regular Pap tests (Canadian Cancer Society, 2006; Saskatchewan Cancer Agency, 2006). In addition, the Canadian Cancer Society recommends that women participate in CCS every 1 to 3 years. For women, development of this self-directed health behaviour is important.

In Canada, the incidence rates of cervical cancer have steadily decreased from a rate of 25 per 100,000 in 1969 to 15 per 100,000 in 1995. The national mortality rates have also steadily decreased, from a rate of 11 per 100,000 in 1951 to 2.39 per 100,000 in 1995 (Public Health Agency of Canada, 2003). Despite the overall decreasing provincial and national rates of cervical cancer, these rates continue to increase for Aboriginal women. “Cancer is the second most common cause of death in Aboriginal women in Saskatchewan” (University of Saskatchewan's Northern Medical Services Research and Development Committee, 2000, p. 1), with cervical cancer among the most common types. Gillis, Irvine, Tan, Liu, and Robson (1990) found that, in Saskatchewan, the incidence rate of cervical cancer in status Indians was 10 times higher than

the provincial average. Mortality rates due to cervical cancer for this population are four to six times higher than for non-Aboriginal women (Clarke et al., 1998). Why does this population's prevalence to cervical cancer continue to increase, in direct contrast to the trend seen in their non-Aboriginal counterparts?

Hislop, Deschamps, Band, Smith, and Clarke (1992) stated that in British Columbia participation in Pap testing of Aboriginal women was 30% lower than that of non-Aboriginals. Pap testing is an invaluable self-directed health behaviour. The earlier in life this behaviour is adopted and established as a routine, the greater the chance of early detection of cancer, which can ultimately lead to a decrease in mortality due to cervical cancer.

1.2 Statement of the Problem

Aboriginal women have low rates of CCS and a high incidence of cervical cancer (Band et al., 1992; Clarke et al., 1998). What factors enable or hinder Aboriginal women to regularly participate in CCS? In order for health professionals, especially nurses who provide the majority of health services to Aboriginals (Clarke et al.), to effectively work with this population, factors affecting CCS participation need to be identified from this population's perspective. In the past, only a limited number of Canadian studies have investigated factors affecting CCS participation of Aboriginal women. Furthermore, none of these previous studies were conducted in Saskatchewan. The phenomenon of interest has not been previously examined with this specific population.

1.3 Purpose of the Study

The overall purpose of this proposed study is to understand select Saskatchewan Aboriginal women's experiences with participating in CCS. The specific aim of this study is to

describe Saskatchewan Aboriginal women's experiences with participating in CCS and factors influencing their participation.

1.4 Relevance and Significance of the Study

Health promotion and disease prevention are keys to a healthy society. Participation in CCS is a health seeking behaviour that promotes the health of women and may prevent invasive cervical cancer. As stated earlier, Aboriginal women have low rates of CCS and a high incidence of cervical cancer. Cervical cancer remains a health issue for all women, especially Aboriginal women, which heightens the need for health promotion, disease prevention, and lifestyle changes.

The Aboriginal population in Saskatchewan is significantly younger than Saskatchewan residents as a whole. According to the most recent census (Government of Saskatchewan, 2005), 61 percent of the female registered Indian population in Saskatchewan is between 10 and 44 years of age, while the provincial population for females between 10 and 44 years of age is at 48 percent. Hence, Aboriginals have a significantly higher percentage of females in the child bearing years and the general Aboriginal population is the province's fastest growing segment. Without further CCS interventions, cervical cancer rates may potentially increase among Aboriginal women having disastrous implications on quality of life as well as unnecessary demands on health care.

Exploring Aboriginal women's experiences of becoming CCS participants will result in the identification of factors these women believe facilitate or hinder their CCS participation. The results of this proposed study may assist nurses and other health care providers to recognize and value the experience of CCS participation of Aboriginal women. This newly acquired

understanding and knowledge may assist in the development of effective, culturally appropriate interventions to increase CCS participation among this population.

Through the use of a qualitative method this proposed study will give a voice to Aboriginal women regarding their views and perceptions related to CCS. As well, the proposed study will address a population not previously examined, potentially fill a current gap in the knowledge base regarding factors affecting CCS participation of Saskatchewan Aboriginal women, and provide a foundation for future research in this area.

2 BACKGROUND

2.1 Theoretical Framework

Since little is known about the experience of CCS participation among Aboriginal women and factors affecting their participation, a qualitative exploratory approach is an appropriate research method. Qualitative research involves the study of “things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them” (Denzin & Lincoln, 2000, p.3). This study used the noncategorical qualitative approach of interpretive description (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997; Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004; Thorne, 2008).

Interpretive description was generated from the need for an alternative to the conventional qualitative approaches such as ethnography, grounded theory, and phenomenology. Thorne (2008) argues that these conventional qualitative approaches derived from social sciences, such as anthropology, sociology, and philosophy, are inadequate for nursing research. Traditionally, research designs would follow such particular methodological traditions and their associated rule structure meticulously to ensure credibility. However, these traditional qualitative approaches are grounded in non-nursing disciplines and are grounded in certain assumptions and

rule structures that are not always applicable to applied health research. “Theoretical traditions of the social sciences would contribute greatly to social theorizing without necessarily producing knowledge that could be put to any direct applied use” (Thorne, 2008, p. 33). This tension between theoretical integrity and utility was the key element in the development of interpretive description. This study, influenced by Thorne’s interpretive descriptive methods, explored participants’ experiences of participating in CCS. This interpretive description was initially similar to a phenomenological approach; however, it went beyond the description of lived experience to generate a theory that is applicable to nursing practice. Phenomenology seeks to elucidate the meaning and essence of the lived experience and, aims to identify and describe the subjective experiences of participants (Patton, 2002). Whereas, the analytic procedures in interpretive description involve synthesizing, theorizing and recontextualizing, rather than simply sorting and coding and describing, in order to understand the phenomena under study and ultimately generate a theory (Thorne, 2008).

Interpretive description is “grounded in an interpretive orientation that acknowledges the constructed and contextual nature of much of the health-illness experience, yet also allows for shared realities” (Thorne et al., 1997, p. 172). Interpretive description does not propose a prescribed set of procedures that must be adhered to, rather it consists of few guidelines that allow the researcher to accommodate the research method to fit research purposes with reasoned and mindful integration of theoretical and technical devices (Thorne, 2008). Studies using interpretive description are bound by several assumptions about human experience and about the nature and production of knowledge pertaining to it, which are discussed in section 2.2.1.

This method provides direction for an interpretive description that is generated on the basis of informed questioning and uses techniques of reflective, critical examination to

ultimately guide and inform disciplinary thought (Thorne et al., 2004). As a result of following general principles for analytical frameworks, sample selection, data sources, data analysis, and rigor, this study creates a sound interpretive description that contributes directly to our understanding of how Aboriginal women experience CCS and what nursing can do to make a difference (Thorne et al., 1997).

The use of a qualitative research approach such as interpretive description allowed the researcher to understand the individual perspectives of the participants in this study and enhance understanding of both unique and common realities. This study followed Thorne's interpretive description method which provided an understanding of Aboriginal women's "constructed realities" and reflected the socio-cultural contexts that influence their participation in CCS. These constructed realities emerged from interviews, researcher-participant interactions, and researcher interpretation of the data. In keeping with the tenets of interpretive description, for this study, the researcher took a reflexive stance toward the research process, attempting to acknowledge and understand how her own knowledge, beliefs, and values affected the research.

2.1.1 Philosophical Assumptions of Interpretive Description

Interpretive description studies:

- are conducted in a naturalistic setting that is respectful of participants,
- value subjective and experiential knowledge as a fundamental source of clinical insight,
- acknowledge common as well as unique realities,
- focus on timeless issues, while acknowledging the time and context during inquiries,
- acknowledge that human experience is socially "constructed" and may lose meaning if separated from its essential nature,

- “reality” involves multiple constructed realities that may well be contradictory, and
- the researcher, participants, and issue being studied each influence one another.

(Thorne, 2008)

2.2 Review of Literature

The literature review considers the current knowledge related to CCS participation among Aboriginal women living in Saskatchewan. For the purpose of this study, CINAHL (1982-2006) and Medline (1966-2006) databases were utilized. In order to locate literature the keywords selected included Aboriginal, First Nation, Indian, Pap smear, cervical screening, screening, factors, predictors, enablers, and barriers. All keywords were limited to research, female (where applicable), English, and peer reviewed journals.

Searches for numerous combined keywords were performed first on CINAHL and then on Medline. The searches produced the following results from CINAHL and Medline respectively, Aboriginal/cervical screening/factors (4, 8), Aboriginal/screening/factors (7, 42), Aboriginal/cervical screening/barriers (4, 4), and Indian/screening/factors (24, 135). When the combined 228 articles were refined to Saskatchewan, zero results remained. Since there were limited results for Canadian studies, the literature review was open to any geographic location. Abstracts for the 228 articles were retrieved on-line and reviewed for relevance to the topic of interest. All abstracts pertaining to Aboriginal women and CCS were further examined to identify the articles considering cancer screening practices, producing less than 10 articles from the original 228 articles. Eight research articles were obtained from the databases and the University of Saskatchewan library. Two additional articles were retrieved from reference lists in the existing articles for a total of 10 articles reviewed in this thesis.

Each article was reviewed individually using techniques suggested by Pinch (1995) and was set up in the form of a matrix (see Appendix A). The matrix allowed for a more manageable grouping and synthesis of the research articles. Five major themes emerged from the review: cervical cancer, knowledge and attitudes, cervical cancer screening, cultural factors, and cervical cancer screening programs.

2.2.1 Cervical Cancer

Cervical cancer remains a health issue for Aboriginal women. The reviewed literature illustrated that Aboriginal women continue to have higher incidence and mortality rates of cervical cancer than their Caucasian counterparts.

In discussion of cervical cancer, Smith, Christopher, and McCormick (2004) noted that the incidence rate of cervical cancer for Native American women was two to five times greater than for their Caucasian counterparts. Wilcox and Mosher (1993) stated that American Indian women have twice the risk of invasive cervical cancer than Caucasian women.

American Indian women have poor survival rates from cervical cancer, one of the most common cancers among this population, as compared to non-Native American women (Gordon, Campos-Outcalt, Steele, & Gonzales, 1994). In British Columbia, the mortality rate of First Nations women from cervical cancer was four to six times greater than the rate for non-Aboriginal women (Clarke et al., 1998).

Smith et al. (2004), who noted high rates of cervical cancer among Native American women, identified possible risk factors associated with cervical cancer, such as smoking, sexually transmitted infections, especially Human Papilloma Viruses, intercourse prior to age 18, multiple sexual partners, and multiple pregnancies. These factors may increase a woman's risk of developing cervical cancer; however, cultural, social, and economical issues may also contribute.

These findings are alarming at a time when precancerous conditions of the cervix can be detected early with regular CCS and follow-up medical treatments can ultimately prevent cancer from progressing to advanced stages. A better understanding of the CCS behaviours of Aboriginal women may be achieved by examining knowledge and attitudes, screening practices, and cultural factors related to both cancer risks and cancer prevention.

2.2.2 Knowledge and Attitudes

Knowledge and attitudes can affect one's health behaviours and are important to consider. Various reviewed articles discussed Aboriginal women's perceptions of cancer screening, while others explored this population's awareness and understanding of CCS.

A quantitative study in the United States, which included a small sample representing 12 percent American Indian women, stated that cancer screening may not be viewed as a major health concern among American Indian women due to other health issues common to that population, such as diabetes (Foxall, Barron, & Houfek, 2001). A qualitative case study on CCS services utilization was conducted in a western Canadian city and examined factors influencing full implementation of women-centered care (Bottorff, Balneaves, Sent, Grewal, & Browne, 2001). Bottorff et al. reported that First Nations women often prioritize meeting basic needs over preventative health care.

A common finding from the literature included a lack of knowledge regarding Pap tests. Studying the understanding and beliefs of Apsaalooke women concerning cervical health, Smith et al. (2004) revealed that 30 percent of the participants were unaware of a test to check for cervical cancer. Further, a Canadian qualitative study involving First Nations women from 30 bands (Clarke et al., 1998) and an American study focused on Lumbee women (Michielutte, Dignan, Sharp, Blinson, & Wells, 1999), illustrated that for women who were aware of CCS,

many had little prior knowledge of the purpose and procedure of a Pap test. Older women were more likely to report lack of knowledge (Michielutte et al.).

Studies found that emphasis on more immediate health issues and needs of daily living held precedence over CCS among Aboriginal women. Further, a knowledge deficit regarding CCS was found among this population, especially among older women. How do these attitudes and knowledge deficits impact Aboriginal women's CCS practices?

2.2.3 Cervical Cancer Screening

There is concern that Aboriginal women are not obtaining appropriate screening for cervical cancer, which potentially contributes to elevated mortality rates for this disease. The rates of screening vary widely from study to study; however, in each case rates have been found to be low. The literature examined CCS rates among Aboriginal women, compared these rates to women from varying ethnic backgrounds, and associated screening rates with social determinants. Similar to findings concerning Aboriginal women, Oelke and Robinson Vollman (2007) found that cervical cancer in immigrant women, a growing population in Canada, is also less likely to be detected early than it is in the general population, as immigrant women tend not to take advantage of screening.

Among the studies that involved multiple ethnic groups as participants, comparisons of CCS rates between these groups supported the existing literature that Aboriginal women have lower rates of participation than those of other ethnic groups (Foxall et al., 2001; Johnston, Boyd, & MacIsaac, 2004; Wilcox & Mosher, 1993). This is reiterated in a British Columbia First Nations women's study which found participation in the CCS program is less regular and less frequent than participation by among other women in the province (Clarke et al., 1998). These

findings further emphasize the need for CCS focused health promotion and prevention interventions for this population.

The study by Johnston et al. (2004) was the only one which compared CCS rates of urban and rural residents. Results stated that women were less likely to have had recent Pap test if they resided in a rural area and were from Aboriginal communities.

In 2004, 35 percent of Apsaalooke women in Southeastern Montana had not received a Pap test in the previous year, while 14 percent had not received one in the past three years or longer (Smith et al.). Pap test screening rates of American Indian women in urban Phoenix were found to be 76 percent in the previous 3 years, dropping to just 49.5 percent in the past year (Risendal, DeZapian, Fowler, Papenfuss, & Giuliano, 1999). These rates were statistically below the national estimate (83.6%) and objective (85%). Gordon et al. (1994) calculated screening rates for Pascua-Yaqui women in Arizona with alarming results; 54 percent of eligible women had at least one Pap test over five years and merely one percent received yearly Pap tests.

The most prevalent finding amongst the research studies was that all women of older age, including Aboriginal women, were less likely to participate in CCS, having lower rates of screening than younger women (Coughlin, Uhler, & Blackman, 1999; Johnston et al., 2004; Michielutte et al., 1999; Risendal et al., 1999). Aboriginal women of childbearing age are more likely to have a routine CCS (Risendal et al.). However, once past the childbearing age, screening rates declined as many women associated the Pap test with prenatal care (Risendal et al.). Women of childbearing years have more frequent visits to family physicians for family planning and prenatal care (Clarke et al., 1998; Wilcox & Mosher, 1993). Thus, there is need for nurses to emphasize that educational programs be developed targeting older women past child

bearing years (Michielutte et al.) and for further exploration of CCS underutilization factors among older Aboriginal women (Gordon et al., 1994).

In addition to age and place of residence, the extant literature reports various factors associated with screening rates, primarily those related to social determinants. Johnston et al. (2004) and Wilcox & Mosher (1993) both associated lower income and education levels with lower rates of screening. Further, Coughlin et al. (1999) found that Aboriginal women who did not visit a physician annually had lower cancer screening rates. As well, access to services, including but not exclusive to location (Bottorff et al., 2001), hours of operation (Michielutte et al., 1999), transportation and child care issues (Michielutte et al.; Smith et al., 2004), and inconsistent medical checkups (Risendal et al., 1999), were seen as barriers to CCS participation. Physical and emotional distress, such as discomfort from the procedure (Bottorff et al.; Michielutte et al.), anxiety (Clarke et al., 1998; Foxall et al., 2001), embarrassment (Clarke et al.; Michielutte et al.), and history of abuse (Bottorff et al.; Clarke et al.) were negatively associated with screening rates.

In reviewing the literature, it was found that Aboriginal women's CCS rates were lower when compared to screening rates of Caucasian. In addition to race and ethnicity, various factors such as aging, rural residency, lower education, lack of annual physician visits, and emotional distress, were associated with lower screening rates.

2.2.4 Cultural Factors

There are numerous definitions of culture from various disciplines. In the field of nursing, Leininger (2006) defines culture as “the learned, shared, and transmitted values, beliefs, norms, and lifeways of a particular culture that guides thinking, decisions, and actions in patterned ways and often intergenerationally” (p.13). An appreciation of cultural factors is

important in recognizing and understanding how individuals conceptualize health and illness and how these conceptualizations affect their health behaviours (Burnard, 2005; Kleinman, 1980). Throughout the reviewed literature notable cultural factors have been identified regarding cancer, CCS, and Aboriginal women.

Cancer is indiscriminant, crossing cultural boundaries and evoking feelings of fear, anxiety, depression, and anger. Aboriginal cultures share these same feelings, but how these emotions are uniquely interpreted through cultural beliefs and values of wellness and illness influence health behaviours. For example, in the Apsaalooke culture, it is believed that to say the word “cancer” is asking for the disease to be brought on them (Smith et al., 2004). Thus, it may not be common for some First Nations to discuss cancer due to a belief in the power of language.

Death and surgery were two other fears that women perceived when asked about cervical cancer. Almost 20 percent of American Indian women surveyed on knowledge, attitudes, beliefs, and behaviours regarding CCS believed that cervical cancer meant death (Risendal et al., 1999). When asked if there were things a woman could do to prevent or control cervical cancer, over 25% of women responded “no” (Smith et al., 2004). This fatalistic attitude was found to be more common among older women, as they believed cervical cancer to be incurable (Michielutte et al., 1999). Further, Michielutte et al. found that nearly half of women surveyed feared that a hysterectomy would be necessary if cervical cancer was detected. These beliefs about cancer often deter adoption of health prevention behaviours and early detection.

Participation in CCS may be hampered by a lack of female healthcare providers. Having a male physician perform intimate examinations such as a Pap test raised cultural and personal issues of modesty, embarrassment, and inappropriateness (Bottorff et al., 2001; Clarke et al., 1998; Michielutte et al., 1999; Smith et al., 2004). Smith et al. stated taboos regarding opposite

gender healthcare providers are part of cultural beliefs maintained in many Aboriginal First Nations.

According to Clarke et al. (1998), for some First Nations women, seeking out health care when one is not ill has a negative health focus. Many Aboriginal women feel that a Pap test is unnecessary if a woman is asymptomatic. Foxall et al. (2001) discovered that, although American Indian women had lower screening rates than Caucasian and African American women, they were “more aware of and sensitive about their bodies” (p. 734). Foxall et al. suggested that this awareness of one’s body may lead to a perception of decreased need for screening participation.

There were a few inconsistencies in the findings among the studies reviewed. Clarke et al. (1998) found that Aboriginal women talked to friends and family rather than health care providers to receive health-related information, while Smith et al. (2004) found that Aboriginal women were uncomfortable talking to friends and family about cervical health. Informal communication between friends and family through story telling or talking circles is a common way for Aboriginal women to obtain health information. Aboriginals use the tradition of oral communication as a method of sharing and remembering stories and experiences (Crazy Bull, 1997 as cited in Smith et al.). Crazy Bull described oral communication as face to face and placing emphasis on tradition and continuity. The sensitivity of this topic may oppose traditional ways of communication for Aboriginal women due to its uncomfortable nature; therefore, it is important for health care providers to address the topic of cervical health in a culturally sensitive and appropriate manner.

Cultural factors regarding cancer, CCS, and Aboriginal women identified in the literature included: power of language, beliefs that cancer is incurable and results in death, opposite gender

healthcare providers are taboo, asymptomatic women do not require health care, and oral communication is a traditional form of communication. Cultural similarities exist among Aboriginal women in general, but specific beliefs across First Nations. These First Nations specific beliefs uniquely impact screening practices; thus, it is important for researchers and healthcare providers to focus research and programming toward individual First Nations.

2.2.5 Cervical Cancer Screening Programs

A few projects on CCS have been conducted, implemented, and evaluated with Aboriginal women. In particular, one participatory research project (Clarke et al., 1998) and one clinic targeting cervical cancer (Bottorff et al., 2001) involved working with First Nations Bands, organizations, and individual women. In both instances, cultural relevance was emphasized for planning and implementing research and programming.

In British Columbia, initiatives aimed to enhance CCS participation among First Nations women were implemented and evaluated (Clarke et al., 1998). The project developed culturally sensitive initiatives regarding knowledge, environment, and health care worker issues that were previously identified through qualitative interviews. First Nations women from 30 local Bands were involved in the research project from the beginning, not only as research participants, but also as members of the research team. The print material intervention was deemed successful as it was culturally suitable, accessible, and provided an overall message of health promotion. However, the First Nations Women's Pap smear test clinic was not a successful intervention in terms of attracting a large number of women to the service, mainly due to accessibility barriers, such as location and time (Clarke et al.). Long term evaluation of the study's interventions is still required.

A First Nations clinic in urban western Canada that focused exclusively on cancer screening made efforts to become more culturally relevant and welcoming to First Nations women (Bottorff et al., 2001). Despite interventions including an informal reception environment, providing snacks, displaying culturally appropriate posters, employing female staff, and flexible scheduling, clinic attendance remained low. Key informants reported that the clinic's location and exclusive cancer screening focus deterred women from attending. In addition, the clinic relied on informal advertising, a traditional method of communication among First Nations people; however, the clinic needed a larger mass of women to "spread the word".

Wilcox and Mosher (1993) suggested that "interventions to increase access to medical services may be more efficient for promoting health benefits than separate interventions directed to specific conditions" (p. 85). However, Michielutte et al. (1999) stated that programs need to address a variety of barriers specific to the target population. Risendal et al. (1999) concurred, stating that "the identification of factors in specific communities that affect screening participation is critical in the development of effective cancer prevention and control programs" (p. 516). This finding identifies a need for research to be conducted with individual Aboriginal communities rather than mixed or diverse groups, such as in a national study.

The literature emphasizes cultural relevance and community specific interventions to assist with overcoming existing barriers to CCS for Aboriginal women.

2.2.5.1 Saskatchewan's Cervical Cancer Screening Program

Since the 1970s, opportunistic screening for cervical cancer has occurred in Saskatchewan and has played a significant role in reducing the incidence of and mortality rates associated with cervical cancer. Incidence rates decreased steadily in the 1970s and early 1980s, then began a more moderate decline since the mid 1980s. The opportunistic screening approach

hit a plateau in the reductions of incidence and mortality, creating a need for a more organized and systematic screening approach. A comprehensive approach to CCS was approved in 1997 and included implementation of an information system with registry and recall functions, targeted recruitment, quality assurance in the laboratory and clinic, public and professional education, ongoing surveillance, and education. This comprehensive approach, currently known as the Prevention Program for Cervical Cancer (PPCC), was implemented in 2003 and is operated by the Saskatchewan Cancer Agency (SCA). The SCA is responsible for the provision of cancer treatment, prevention and early detection programs, research, and education services to the people of Saskatchewan. (Saskatchewan Office of the Information and Privacy Commissioner, 2005)

The PPCC is a screening program dedicated to the prevention of cervical cancer and was developed to ensure that all Saskatchewan women between the ages of 18 and 69 are regularly tested for cervical cancer and receive appropriate follow-up when needed. The PPCC provides education about cervical cancer and screening, informs women by mail when they are due for a Pap test (“reminder letter”), notifies women by mail of their Pap test results, and works with physicians and nurse practitioners to ensure appropriate follow-up of abnormal test results. Reminder letters are sent to women annually. Once a woman has had two concurrent Pap tests with normal results (indicating change in the cells of the cervix has not been detected), the PPCC recommends regular screening every three years instead of annually and reminders are sent out accordingly. All Saskatchewan women are automatically registered in the PPCC when they turn 18 years of age; however, women can choose not to participate in the PPCC. (Saskatchewan Cancer Agency, 2010)

2.2.6 Gaps in the Research

Identifying limitations and gaps in the reviewed literature are important considerations of this research. As stated earlier, there is a scarcity of research regarding factors affecting CCS among Canadian Aboriginal women. Only one Canadian study was found focusing exclusively on Aboriginal women and this study produced only generalized themes as it involved 30 different Aboriginal bands. Two other Canadian studies reviewed had limited data from Aboriginal women due to small sample sizes from this population. Caution must be exercised when generalizing findings of national studies to Saskatchewan Aboriginal populations. Too small a sample size imposes many problems with the statistical validity of a study (Burns & Grove, 2005). Furthermore, no studies from Saskatchewan or with reference to Saskatchewan Aboriginal women were found. Neither the SCA nor Saskatchewan Health had segregated data regarding CCS rates, incidence of and mortality rates for cervical cancer among Aboriginal women. This finding suggests a great need for research involving Saskatchewan Aboriginal women, a population not previously examined.

A lack of homogeneity among subjects has been identified above as a gap in research. As stated earlier, programs need to address a variety of barriers specific to the target population, therefore research should be conducted with individual Aboriginal communities rather than mixed or diverse groups.

The majority of research designs were quantitative, predominantly using secondary analysis methods. This trend suggests a need for continued research using both quantitative and qualitative designs. However, the lack of qualitative studies verifies the scarce exploration in this area. As well, the modest knowledge base regarding this topic necessitates the need for a qualitative study, which will explore the phenomenon in depth and further contribute to this

knowledge base. Qualitative studies are essential because “further research is...required in developing and testing frameworks and theories to guide the development of culturally suitable nursing and health care” (Clarke et al., 1998, p. 41). Since only four of the 10 research articles were published in the past 5 years, current research studies are necessary to contribute to and refresh the knowledge base on this topic.

Self-reported screening practices used as a measurement for screening utilization in many of the studies limited the validity of the data. “It has been found that self-reports of history of Pap tests received are often inflated when compared to medical records so the actual proportion of women screened could be lower” (Michielutte et al., 1991, as cited in Smith et al., p.80-81). However, there is existing literature to support the conclusion that CCS rates of Aboriginal women are lower compared to non-Aboriginal women even when health records are utilized to measure screening rates (Gordon et al., 1994; Johnston et al., 2004). This supporting evidence shifts the emphasis of further research inquiry from examining screening rates to focusing on an understanding of why these rates are low.

The variables used to examine factors affecting CCS participation differed greatly from one study to another. This revealed a need for an understanding of factors prior to examining associations or correlations to screening participation. For example, Michielutte et al. (1999) had a list of 17 specific psychosocial factors that “did not represent a comprehensive list of all possible barriers to cervical screening” (p.4). The 17 factors included statements such as “If I have cancer, I don’t want to know about it” and “I don’t need a Pap smear if I’m not having more children” (p. 13), while Coughlin et al. (1999) examined factors such as marital status, physician visits, and substance use. These predetermined lists with “yes/no” answers did not

allow the researchers and participants to explore all factors affecting participation. This variability again points to a need for qualitative research.

2.2.7 Summary

A review of literature has been conducted to explore the extant knowledge regarding factors affecting CCS participation among Aboriginal women. Ten articles acquired from comprehensive searches on the CINAHL and Medline databases were collectively reviewed to determine the current knowledge on factors affecting CCS participation among Aboriginal women. Five common themes emerged from the literature: cervical cancer, knowledge and attitudes, cervical cancer screening, cultural factors, and cervical cancer screening programs. Cervical cancer remains a health issue for Aboriginal women, who have higher incidence of and mortality rates due to cervical cancer than their Caucasian counterparts. Knowledge regarding CCS, including its purpose and procedure, is minimal among the Aboriginal female population in general; however, this finding was more predominant among older Aboriginal women. Emphasis on more immediate health issues and needs of daily living held precedence over CCS among Aboriginal women. Of significance were the findings that Aboriginal women have lower rates of CCS, attributable to multiple factors. In general, older women are less likely to participate in CCS than are younger women; this finding was also noted among Aboriginal populations. Most of the studies looked at utilized quantitative methods; however, qualitative methods are particularly appropriate since they value Aboriginal oral traditions of communication. The use of qualitative inquiries to examine issues related to CCS practices and behaviours capture the richness of the data while respecting Aboriginal ways of knowing. Some of these studies could have contributed to increased stereotyping while marginalizing these women further in obfuscating the social, cultural, and historical context that influence Aboriginal

women's sexual or reproductive health and willingness to participate in CCS. Literature regarding CCS projects and evaluations of existing CCS programs emphasizes cultural relevance and community specific interventions to assist with overcoming existing barriers to CCS for Aboriginal women. Limitations identified throughout the review were addressed as gaps in the research and highlighted the need for further research. An appropriate direction for future research would see the inclusion of qualitative studies with Aboriginal women. Qualitative research would facilitate the development of theories for the guidance of culturally sensitive and appropriate nursing interventions. A further learning from the literature is the need to respect the uniqueness of each culture, indicating that bands should be examined separately; therefore this study considered a single reserve setting in Saskatchewan.

2.3 Research Questions

Two research questions led to the understanding of select Saskatchewan Aboriginal women's experiences with participating in CCS: (a) How do select Saskatchewan Aboriginal women describe their experiences of and feelings toward CCS and (b) What are the factors affecting CCS behaviour as perceived by select Saskatchewan Aboriginal women.

3 METHODOLOGY

3.1 Research Design

A qualitative methodology was used to elicit select Aboriginal women's perceptions of their experience of CCS participation. Qualitative methods facilitate the exploration of the participants' experiences in depth and detail (Patton, 2002) through a traditional method of communication. Qualitative research involves the study of "things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them" (Denzin & Lincoln, 2000, p.3). The research design utilized in this study was a qualitative

exploratory study using Thorne's interpretive description as the methodological approach. The interpretive description paradigm, through reflexivity, acknowledges and attempts to identify the influence a researcher and participants may have on the research process and outcomes. As well, interpretive description assumes that reality and knowledge are socially and culturally constructed as individuals create meaning through their interactions with one another and their environment; thus the participants' culture has been acknowledged and respected. The researcher demonstrated respect for participants and their culture through establishing rapport, as well as learning about and understanding participants' views and experiences from their perspectives (Charmaz, 2006). Maintaining fundamental underpinnings of interpretive description, the researcher was able to acknowledge and gain an understanding of unique individual perspectives as well as common realities.

3.2 Setting

Data collection took place in Standing Buffalo First Nation Reserve located in southeastern Saskatchewan approximately 85 kilometers from Regina. A community health station is located on reserve land, which provides health services. A working research relationship between the Standing Buffalo population and the researcher's supervisor has been established and strengthened over the past several years. Prior to this study, the researcher met two Elders from the community and the Director of Health in conjunction with a previous research project. These relationships facilitated a smooth transition, for the researcher, into the field and to begin the process of becoming familiarized and engaged with the community.

Face-to-face interviews were conducted at the community health station. This naturalistic approach allowed for a more real world setting, avoiding manipulation of the phenomenon of interest (Charmaz, 2006; Patton, 2002). Only the participant and interviewer were present in the

room during the interview. This approach encouraged comfort and openness for the participant, as well as provided a safe environment for the participant and researcher.

3.3 Sampling Strategy and Sample

The sampling strategy consisted of purposive sampling to select participants who knew the experience of CCS participation. Thus participants were selected on the basis of their ability to contribute to the knowledge under investigation. Initially, potential participants who met the eligibility criteria were identified by the community's Director of Health. After initial participants were interviewed, variation sampling was used to select subsequent participants within the age range from 40 to 69 years. Variation sampling is a strategy for purposeful sampling that "aims at capturing and describing the central themes that cut across a great deal of variation" (Patton, 2002, p. 234-5).

The community's Director of Health was contacted to assist with recruitment of participants who met the eligibility criteria. Through the use of variation purposive sampling, to direct further data collection, new participants were selected on the basis of age and ability to contribute knowledge, ultimately changing the sample criteria to meet the variation criteria. The Director of Health was provided with an information letter outlining the study's purposes and procedure, potential risks and benefits, confidentiality and storage of data, participant's right to withdraw, and researcher's contact information. Women in the community were approached by the Director of Health to consider participation in this study. The Director of Health provided the researcher with names and contact information of women who expressed interest in the study. However, due to the fact that a number of community members did not have a working telephone line, interviews were set up by the Director of Health. Interviews were arranged at a convenient time for each participant in which to conduct the interview at the community Health

Station. In total, 16 women were scheduled for interviews over a 6 week period of time. Five women did not show up for their scheduled interview and were considered as withdrawals from the study prior to their interview for unknown reasons. A total of 11 women participated; each was interviewed once. In order to maintain confidentiality, the Director of Health was unaware of who participated in the study.

For this study, the initial inclusion criteria for participants during initial sampling were: ability to speak and read English; Aboriginal ancestry; resident of Standing Buffalo First Nation; between 18 and 69 years of age; and having had a Pap test within 36 months prior to participating in the study. A focus on Saskatchewan Aboriginal women having residence on a reserve and from a single band allowed this research to potentially fill a current gap in this area of study. Women with a known history of cervical cancer, either personally or a known immediate family member, were excluded from the study as their focus may have shifted from CCS participation to cervical cancer treatment. As well, this topic may have been too sensitive for those particular women to explore. After initial sampling, subsequent participants were selected based on their age and ability to contribute knowledge regarding irregular CCS participation. Selection then focused on women between the ages of 40 and 69 years, since all previous participants were under 40 years of age. Women interviewed in this particular age range tended to either have irregular (4 or more years since their last CCS) or nonexistent CCS participation status, and their perspectives on CCS were explored as well. The researcher modified the interview guide to accommodate for this change in participation knowledge to reflect future-tense rather than past-tense questions to capture thought patterns, since there was an absence of action (participation) among non-participant women.

Interpretive description can be conducted with various sample sizes, but typically tend to be relatively small (Thorne, 2008). Sandelowski's (1995) principle for determining sample size is that "an adequate sample size in qualitative research is one that permits the deep, case-oriented analysis that is a hallmark of all qualitative inquiry, and that results in a new and richly textured understanding of experience" (p. 179). Often time and money constraints make it difficult to recruit a larger number of participants. Eleven semi-structured interviews were conducted. Since a formal formula does not exist to determine sample size in qualitative research, the sample size for this study was determined by saturation. Saturation, as defined by Thorne as repetition of themes in the data, was reached with the first seven participants; however, interviews with an additional four participants were conducted and included in this study to be respectful to the women who were already scheduled for interviews and to acknowledge the community's interest in this study. Acknowledging that there is always more to discover (Thorne, 2008), the researcher found the data gathered from the small number of participants in this study had uncovered a new understanding of the phenomena under study.

3.4 Ethical Considerations

The researcher addressed ethical issues prior to, during, and following the study. Copies of the full research proposal were submitted for review to the University of Saskatchewan's Behavioural Research Ethics Board (BREB) and Standing Buffalo First Nation's Chief and Council. Approval from each was obtained prior to study commencement.

This study adhered to the Aboriginal ethics principles of ownership, control, access, and possession (OCAP) in order to lessen the power differential between researcher and participants and between researcher and community (Schnarch, 2004). Standing Buffalo First Nation community owns the information collectively, in the same way as individual participants own

their personal information. The community has the right to seek control over the research process and information management and has access to their collective information. Although the data is owned by Standing Buffalo First Nation community, raw data remains in the possession of the researcher, which emphasizes the need for trust between the two parties. The application of OCAP principles was beneficial to all parties involved in this research study and helped establish or rebuild community trust with the researcher and research (Schnarch). The principles of OCAP “open up new avenues for the expression of self-determination and self-governance in the areas of research and information and provide a measure of hope for positive change” (Schnarch, p. 81).

Aboriginal people and communities have often been exploited and damaged due to negative experiences with research that have solely benefited outside researchers (Crazy Bull, 2007 as cited in Smith et al., 2004), resulting in a feeling of being over studied and undervalued. In conjunction with following the Aboriginal OCAP principles, reciprocities are important in establishing a researcher-participant and researcher-community partnership. Patton (2002) stated “participants in research provide us with something of great value, their stories and their perspectives on their world. We show that we value what they give us by offering something in exchange” (p. 415). Ignoring reciprocities weakens possibilities of gathering rich data and dehumanizes research participants (Charmaz, 2006). The researcher provided an honorarium of tobacco, cloth, and money to Elders involved in the study and a culturally suitable gift to each participant as reciprocity and to demonstrate respect for their time.

A written informed consent was obtained from each participant for auditability. The written consent form outlined the purpose and procedures of the study, possible benefits of the study, all foreseeable risks, and availability of counseling services if untoward effects should

occur. In addition, the consent form contained information on storage of data, protection of confidentiality, rights to withdraw from the study, data utilization, ethics approval, further possible interviews, contact information (i.e., researcher, supervisor, and ethics board), and consent to participate (refer to Appendix B).

To ensure confidentiality the participant's name did not appear on the demographic form or on the interview guide; a code number was issued in its place. Pseudonyms were used to replace participants' names in the written report. The Director of Health was a liaison for recruiting participants, but was not informed of which recruits participated. Anonymity of the participants may be compromised due to the small size of the community, the use of direct quotes from participants in the written report, and culturally sensitive or personally identifying information. In addition to the possible loss of participant anonymity, a transcript release form was signed by each participant in order for the researcher to utilize data gathered and gain affirmation from participants in later member-checking. As previously addressed, five women did not show up for their scheduled interview and were considered withdrawals from the study prior to their interview for unknown reasons. The women were not coerced into participating in this study by the Director of Health and, they had the ability to freely choose to whether to participate after speaking with her. Although, there was no evidence of coercion to participate, a different approach to recruiting, such as the use of posters or flyers, may have been more appropriate for maintaining confidentiality. Interviews were conducted at the community Health Station. Pap testing is not offered at the Health Station; therefore, the women would not run into their health care providers who perform their Pap tests during the interview. Study participants were able to access an alternative entrance to the Health Station in order to keep their presence

unknown to the main entrance reception staff. The interview room was located down a quiet hallway and interviews were never interrupted.

The supervisor was available to the researcher for debriefing regarding the research process and any negative feelings that may have surfaced, as well as to provide guidance with the appropriate procedures necessary for any ethical dilemmas that may have arisen. However, no ethical dilemmas were raised during the research process of this study. With the Director of Health's approval, a counselor from the community clinic was available to participants for any counseling needs regarding issues that may have emerged from the study. In addition, a crisis hotline phone number for 24-hour support was provided to each participant.

3.5 Data Collection

Ethics approval from the BREB and permission to conduct this study from Standing Buffalo First Nation's Chief and Council were obtained before the commencement of data collection. Personal contact was made with Chief and Council. As well they were provided with documentation outlining the study purpose, data collection procedures, and knowledge transfer. With their acceptance, the Director of Health for the community was then approached to assist with recruiting eligible participants.

As soon as eligible participants were identified, data collection began. Data collection, conducted by the researcher, was in the form of personal intensive interviews. Intensive interviewing is a practical method for interpretive inquiry.

Before each interview commenced, information regarding the study was reviewed and an information/consent letter was signed by both the participant and the researcher. Following written consent, a demographic form was completed by the participant (refer to Appendix C).

A semi-structured interview guide was used as a means of collecting data (refer to Appendix D). In keeping with interpretive description's philosophy to acknowledge common as well as unique realities, the interview guide consisted of open-ended questions allowing the researcher to elicit each participant's own experience and explore a wide range of experiences in order to discover commonalities. Each of the interviews was audiotaped, which was beneficial for future data analysis, but was sometimes a barrier to gathering "good data" during the interviews. Although the tape recorder was very small in size, the women were conscious of its presence, affecting what and how they shared their experiences. Often once the interview was complete and the tape recorded was turned off, the participants would relax and talk more freely and naturally. Following each interview, the researcher transcribed the audiotape verbatim. Participants signed a transcript release form and were provided with a copy of their own interview transcripts upon request. Initial interviews were booked by the Director of Health due to researcher difficulties in accessing participants (ie. participant did not have a phone). Difficulties continued during attempts to reconnect with participants and only two select participants were available for member checks. Member checks were used as a form of "confirmation, clarification, and elaboration on the essential relationships...within the overall data..." (Thorne, 2008, p. 159). Member checks consisted of sharing a synthesis of overall findings with participants, rather than having them reflect on their own contributions, and did not result in any changes. Due to the inaccessibility of reconnecting with participants, member checking is considered a limitation of trustworthiness. Triangulation of data sources should be considered in future studies in order to maintain anonymity and increase trustworthiness.

Field notes were written by the researcher describing the setting and environment of the interview and community, as well as nonverbal communication and interaction between the

participant, researcher, and environment. Immediately following the interview the researcher documented her personal thoughts and feelings regarding the interview.

Memos were written by the researcher from the onset of data collection to the final report. Memos consisted of the researcher's ideas or insights regarding themes and emerging patterns from the data. Through memoing, the researcher reflected on how personal ideas or feelings were affecting data interpretation. This reflexive stance was in congruence with the interpretive descriptive method. These procedures provide a record of the research and analytical progress.

3.5.1 Data Trustworthiness

Data trustworthiness, parallel to the term rigor, exhibits strict, particular, and complete systematic methods to yield high quality data (Patton, 2002). The basic question regarding trustworthiness in naturalistic inquiry is: "How can an inquirer persuade his or her audiences that the research findings of an inquiry are worth paying attention to?" (Lincoln & Guba, 1985, p. 290). Lincoln and Guba (1985) include four criteria for evaluating qualitative findings and enhancing trustworthiness: truth value, applicability, consistency, and neutrality.

Lincoln and Guba (1985) suggest that credibility be the criterion for evaluating the truth value of qualitative research. "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 from those descriptions or interpretations as their own" (Sandelowski, 1986, p. 30). Fittingness is the criterion for evaluating applicability of qualitative research and is an assessment of how well the research findings fit with the data from which they derived. Fittingness is also met when its findings can fit into contexts outside the study situation and are viewed as meaningful and applicable to its audience (Sandelowski, 1986). Auditability is

the criterion relating to the consistency of qualitative findings and refers to a clear “decision trail” used by the researcher throughout the study. Findings are also auditable when another researcher could interpret the data with comparable results. Confirmability is the criterion for a qualitative study’s neutrality and is achieved when the first three criterion are established (Lincoln & Guba, 1985; Sandelowski, 1986). The following strategies were utilized during the research process to enhance data trustworthiness:

The researcher transcribed each interview audiotape verbatim and was repeatedly immersed in the data throughout analysis. Direct quotes and participants’ words were used in analysis and findings. Findings were grounded in the data and were verified with select participants. The inclusion of member checks, as described in the previous section, was another method that increases credibility. As well, data was reviewed and analyzed by the thesis supervisor independently from the researcher and confirmed similar findings of those found by the researcher. These independent analyses add to the credibility of the findings.

Prior to the study, the researcher acknowledged and reflected upon any prior biases or ideas that may have influenced the research project. Memos were written throughout the research process to outline the researcher’s thoughts, insights, and ideas regarding the data, thereby leaving a decision trail (refer to Appendix E for an example of reflexive journaling). Through memoing, the researcher reflected on how personal ideas or feelings were affecting data collection and data interpretation. This reflexive stance was a continuous process, and the importance of it became evident during data collection. For instance, the researcher was aware of an a priori idea, stemming from literature and personal experience, that a male health care provider performing CCS procedures would be an issue for women. During two of the eleven interviews, the researcher probed the participants about their comfort level with having a male

doctor perform their Pap test. Realizing that this was the researcher's idea of a possible barrier to CCS participation and not necessarily reflective of the women's perceptions of their experiences, the researcher did not continue with this inquiry during other interviews unless it was raised by the participant first. However, the gender of the health care provider was not raised by any other participant in this study, and for the two participants who were probed by the researcher, their responses contradicted one another.

A record of the inquiry process including memos, as well as copies of taped interviews and transcripts has been maintained. The proper storage of all forms of raw data and analysis for an audit trail ensure auditability.

The thesis committee reviewed the methodology and analysis process for consistency and applicability. Suggestions from the thesis committee were graciously accepted and incorporated to enhance the data trustworthiness. All of these approaches helped ensure the analysis or interpretation is true to the data and truly reflects the participants' described experiences.

3.6 Data Analysis

The demographic form consisted mainly of categorical data and was descriptively analyzed to describe the participants as a whole. For example, the number of participants living on reserve will be expressed as a frequency. Collecting this important data helped direct subsequent sampling.

Data analysis was inductive, which required repetitive immersion in the raw data and recording new thoughts and ideas (Thorne, 2008). The audiotaped interviews were transcribed verbatim by the researcher, allowing the researcher to become immersed in the data and the

nuances including: intonations of the participant and researcher, use of pauses, as well as any nonverbal communication that was recorded.

Initially, the researcher was immersed in individual transcripts in attempt to understand individual experiences prior to memoing ideas in the margins and highlighting quotes. Thorne (2008) cautions researchers regarding the overuse of codes for data analysis, rather encourages broad-based themes or ideas. With this in mind, direct quotes from individual transcripts were highlighted line-by-line, coded, and then copied and pasted into an electronic file with other participant quotes that reflected thematic similarities (refer to Appendix F for an example of codes to theme). Grouping of data into thematic similarities assisted in the management of data, while “making sense of what relationships the various groupings have one to another, and inductively building some sort of coherent whole...” (Thorne, 2008, p. 149). This allowed for a shift from individual experiences to the data set as a whole. Following general sorting and organizing of data into patterns or themes, similarities and differences were considered among the data within each grouping, as well as compared to other groupings in search for understanding of relationships (Thorne, 2008). Findings were written with the purpose of allowing the reader to learn and “understand” something new about the experiences of CCS as perceived by Aboriginal women (Thorne, 2008). For that reason, direct quotes from original transcripts were used to represent individual experiences and to organize themes as a whole.

4 FINDINGS

4.1 The Sample

Demographic information was requested prior to the commencement of each interview to provide an overview of participant characteristics. These demographic characteristics are described below and illustrated in table format in Appendix G. Participant ages ranged from 22

to 68 years with a mean age of 47 years. Approximately half of participants were in their childbearing years; the other half were beyond childbearing years. All of the women who participated were self identified Dakota First Nation individuals and lived on the Standing Buffalo Dakota First Nation Reserve. The majority of participants had at least some post secondary education. Forty-five percent of the participants were employed full-time, while the remainder were either unemployed or retired. All participants who chose to declare household income were below \$40,000 per year, more than half being below \$20,000. More than half of the participants stated they were single; 27% were married or in common-law relationships, and 18% were widowed. The number of pregnancies per participant ranged from 0 to 8, with a mean and a median of 4 pregnancies per woman. Three participants denied ever having had a Pap test before their interviews. However, of the women who had previously experienced a Pap test the average age at their first Pap test was 28 years old, with a range from 16 to 55 years and a median of 21 years. The majority of women stated that the frequency of their participation in Pap tests was every four or more years, and that the tests were performed by a doctor at an off-reserve clinic. The demographic data illustrate the diversity among the participants' backgrounds, experiences, and care seeking behaviors related to Pap testing.

4.2 Shared Insights

In a qualitative inquiry, it is essential to view the world as seen by the research participants. In this study, Aboriginal women's experiences regarding CCS participation is seen through the participants' eyes, and told using their words, emphasizing their experiences and relating their perceived needs. This method allows the researcher to see these women's lives and how they view their world.

To attain an understanding of these experiences as perceived by these Aboriginal women, and to describe these experiences, eleven in-depth, semi-structured interviews were conducted. These interviews involved open-ended questions in order to elicit each woman's interpretation of her experience; due to diverse experiences between participants the interviews varied in length. The in-depth and open-ended nature of these interviews encouraged participants to share their experiences in a story-telling like format, respecting and following Aboriginal cultural ways of knowing. In order to preserve the women's construction of their realities regarding their CCS experiences and, in accordance with interpretive description, direct quotations from the interviews have been incorporated into the analysis with minimal editing for confidentiality purposes.

Semi-structured, open-ended interviews would appear to construct a wide range in quality of the women's responses; however, each of the women, in her own way, described a similar process. While personal experiences and behaviours differed, in terms of stories and stages of participation, six general shared insights to CCS participation amongst these Aboriginal women were revealed and were consistent across all interviews. These six shared insights conceived: context, point of entry, experiencing the negatives, receiving information, living healthier, and across the generations. Together these shared insights regarding the women's experiences reflect a transition from experiencing the negatives of CCS participation to living healthier, and are depicted in Figure 1 – Dream Catcher Model and discussed at length in the following sections 4.3 to 4.8.

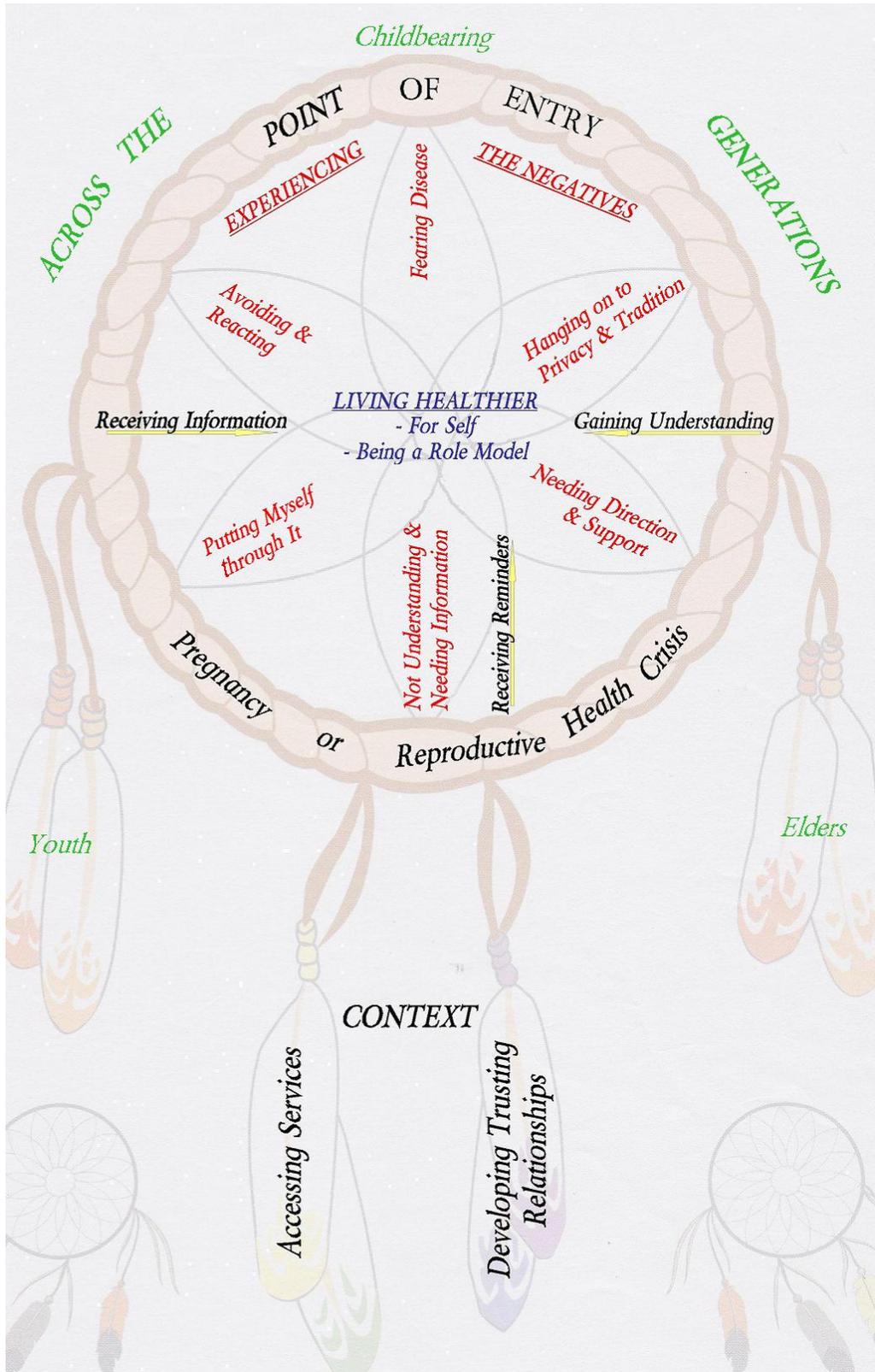


Figure 1: Dream Catcher Model – Transitioning from Experiencing the Negatives of Cervical Cancer Screening Participation to Living Healthier

4.3 Context

Although context was an outside factor, and therefore depicted as the bottom feathers hanging from the dream catcher in Figure 1, it had an impact on the women's CCS experiences. The contextual factors discussed in the interviews included accessing services, developing trusting relationships, and across the generations.

4.3.1 Accessing Services

The Health Centre located at Standing Buffalo First Nation Reserve does not provide CCS service; as a result travel is necessary for residents to access such services. For these women, CCS services are offered at physician offices, medical clinics, and hospitals in Fort Qu'Appelle and Regina, located 14km and 76km from Standing Buffalo First Nation Reserve respectively. The Health Centre does not offer its own CCS services; however, it provides transportation via "the medical van" to Fort Qu'Appelle as needed for residents of Standing Buffalo to access these health services at the hospital and walk-in clinic. Regardless of the chosen location and facility, the majority of the women reflected on the lengthy wait times in the waiting rooms for a Pap test, "Sitting at a doctor's office in a small town you're waiting...two, three hours." Many of the women expressed that there was a long wait regardless of whether their Pap test appointment was pre-booked or by walk-in. For some, the wait was so long they were not seen that day, "I was going to this...doctor in Fort Qu'Appelle...and would have to wait and wait. It was a walk-in clinic. Sometimes I would walk out because it was quarter to six (and I was still waiting to be seen)."

This lengthy wait often posed difficulties with child care and activities of daily living. A woman, who choose to travel to Regina for CCS, expressed her frustration, "I always had my mother come and watch my kids while I went and seen the doctor." She reflected on one

particular Pap test appointment, “I had my mother and my boys waiting in the van and it took a long time in the doctor’s office, about forty-five minutes. So that was kind of hard.” She later attended a medical clinic in Fort Qu’Appelle and found it easier to make appointments, “now this way in Fort Qu’Appelle it’s just there and I make appointments. We can just sit there and wait, and they have a little play area for the kids. So that’s good.”

Although the majority reflected on the wait times in the waiting rooms, the length of time between booking an appointment and being seen by a health care provider was not discussed by any of the women.

4.3.2 Developing Trusting Relationships

Health care provider interactions, whether prior to, during, or after the CCS procedure, had an impact on the women’s experiences with participation in CCS. These women were seeking trusting professional relationships with their health care providers.

The women, who had transitioned from non-participants to regular participants in CCS, had expressed the importance of the trust they had established with their health care providers. One woman explained “having trust in my doctor” has “made it easy for me (to participate in CCS).” This particular woman had “only...one doctor since [she] started having babies” and was able to build a trusting relationship with this physician. She claimed that trust and a long term relationship allowed her to feel “really comfortable” with her health care provider, stating “he explained to me a lot of things about being a woman that I had never heard from my mother.” Another woman echoed this importance of having a trusting relationship with her physician; claiming “having a long term relationship with my doctor since I was a child” facilitated her participation in CCS. These women have access to CCS services in Fort Qu’Appelle and Regina; however, all of the regular CCS participants chose to travel 76km to Regina rather than 14km to

Fort Qu'Appelle for their Pap tests. These women explained that they chose to travel farther for Pap tests because they "had trust" in their physicians in Regina. One woman, who had seen a physician in Regina for CCS, but has previously attended the health clinic in Fort Qu'Appelle for other health related issues, claimed "I wouldn't mind (attending the health clinic) in Fort Qu'Appelle, but...I don't know the doctor. Actually, this is probably my fourth doctor [in Fort Qu'Appelle]; it's the same office, but the doctors don't stay there long."

This constant change in physicians at the Fort Qu'Appelle health clinic made it difficult for these women to build a trusting long-term relationship with their health care providers. One woman expressed how this lack of relationship affected her, "the doctor...dealing with you doesn't know your personality, so what happens is they put a fear into you because you're already afraid." Her example, referring to a Pap test, was "when you're told something straight forward... 'If you don't take care of that, there's a risk of cancer...and you can die...'" Another woman articulated how impersonal CCS was without this relationship "the hard part is...it was like legs up and you're tested and they're gone."

These women did not have control over the health care providers' actions; yet, these actions directly affected their experiences with CCS participation. This was evident in one woman's case:

The second [Pap smear] I had...sticks in my mind yet, because the doctor forgot me...in the room. He put that device in me and took the Pap smear...and he just left me there with the object inside of me...and I was lying there for twenty minutes maybe longer...so I was turned off by that. I thought I'm not coming back and if he requests it, I'm not going to get it done here.

In addition to a trusting long term relationship with their physician, the women who participated regularly in CCS had experienced open and honest communication during their visits to these physicians. One woman was grateful that her physician explained the procedure to

her prior to the examination; “It was before the procedure and then during the procedure ... everything he said that would happen went the way it was suppose to and I knew what was going on...so I wasn’t so nervous anymore.” Another woman expressed appreciation that her physician was “open, especially with the Indian women...She used the terms that Indian women use and my daughter was comfortable with it (too). She used the term spoon...whereas [western medicine] uses vagina.”

Trust that health care professionals will keep information confidential was a necessity for the women’s participation in CCS. “Can I trust them?” and “I don’t know if it’s confidential here” were a couple of thoughts that ran through participants’ minds while considering participating in CCS. When trust was lacking or questioned, participation ceased. A couple of participants shared their experiences where health care providers had breached confidentiality. These women expressed feelings of embarrassment and were afraid to continue as participants due to these experiences.

One woman wondered if her personal information was going to be shared outside her circle of care and asked herself, “Is it going to stay there?” She continued to describe an incident where her medical information was indiscreetly, unprofessionally, and inappropriately shared in a public setting:

When I went for my one Pap test...they said I had chlamydia. It got back here to the health station and that upset me because a nurse approached me [during a public event]...and that hurt me. It embarrassed me...I thought that was supposed to be confidential...I felt she had no right to approach me in that way. She could have brought me [to a private room], but instead she approached me in front of everybody...So I wonder if it is safe because they said it’s confidential and I don’t know who to trust.

Another woman explained her situation regarding a breach in confidentiality:

I know some people that work at our hospital...when [I] have blood work and things I don't want it out and about. People know me here; know me at the hospital and at the doctor's office. There are some things that...my mom found out...about me. It was supposed to be confidential and she found out.

She later explained the effects that this experience had on her participation in CCS, "I'm just kind of hesitant...scared that if I had something everybody's going to know about it."

4.4 Point of Entry

The women's point of entry into CCS is represented as the hoop of the dream catcher in Figure 1. Cervical cancer screening was initially introduced to each participant in one of two manners, either through routine perinatal care or examination of a reproductive health crisis. As a result, each woman related her first experience of a Pap test to reproductive health intervention. When asked how she decided to start participating in Pap tests, one woman claimed, "After I had my first son. ... Just from the doctor, because before I even had children I don't think I would've gone." Another stated, "It should be done. That's just my view, because it's been told to me when I was a first time mother." While each story was unique to the woman telling it, the comments among the participants had a consistent reproductive health theme. "I got pregnant at fourteen, had my baby at fifteen and, in the hospital, they explained to me about doing annual Pap tests." One woman recalled:

After I finished [having] my child, I think I had one Pap test when I was 40 years old because...my menstrual cycle all of a sudden went out of whack and I had my menstrual cycle for about two weeks straight...and of course the examination included a Pap test, so I went through one.

In every case, the first Pap test was performed at the physician's request, rather than at the request of the individual. One woman stated "[I] went when my doctor told me I had to go for one..." Another claimed "I think it was just because it was a request from a doctor. That's the

only reason why I co-operated.” The majority of the women were left feeling they did not make the decision themselves, almost as if there was no choice. “I felt like I was forced, after, like just from being, because I was pregnant then...” Often when a person feels like they are forced into a situation, they separate any feelings or connections with that particular task. For example, one woman described her feelings toward her first Pap test in the following quote:

When I first started to hear about it and my doctor requested it, I didn't really feel anything...about it other than it was a test that this doctor had to do. So, I just went ahead with it and got it done.

Due to association between reproductive health and CCS, many of the women continued with CCS only if they became pregnant or experienced a reproductive health crisis. In either case, their participation remained at the physician's request. One woman recalled:

When I was forty-years-old, I did go through a Pap test (referring to her first Pap test). Then afterwards when I was about fifty-five, my moon cycle stopped and then all of a sudden when I was fifty-seven I got them again. And again that was a very scary part, but this time I had my cycle for three months...So then I went and was seen by...my doctor here and he sent me to a gynecologist in Regina and he did a Pap test on me then again.

Another woman described her CCS pattern in these words:

I was kind of ignorant in that area for a while until I was, until I had my second baby (referring to second Pap test). Then that's when they explained to me I should get it done every year no matter what because there's a lot that can be told from a Pap smear. So even then I was a little bit ignorant and I still didn't get one done until about four or five years later...that was when I was having heavy periods again.

Introduction to CCS participation revolved around perinatal care and reproductive health crises, and some women decided to continue only when these issues recurred.

4.5 Experiencing the Negatives

Each of the women interviewed expressed some negative feelings or experiences toward CCS, regardless of where they were on the participation spectrum (ranging from non-participant

to regular participant). In Figure 1, the woven web represents these expressions of experiencing the negatives, similar to a dream catcher where bad dreams are trapped in the web (Andrews, 1998). Experiencing the negatives were categorized into six themes: fearing disease, hanging onto privacy and traditional ways, needing direction and support, not understanding and needing information, putting myself through it, and avoiding and reacting.

4.5.1 Fearing Disease

Fear was a common response when participants shared their thoughts and feelings towards the Pap test, stating they “get scared to know, to know what’s wrong.” Participants further described that “it’s more a fear of the unknown, of what can happen.” Specifically, one woman felt “people are afraid of facing what they may have.” This focus on negative outcomes prevented these women from viewing the screening as a positive preventative measure, ultimately impeding their participation in Pap tests.

Fearing the unknown was further reflected into two categories: fear of cancer and fear of sexually transmitted infections (STIs). Cancer was viewed as a “serious issue” and one that is “going to be the main disease.” Some participants shared a “fear of getting cancer” which led to “worry” and impeded participation. The realization “it could be just anybody” who develops cancer accentuated this worry. One woman, who had never had a Pap test, described her fear, “That’ll scare me more than anything else, if you have to tell me I had cancer and all these years thinking I’m okay.” This fear was so paralyzing for some that they would rather not know. One woman recalled the following:

There was fear within me to think that maybe yes there is something wrong...I remember waiting for the doctor to call me. I felt like just standing up and leaving...thinking well maybe if I pray hard enough, maybe if I do not go through with it, it’ll work itself out.

A lack of knowledge about CCS and cervical cancer was an overriding theme in each interview. Facts about cervical cancer and the high survival rate, if caught early by a Pap test, were unknown to each woman. The fear of cancer contributed to their non-participation in CCS despite the fact that CCS could ultimately decrease their survival rate should they develop cervical cancer. Again, this fact was not known among the participants.

At the beginning of each interview participants were asked to reflect on the words Pap test. In response to this reflection, one participant claimed, “I think of, well, sexually transmitted diseases...” Although cancer was seen as a “really fearful word” to many participants, the majority thought of and feared STIs when hearing the words Pap test. Another woman believed that historically Pap tests were required due to an increase in promiscuity, infidelity, and a lack of safe sex practices within society. Reflecting on the past, another woman stated she used to “feel scared because I used to have many sexual partners”. This participant, as did many, related the Pap test to STI screening and the fear of being informed she had contracted a STI, hence contributing to her reticence in participating in CCS. Conversely, those who were not sexually active with multiple partners felt a Pap test was unnecessary due to this fact. One participant assumed she “didn’t need a Pap test because I wasn’t sexually active with a whole bunch of people, just with my common-law.” She highlighted this common belief among her community, stating, “That’s what people, a lot of girls think too; we don’t need to get it done because we’re in one relationship.” Another participant had a daughter who had received treatment for an abnormal result from a Pap test. She claimed this did not weigh on her mind when thinking about going for a Pap test herself because she did not mirror her daughter’s sexually active “lifestyle”. Since she was not sexually active herself, she viewed CCS as unnecessary.

This tendency to relate CCS with STI screening resulted in sporadic screening behaviours at best and avoidance at worst. Those who were sexually active feared finding out they had a disease or infection and therefore avoided screening. While those who were not sexually active also did not participate as they felt screening was only for those who were sexually active or had more than one sexual partner. The end result, whether one was sexually active or not, was a lack of participation in CCS. Again the primary misconceptions regarding the reasons for and purposes of the Pap test were due to a lack of knowledge. Furthermore, fear of disease, whether it was fear of cancer or STIs, was also found to relate to a lack of knowledge regarding Pap tests.

4.5.2 Hanging on to Privacy and Traditional Ways

Sexual and reproductive health topics are often viewed as sensitive topics. It was apparent in many of the interviews that CCS was a sensitive topic for the participants to discuss. Many felt “too shy just because of the topic”. One woman stated “it’s more like a shameful thing, I guess, when you talk about sexual things.” Some would laugh uncomfortably instead of finishing a thought. Others would motion their hands in the general direction of their vagina stating “you know, down there” when providing explanations about their experiences with Pap tests. These feelings of discomfort during the interview echoed their expressions of discomfort during Pap tests. One woman, who felt shy about the topic, explained that her lack of participation in CCS was due to “the shyness, I guess, like scared to show myself.”

Feelings expressed regarding CCS predominantly portrayed emotional discomfort, which included feeling shameful, shy, nervous, different, helpless, and even “a feeling of great invasion”. One woman described her feelings about having a Pap test in the following words: “It’s a very strange feeling...that feeling of invasion and you broke some kind of a rule and you know you never let anybody else do this to you or anything like that.” Another woman explained

“to me it...hindered my privacy. It’s like they (the doctors) would know, they would know what kind of history I had if I allowed them to do that and I didn’t want them to know.”

Maintaining privacy was a common concern among the women regarding the intimate nature of the Pap test. Often this need for privacy was related to cultural ways and traditional beliefs. As one woman shared a story about her daughter, “they asked her to come in. She thought she was going to be examined and she said I don’t want anybody to...see me where nobody’s suppose to see me. So, she stayed home”, she revealed a custom within her culture “we’re so closed in...about our lives, we never open up to some of the things.” This cultural custom was described as a “mindset”. “We have a lot of privacy about our bodies and the bottom...So we don’t do that (Pap tests)...” “Us Dakota women, we don’t let people bother us down here...but, now it’s getting more crucial with all these diseases and it’s best to get checked up, get examined.” One woman expressed the need, for women in her culture, to be made “aware that [cervical cancer] not only happens to non-Native people. It happens to First Nation people too, and yet we don’t know because we are so...quiet about it...its hush, hush to us. We’re not supposed to talk about things like that.” She stressed the need for Aboriginal women to be “open” and talk about CCS, “especially our young people.”

Traditional beliefs opposed the invasive nature of CCS. One woman discussed the belief that the body is “sacred” and the mind is “powerful”, and how the Pap test goes against this belief. She referred to “*wakonza*”, a spiritual belief that if you think something is going to happen, then it will happen. She reflected on a teaching from an Elder prior to her first Pap test:

“I always remember her saying...you should never let anybody like a doctor, somebody strange, go into your body, especially that way... I told her they said it’s something for an illness and it’s going to be helpful... She said, if you believe in your spiritual way, your traditional way, you pray about these things...it will never happen...putting something inside you and pulling it out...that’s not our way at all...to us, in our way, it’s sort of wishing something like that will happen

and it's...a belief system we have...rather than go through this...I believe that you pray hard, you smudge yourself, and walk that way. The expectation is that you know that yes it will happen...in our language it's called a *wakonza*, when they do things and it has happened...it's a spiritual thing."

Those who followed traditional ways struggled with participating in CCS due to the nature of the Pap test procedure. One woman described her struggle:

When I read about how the procedure of the Pap test was done, I kind of backed away. I guess the reason for that was because of my traditional beliefs. I guess in the Dakota way, Dakota women, the Elders used to tell us that...you should never...let anybody fool around within your body in any way like that... I had to kind of get used to the idea (of a Pap test) so I weighed the pros and cons of it I guess.

She was not alone in this struggle, "I guess I'll have to let go of some of my traditional ways and get checked up because this cancer is a new disease..." This woman struggled with hanging onto traditional ways, while recognizing that although the Pap test is invasive, it is a "way to find out if you have [cancer]". She stated "I'll just have to let go of some of my traditional way in cases like this; it's for life", yet continued to remain a non-participant in CCS.

4.5.3 Needing Direction and Support

During discussions about factors that would facilitate participation in CCS, many of the women stated if they had direction or support from another person, whether it be a family member, friend, or physician, they would more likely go for a Pap test. For some, a simple "nudge" from someone else to get things going was all they desired. "If somebody were to come and tell me...you have to go for tests...I think I would go." When asked what would make it easier for her to participate in CCS, an elder claimed "Well just somebody to tell me...you should go for this...at your age...and tell me...this will be very good for you to go through." Participation from elders relied on that outside direction; to be asked to make appointments and participate in CCS, or to give responsibility of their own health to others. "If my doctor tells me,

then I will do it regularly,” stated another woman regarding Pap tests. She continued to describe another health related condition she was experiencing that required direction from her physician and claimed “he’s taking control of that”.

Others stated it was support rather than direction that was needed. Support had different meanings to the women in this study. Support was seen by some of the women as the physical presence of their relatives or friends during their Pap test: “What would have really helped is if maybe my husband or maybe a relative, maybe a friend, a close friend, maybe one of my daughters came in with me...I think if we, I had someone there...it would have helped, and put me at ease and like I wasn’t there alone.” Support also meant knowing that other people in the community were experiencing Pap tests and having them share these experiences. One woman claimed it would be easier to consider going for a Pap test “if there’s more support, like more people around that actually do it... I have all my friends and...I don’t even know if any of them do it, like get it done.” Another woman stated, “I just hear women talking about...going for a Pap test, but never talked about why they were going for a Pap test...”

4.5.4 Not Understanding and Needing Information

A general knowledge deficit regarding CCS was found to be the central barrier to regular participation for these women. One woman who had previously participated in CCS on several occasions, albeit irregular participation, expressed her frustration: “To this day I still don’t know what it’s for.” She claimed she did not receive information about the Pap test, merely reminders for when the next one was due. “Not knowing and understanding what it was about and the purpose of it” left many women hesitant to continue with CCS or even start. This lack of understanding negatively impacted many participants’ screening behaviour, contributing to irregular, sporadic screening behaviour at best and an absence of screening behaviour at worst.

One woman stated, “I shouldn’t say it’s not important; but, it’s just something that I never thought about...I just felt I didn’t need to do that.”

The majority of these women did not have an adequate understanding of CCS. Many had “no idea what it was for” and, consequently, “wondered why” the Pap test was performed. Despite this lack of understanding, many failed to seek out information. For instance, one woman felt it was her responsibility and her fault she did not know about the Pap test, yet she did not request more information:

I didn’t know what it was about...my doctor didn’t really explain it to me because he must have thought that I knew what it was about and I didn’t. So, it was just a lack of understanding on my part.

As mentioned earlier, under the ‘point of entry’ discussion, these women most often do not receive information until they become pregnant or experience a health crisis. One participant stated “before I had my son, I actually didn’t know anything about [Pap tests]. Nobody told me or talked to me about sex or Pap tests or birth control or nothing like that...It didn’t mean anything, I guess, then.” Information is not reaching these women before this ‘point of entry’, and often there remains an uncertainty about the Pap test after point of entry occurs. Another woman with a similar experience expressed her need for more information as:

Nothing was explained to me by [the] doctors. They just said that a Pap test had to be done and that it went along with the physical... I still think it would help to know more about why it’s done and the procedure.

There is a need for proper and complete information in order for these women to make an informed decision. One participant explained that knowing “what’s going to happen and what exactly they’re going to do and where the test is going to go and how I’m going to find out if everything is going good” would facilitate her own screening participation. A lack of information not only leaves these women with a sense that there is no purpose for them to receive a Pap test,

it also results in an uncomfortable feeling for them when they receive a procedure without knowing how or why it is performed.

4.5.5 Putting Myself through It

A knowledge deficit along with emotional discomfort, contributed to these women's lack of enthusiasm toward the Pap test and, therefore, the attitude of "just get it done". The common and frequent responses of "just get it done" and "go through it" were not only consistent throughout all the interviews, but were repetitive within each interview. "Not knowing the purpose and procedure" of the Pap test led to emotional discomfort, and the women had to either overcome their emotional discomfort or ignore it, the latter being the most common approach. One woman stated, "It's just like geez I have to get it done. Get it done, just over and done with." Many described the Pap test as something they had to "go through". This attitude of "just get it done" and "put myself through (it)" generated a disconnection between the women's emotional and physical state, preventing them from achieving a holistic balance of health. For instance, one woman explained "I had to fight with my emotions sitting there, but I just let it go and...I went through with it."

4.5.6 Avoiding and Reacting

Those women who struggled with setting their emotions aside often avoided the procedure altogether. Despite the fact that one participant was receiving an annual reminder of her Pap test anniversary date, her CCS pattern varied with an average of one Pap test every few years. "I'll be there when I feel like going" was her response to the annual reminder. Although it had been three or four years since her last Pap test, she repeated that the exam was not a priority, stating "but I'll go get one yet", while other women "just never bothered with it."

Avoidance led to a reactive stance rather than a proactive one. “If at all possible I would avoid a doctor and the only time that I went to a doctor is if I was feeling sick...even that sometimes I would doctor myself...” There was an overall theme among the majority of the women that “if something happens with my health then I deal with it then.” One woman stated:

There has to be like a breaking point. There has to be an issue...I don't deal with things until something happens and then because I feel if I do things all along, then I'm worrying myself and I'm causing myself more stress than I need...

Another woman vowed “(a Pap test) is not going to better my health.” This mindset had the women believing that there was not a need for CCS; furthermore, it was stress inducing to have a Pap test.

4.6 Receiving Information and Gaining Understanding

Receiving information was identified as the main facilitator for making it easier to participate. “As long as you're informed as much as you can be, it's very easy to go through. To be educated and informed on the topic makes things a lot easier.” This theme is represented in Figure 1 by the arrows leading toward the centre hole entitled “living healthier”.

In addition to receiving information about the reasons for a Pap test, becoming familiar with the procedure was also found to be beneficial. One woman stated that viewing the instruments in advance allowed her to better understand the procedure “It was just having a better understanding ... knowing exactly what to expect...I saw the tools that were going to be used, what's going to happen, and the swabs and things like that.” She continued to express how this opportunity allowed her to transition from being a non-participant to a full participant in her care.

Many of the women expressed a similar feeling of increased comfort after receiving information about the procedure and reasons for a Pap test. One woman stated “I felt comfortable

with it and I felt I had enough information of why...this was going to be done.” She continued to credit “the information that I received from my doctor and why they were doing this” as the main factor that facilitated her participation.

Receiving information was deemed to be a powerful motivator for health related behaviours. One woman described her experience with another health issue and how that allowed her to gain perspective on other areas of her life, including CCS: “The knowledge I gained...helped me...to change my lifestyle. It helped me to realize that in order to be healthy and to live longer...these are the things that I have to do.”

4.6.1 Receiving Reminders

While information was found to be the gateway to initial participation, regular reminders were the catalyst for continued participation. Each of the women who had previously participated in CCS, especially those who participated in a regular manner, described receiving pamphlet reminders in the mail as an integral part of encouraging participation. Pamphlet reminders are mailed out annually to women who have initiated CCS participation. “It says you are now due for your annual pap smear. It’s like your annual oil change”, was one woman’s description of the pamphlet reminder.

When asked what motivates her to get the next Pap test, one woman explained “I just got letters in the mail and I just felt that I had to keep on going...If I get something in the mail, [then] I will go.” Another woman emphasized the importance of receiving these pamphlet reminders related to her continued, regular participation; “They send you the pamphlets in the mail and they remind me...our year is up and it’s time for a pap test.”

Although the reminders did not always initially facilitate participation, they provoked thought and consideration for CCS at the minimum. One woman stated “so lately...when I check

my mail, there's papers in there, pamphlets about cancer...about getting pap smears...so I look at it and then I think...I need to go in." Whether it was the first pamphlet received or several pamphlets later, eventually most participants indicated their thoughts would turn into action. One woman, who eventually phoned the health clinic to book an appointment for a Pap test, described her process of receiving reminders:

I'd get those pamphlets in the mail stating that it would be a year for it. At first...I just thought it was just junk mail and I'd throw it away. Then finally I opened and read it...They just said that you're due for a Pap test...and just to go and make an appointment and to get your Pap test done. I actually didn't know what it was before, because I don't read my mail. I just look at it and then throw it away if I don't think it's important. But, then I opened it one day and I was reading about it because I actually thought well I keep getting these...what are they for? I finally read it and thought about going for a Pap test and taking care of yourself and your health.

4.7 Changing Perspective: Living Healthier

The few women who had transitioned into regular CCS participants attributed this behaviour to their desire for living healthier for themselves, as well as living healthier and being a role model for their children. "Living Healthier" is represented in Figure 1 as the centre hole of the dream catcher, where good dreams pass through to the sleeper (Andrews, 1998).

4.7.1 Living Healthier for Self

Those women who took control of their own health and participated in CCS for themselves were more likely to become regular participants. Many of the regular CCS participants viewed their participation as a part of living healthier and caring for themselves holistically. One woman described her own health as the reason for becoming a participant, "I considered my health and I knew it was a test for cancer as well. I don't have a history of cancer within my family, but for precautions on myself." Another woman stated, "I've been trying to take care of myself and my body, and respect myself more." She claimed that becoming a

participant in CCS contributed to her behaviour of “practicing safe sex” and increased her desire “to be healthy.”

Attaining “a frame of mind of living healthier” and “looking after [one’s self] holistically” were motivating factors which created a positive view point of CCS and facilitated participation in Pap tests. One woman indicated “I try to live healthier today...I always believe in looking after myself holistically...I thought, well, the other three parts are doing just fine; spiritually, mentally and emotionally, but my physical part I thought that’s the part I’m neglecting...” She continued to explain how her holistic reflection led her to decide to participate in CCS:

Actually, I am going to be going to that woman’s clinic. That was going to be my next stop. You know, after the nutritionist and the fitness person...I feel like I’m being guided...having that spiritual connection. That I’m being guided to places that are to help me...and I thought well that’s another place that I need to go...to get checked and other things that I have been putting off. ... I say spiritually because...it connects me to everything...it gives me strength to look into things.

4.7.2 Living Healthier and Being a Role Model for Their Children

Family was an underlying motivation for living healthier. Being there for family and acting as a role model were priorities for many of the women and served as facilitators in their CCS participation. When asked what motivates or influences their decision-making to participate in Pap tests, most of the women replied that it was their children. “I want to make sure I stay as healthy as possible and go through whatever tests I need to go through to make sure I’m healthy for my children.” The desire to maintain a good health status, whether for themselves or their children, positively affected participation in CCS. One woman stated it was important to have Pap tests “on a regular basis because of my children. I have children, two that need me and just to make sure I’m healthy...”

In addition to living a longer, healthy life, most of the women mentioned being a role model for their children: “I guess, trying to be a role model for my daughter, try to take care of myself, letting her see that I am doing things.” One woman discussed factors that affected her participation in Pap tests and said, “For me it’s...doing things to be that role model for my family.” There was a common belief among participants that if they chose positive health behaviours, their children would follow their examples: “If I go, then maybe my daughters will go get checked too.” Another woman reflected on her relationship with her daughter, stating, “I talk to her about pretty well everything openly and I think she’s a follower too, like when she sees me do something she tends to try and follow behind...” She believed that her participation in CCS would positively affect her daughter’s decision to become a participant as well.

4.8 Across the Generations

In this community, information regarding CCS and other health related issues was shared across the generations originating from the women who were in their childbearing years. Rather than CCS information being passed down from one generation to the next, such as elders to childbearing to youth, information was passed on from the childbearing generation both down to the youth and up to the elders. This pattern of communication across the generations is depicted as the side feathers flowing down from the dream catcher in Figure 1. As good dreams pass through the centre hole (representing childbearing women who have transitioned to living healthier), they slide down the feathers to the sleeper (representing information being passed down to the youth and elders of the community) (Andrews, 1998).

Women from the childbearing generation expressed that elders, including their own mothers, were more “traditional” and therefore were not “open in sharing” such information as CCS. Reflecting back to her youth, one woman claimed “My mom has never talked to me about

anything like that”, leaving her to rely on other sources for information. Another woman stated “No, my mom’s a very traditional woman and when it comes to things like that she wasn’t very open in sharing those things with me...” Some of the elders, who participated in this study, expressed witnessing the same behaviour from their elders when they were younger.

Women in this study did not receive information regarding CCS during their youth from the elder generation, and this remained constant in their childbearing years. However, now that these women were in their childbearing years, they began to open up lines of communication and share CCS information with their elders.

Elders in this study discussed receiving information about CCS from their daughters: “I just talk with my girls...they’re knowledgeable of that.” One elder considered participating in CCS due to previous conversations with her daughter, “I was talking to my daughter about that and she said, ‘Yeah, it’s going to be very important’. So I think that’s what I’ll do.”

In addition to sharing CCS information with the elders, the childbearing generation also shared information with the youth. “I’m very open with them and they ask questions,” said one woman regarding sharing information about CCS with the younger females in her community.

Many of the women discussed providing support for the youth:

So I’m thinking about gathering up a bunch of girls and bringing them there (to the Fort Qu’Appelle clinic)...orientating them into it (CCS) and having them see that this is important to get it done every year. There will be no problem for us to transport them every year there as long as we have a schedule. Make it routine for them because I know a lot of these young girls are not confident or comfortable telling their parents, their mothers about it.

Another woman discussed how she and her daughters provided support for one another, “Last year we were reminding each other and then my eighteen year old said she didn’t need to get one... She said that she’s in one relationship. I said, ‘No no, no, no, no’...I was forward, straight forward with her.”

Although the women in their childbearing years were open about CCS and willing to take the youth and elders ‘under their wings’, information that was being shared maintained a reactive stance rather than proactive.

We’ve never had somebody come here and ask for information on a Pap smear because what we do with the young girls is, if they want to go on birth control or anything, it is explained to them through the planned parenthood or through the woman’s health center. Everything is explained to them in detail in regards to the Pap smear. They would go through the blood tests and everything like that prior to taking the birth control.

Their teachings were congruent with their own experiences – relating the Pap test to sexual health and portraying the “just get it done” attitude. For instance, one woman stated “I tell all these young girls, ‘Just get it done’.” Similarly, another woman told other females in her community “Just to go and get them done regularly, you know. Every year, even if you have to go twice a year...just to be sure... Just to go and get them done...it might help out maybe down the road.”

4.8.1 Shared Vision – Informing Youth in the Community

Although each interview was conducted separately, the women of this study shared a vision of informing the youth in their community about CCS. There was revealed a common belief that it was “very important that [CCS] is being talked about like this in the open”. An Elder, who had been involved with counseling young Aboriginal women, felt that:

It would be very helpful to a young girl...it doesn’t hurt for them to hear things like that because I know that a lot of parents don’t talk to their children about anything as far as when it comes to sexual activities and sexual stuff... The knowledge is not there and parents are not informing their children.

“Getting information within the community, the First Nations community, in regards to Pap smears” was an interest of these women. There were many suggestions made by the women, such as having “really strong, open lines of communication. [If you] tell them what it’s all about

and...expectations of what's going to happen, there'd be no fear." There was an overall vision of having a nurse visit the community to explain the purpose and procedure of CCS, while focusing on its benefits in order to "ease" the general fear. "Otherwise, just by word of mouth...people get scared and say 'well I'm not going to see a doctor, what if I have that'... A lot of the time people need to be shown in order for them to understand something."

A community oriented approach was evident in each of the women's suggestions for this shared vision. One woman stressed the importance of youth becoming informed about CCS:

Young girls of today need to learn [about CCS] because so many of them are sexually active and they pass diseases around...not really caring for themselves, and those diseases can get really bad and be a danger to their health. They don't realize that. ...Something like that should be brought within community and talked about to the girls.

She continued to express a need for a nurse to collaborate with one of the health station employees and a local Elder to host a "community [session] for parents and children to come and to listen to all of this, because a lot of the young mothers don't know about that either." Many of the women in this study mentioned the need for holding a community "health session" for women of Standing Buffalo First Nation. They also emphasized the need to include parents, spouses, and sexual partners to gain an understanding themselves, as well as provide support for the women. One woman recommended providing a support team that educated women and their daughters about CCS; "that would be very helpful for our young girls to learn something about that, because once they start learning more about their own bodies and knowing the things that can happen, a lot of it can be prevented."

Some of the women suggested having pamphlets available and posters visible in the health station, "if you look around the building, there's no information in regards to a Pap smear at all". Other suggestions included providing information in the health station newsletters, and

showing videos and slideshow presentations on CCS. All of these suggestions were made to target the youth. There was a general belief in the community that women beyond their childbearing years were “too old” for CCS. One elder expressed “it’s too late now...I’m getting too old for that.” Another elder stated “I think [CCS] is important for them, especially if they are younger...I’m getting old...but for young people who are sexually active, I truly believe that they need to get more information.”

5 DISCUSSION

5.1 Reflections on Findings

Corresponding with Interpretive Description, the following reflections highlight findings that have special relevance for nursing; specifically, development and expansion of knowledge that pertains to practice, education, and research. Significant findings are discussed in relation to the current body of knowledge; previously reviewed literature was re-examined for comparison of similarities and differences between these findings.

Key findings from this study highlighted one main theme that describes Saskatchewan Aboriginal women’s experiences with participating in CCS and factors influencing their participation, which lead to an understanding of Saskatchewan Aboriginal women’s perception regarding and experiences with participating in CCS. Initial purposive sampling was used to select participants who had experienced a Pap test within the past 36 months, in an attempt to understand and describe their experiences of CCS participation. Variation sampling was used to select subsequent participants between the ages of 40 and 69, since all previous participants were less than 40 years of age. Women interviewed in this particular age range tended to either have irregular (4 or more years since their last CCS) or nonexistent CCS participation status. The sampling strategy was modified to include variation in age and, consequently, a variation in CCS

participation levels among the women. This allowed the researcher to capture not only Aboriginal women's experiences with CCS, but also perceptions of CCS among those who were not CCS participants. Although a couple of the women had never had a Pap test, they described experiencing negative feelings and attitudes toward CCS similar to those women who were active participants in CCS. However, some of the active participants were able to change their perspectives and described positive experiences related to CCS. Transitioning from experiencing the negatives of CCS participation to living healthier is the main theme that emerged from the data. This theme consisted of the women's mind-set (attitudes and cultural beliefs), knowledge, encounters with the health care system, and sharing information across the generations, which included patterns of communication and a community oriented approach.

5.1.1 Transitioning from Experiencing the Negatives of Cervical Cancer Screening

Participation to Living Healthier

While eliciting the women's experiences with CCS participation, the overall theme of transitioning from experiencing the negatives of CCS participation to living healthier was revealed. The women's journeys from experiencing the negatives of CCS participation to living healthier were facilitated as a result of receiving information regarding CCS purposes and procedures. Although each woman had unique experiences with CCS participation, patterns developed revealing common realities. These common realities the women shared included mind-set (attitudes and cultural beliefs), knowledge, encounters with the health care system, and sharing information across the generations.

5.1.1.1 Mind-Set

Mind-set, a revealed common reality among the women, encompasses their personal attitudes and beliefs, as well as their traditional beliefs. The majority of the women in this study

were not regular participants in CCS. The attitudes and beliefs of these particular women largely reflected negative experiences with CCS. It was only those women who became full participants in CCS that expressed attitudes reflecting positive regard for CCS and transitioned to a lifestyle of “living healthier”.

Associating CCS with Reproductive Health Interventions

Findings from this study revealed that introduction to CCS participation generally revolved around perinatal care and reproductive health crises. Consequently, participants related CCS to reproductive health interventions, thus aligning with the findings from a study examining CCS participation among American Indian women living in an urban community (Risendal et al., 1999). This association between CCS and reproductive health interventions was consistent in subsequent Pap tests, often resulting in continued CCS participation only when these situations recurred. Risendal et al. found that, once past the childbearing age, screening rates declined as many women associated the Pap test with prenatal care. Michielutte et al. (1999) indicated there is need for nurses to emphasize that educational programming be developed which targets older women past child bearing years. Although findings from this study coincide with Risendal et al. findings of declined CCS participation from the elder generation, later discussions, under section 5.1.1.4, will counter Michielutte et al.’s suggested intervention plans and consider the childbearing generation as the target group for educational programming. The fundamental questions raised from the association of CCS with reproductive health interventions are: why are these women not being introduced to CCS earlier than perinatal care and why are they not practicing screening behaviours more frequently than following pregnancies or reproductive health crises? Are they receiving proper information about the purpose of and guidelines for CCS at an earlier age?

Fear of Cancer and Sexually Transmitted Infections

Fear was a common response from participants when sharing thoughts and feelings towards the Pap test. Several researchers discovered fear existed among Aboriginal women in regards to CCS and cervical cancer, including fear of death (Risendal et al., 1999) and fear of a hysterectomy (Michielutte et al., 1999). This study revealed participants' common fear of cancer and STIs. Cancer was perceived as a "serious issue" and was viewed as a "really fearful word". Similar to other studies (Michielutte et al.; Risendal et al.; Smith et al., 2004), fear of cancer was so paralyzing for some that it often discouraged adoption of health prevention behaviours and possible early detection. Findings from this study indicated that Dakota First Nation traditional beliefs, that the body is "sacred" and the mind is "powerful", opposed the invasive nature of CCS. "*Wakonza*", a spiritual belief that if one thinks something is going to happen then it will happen, was a common belief in the Standing Buffalo First Nation community. This finding is supported by Smith et al. who discovered, similarly to Dakota traditional beliefs, that in the Apsaalooke culture it is believed that to say the word "cancer" is asking for the disease to be brought on them. Thus, it may not be favorable to discuss cancer due to a belief in the power of words.

For the women of this study, fear extended beyond cancer. Findings showed that the majority of participants related CCS to STI screening, manifesting a fear of being informed they had contracted STIs. This fear prevented the women from viewing CCS as a positive preventative measure, ultimately impeding their participation in Pap tests. Equally, those who were not sexually active or were monogamous felt a Pap test was unnecessary. This tendency to relate CCS with STI screening resulted in sporadic screening behaviours, at best, and avoidance,

at worst. The end result, whether one was sexually active or not, was a lack of participation in CCS.

Fear may be related to a lack of knowledge and understanding regarding the purpose and benefits of CCS. Facts about cervical cancer and the high survival rate, if caught early by a Pap test, were unknown to each woman. The fear of cancer and STIs contributed to their low to nonexistent participation in CCS, which could ultimately decrease their survival rate should they develop cervical cancer. Again, participants were not aware of this fact. To address these fears, this study recommends that education regarding the purpose and benefits of CCS should be delivered in a culturally sensitive manner, a recommendation which is supported by Smith et al. (2004).

Emotional Discomfort, Apathy, and Taking a Reactive Stance

It was evident throughout the interviews that CCS was a sensitive topic for participants to discuss. Emotional discomfort regarding CCS, including feeling shameful, shy, nervous, different, helpless, and even “a feeling of great invasion”, deterred the women’s participation. These findings parallel other studies that found emotional distress, such as anxiety (Clarke et al., 1998; Foxall et al., 2001) and embarrassment (Clarke et al.; Michielutte et al., 1999), negatively impacted screening rates. Bottorff et al. (2001) and Clarke et al. also linked history of abuse with lower screening rates; however, discussions a propos of abuse did not surface in any manner during interviews of this study. This could have meant one of two things, either abuse was not an issue for these women or there was a low level of rapport that hindered the women from disclosing such information to the researcher. Reduced rapport may have been due to the already decreased comfort level of the topic at hand or the noticeable discomfort of having the interview tape recorded. In either case, the topic of abuse never arose and, the researcher did not initiate

exploration of this topic out of respect for the women, as well as, to prevent personal bias from affecting data trustworthiness.

Emotional discomfort was coupled with the women's attitude toward the Pap test of "just get it done and over with". The majority of the women ignored the emotional discomforts associated with CCS, which generated a disconnection between their emotional and physical state and impeded them from achieving a holistic balance of health. Those who struggled with setting their emotions aside often avoided the procedure altogether. Avoidance led to a reactive stance rather than a proactive one. This finding is supported by Bottorff et al. (2001) who found women often prioritized meeting basic needs over preventative health care. It is also supported by Foxall et al. (2001) who stated emphasis on more immediate health issues, such as diabetes, prevented Aboriginal women from viewing cancer screening as a priority. Findings of this study, similar to those found by Bottorff et al. and Foxall et al., revealed that CCS was not viewed as a priority. Women in this study reported they did not seek health services until a noticeable health issue occurred. "Women who reported going to the doctor only when sick were less likely to have had a Pap smear than their counterparts" (Risendal et al., 1999, p. 515). Similarly, Bottorff et al. affirmed a belief existed among participants that CCS was unwarranted if a woman did not display any symptoms of illness. Findings from several studies further emphasized the need for CCS focused health promotion and prevention interventions for this population (Clarke et al., 1998; Foxall et al.; Johnston et al., 2004; Wilcox & Mosher, 1993).

Privacy and Traditional Ways

Privacy, in regards to the women's personal lives and their own bodies, was described as a "mindset" and revealed as a Dakota First Nation cultural custom. The intimate nature of the Pap test opposes this cultural custom; however, the women expressed a need for CCS to take

precedence for health benefits. Internal conflict was illustrated in this study by women who struggled with holding onto traditional ways while recognizing, despite its invasiveness, the Pap test is an important preventative health measure. In addition, participants in this study stressed a need for Aboriginal women to become more “open” and to talk about CCS. The women expressed that the sharing of CCS experiences may be supportive and facilitate their own CCS participation. Traditional communication of sharing stories and experiences (Crazy Bull, 1997 as cited in Smith et al., 2004) is a common way for Aboriginal women to obtain health information. The sensitivity of this topic and a belief in the power of words may encumber traditional ways of communication for Aboriginal women. Therefore, the importance for health care providers to address the topic of cervical health in a culturally sensitive and appropriate manner is reiterated.

Living Healthier

The few women in this study who considered themselves full participants in CCS viewed their participation as a part of “living healthier”. Findings indicated women who attained “a frame of mind of living healthier” and resolved to care for themselves “holistically” were more likely to become regular CCS participants. These women testified that changing their perspective on their overall health created a positive view point of CCS and facilitated participation.

Family, especially children, was an underlying motivation for living healthier. The women desired to maintain a good health status with hopes of watching their children grow up. In addition to living a longer, healthy life, most of the women mentioned being a role model for their children. A common belief among participants was that if they chose positive health behaviours, their children would follow their examples. Being there for family and acting as a role model were priorities for many of the women and served as facilitators in their CCS participation. Thus, it is important for health care providers to emphasize prevention and educate

women about high survival rates of cervical cancer in relation to regular screening behaviours. Moreover, a family centered approach regarding health promotion and prevention interventions would be beneficial.

5.1.1.2 Knowledge

Available studies found knowledge to be a key factor affecting screening participation; either acting as a barrier when at a deficit or as a facilitator when acquired. Findings from this study showed a general knowledge deficit regarding CCS and cervical cancer to be the central barrier to regular participation. This finding is supported by Michielutte et al. (1999) who also identified a general lack of knowledge concerning the Pap test, especially among older women. Consequently, a lack of knowledge among the women of this study led to misconceptions regarding the reasons for and purposes of the Pap test. These misconceptions, such as CCS is unnecessary for women who are monogamous, negatively impacted uptake of screening behaviour. Inadequate information left women with a sense that a Pap test was unwarranted. In addition, without an awareness of how or why it is performed, the women experienced anxiety during the procedure, merely augmenting their emotional discomfort. Thus, without knowledge and understanding of CCS purposes and procedures, many women were hesitant to initiate or continue with CCS. Smith et al. (2004) conveyed similar findings, stating a lack of knowledge may further decrease Pap test rates. Findings from this study suggest a need for a more culturally appropriate and comprehensive program of education and support for CCS, which is congruent with recommendations proposed by Michielutte et al.

Clarke et al. (1998) discovered that women had little prior knowledge and usually did not receive information regarding CCS until their first Pap test. Similarly, findings from this study indicated the women did not receive information until they became pregnant or experienced a

reproductive health crisis, either of which led to their introduction to CCS. Information is not reaching these women before this ‘point of entry’, and often there remains an uncertainty about the Pap test after point of entry occurs. There is a need for proper and complete information prior to the procedure, in order for these women to make an informed decision about continued CCS participation.

Receiving information, in the form of education, was identified as a main facilitator for CCS participation. Correspondingly, Risendal et al. (1999) determined knowledge of the Pap smear procedures and recommended frequency was positively associated with CCS rates. In addition to gaining awareness of the purposes for a Pap test, the women in this study emphasized the value of becoming familiar with the procedure. Findings from this study associated receiving information with increased comfort; specifically, viewing the instruments utilized during a Pap test in advance and knowing what to expect during the examination was found to decrease emotional discomfort. The women valued detailed explanations of the procedure prior to their Pap test, complementing findings of Bottorff et al. (2001). Receiving information was deemed to be a powerful motivator for health related behaviours, including CCS. For some women it facilitated their transition from non-participant to full participant in CCS and from experiencing the negatives of CCS participation to living healthier. Risendal et al. confirmed that knowledge about CCS and cervical cancer was positively associated with recent Pap smear history. The results suggest that educational programs should include step-by-step explanation of the procedure while showing the equipment utilized in CCS.

While information was found to be the gateway to regular CCS participation, “reminders” were also a catalyst for participation. Saskatchewan’s Prevention Program for Cervical Cancer has been sending out annual Pap test reminders to women since 2003. A study

exploring factors that influence CCS participation among First Nations women (Clarke et al., 1998) indicated women preferred to receive reminders about the Pap test. Aligning with Clarke et al., findings from this study highlighted that Pap smear reminders received by mail were an integral part of encouraging participation. Although these reminders did not always initially facilitate participation, they provoked thought and consideration for CCS at the minimum. Whether it was the first pamphlet received or several pamphlets later, eventually most participants indicated their thoughts would turn into action. Therefore, it is important to continue to have these reminders sent out annually, even if a Pap test is not initiated at that time.

5.1.1.3 Encounters with the Health Care System

Available studies reported issues regarding access to services, such as location, hours of operation, transportation and child care issues, and inconsistent medical checkups, which were seen as barriers to CCS participation (Bottorff et al., 2001; Michielutte et al., 1999; Risendal et al., 1999; Smith et al., 2004). Since CCS services were not offered at Standing Buffalo First Nation, travel was necessary to obtain these services. Although travel was necessary for the women in this study, transportation was available to Fort Qu'Appelle via the community Health Station's medical van. Transportation was not provided for those choosing to attend health care services in Regina. However, women did not view transportation as an issue and valued the benefits of visiting their physicians in Regina, such as confidentiality and trusting long term relationships with health care providers. The majority of the women stressed lengthy wait time as a barrier to their participation in CCS. Lengthy wait times were reported regardless of whether their Pap test appointment was pre-booked or by walk-in. Although the majority reflected on the wait times in the waiting rooms, the length of time between booking an appointment and being seen by a health care provider was not discussed by any of the women.

For those women who did not change their perspective to “living healthier”, any Pap test they had experienced was performed at the physician’s request. In conjunction with on the spot requests during prenatal care or reproductive health crisis and a general lack of knowledge, women reported feeling they did not make the decision themselves, almost as if there was no choice. This finding is supported by Clarke et al. (1998) who reported women in these situations felt “caught” by the situation. The women, who expressed feelings of being forced into a situation, often separated any feelings or connections from the procedure itself and continued “experiencing the negatives” of CCS participation. Consequently, their participation remained at the physician’s request. On the other hand, Risendal et al. (1999) discovered physician recommendation was positively associated with Pap smear rates. In this study, older women gave responsibility of their health to others and relied on direction from their physicians. Initiation from physicians along with education during physician visits may be a better way to engage the older women in CCS. Although physician requests should continue, there is also a need for education programs to reach women prior to this point.

Health care provider interactions directly impacted the women’s CCS experiences and affected screening behaviour accordingly. The women who transitioned from non-participants to regular participants in CCS, emphasized the importance of knowing that their information would be kept confidential and having trust in their health care providers. Trust accompanied by a long-standing relationship with physicians decreased emotional discomfort and facilitated participation. A study examining CCS in ethnocultural groups highlighted the significance of respectful, trusting relationships with health care providers for First Nations women (Bottorff et al., 2001). It was revealed that trust in physicians was the reason some women preferred to travel farther for Pap testing.

Constant turn over in staff at local health agencies was a barrier to building a trusting long-term relationship with health care providers. Trust and long-standing relationships were seen as mutually exclusive to some of the women and were positively associated with CCS participation. The women who lacked a long-standing relationship with their health care provider reported increased fear and expressed how impersonal CCS was without this relationship. When trust was lacking or questioned, CCS participation was negatively impacted. “Many [First Nations] women hold an overall sense of mistrust of health systems” (Bottorff et al., 2001, p. 44). Consequently, when this conceived mistrust was verified as a breach in confidentiality, the women in this study expressed feelings of embarrassment and apprehension, and hesitancy to continue with CCS participation.

While many studies suggested that having a male health care provider was negatively associated with Pap testing, findings from this study do not present gender as a significant barrier to CCS. As previously described under data trustworthiness, gender was discussed in two interviews and in each case only after the participant’s responses were probed by the researcher. The gender of the health care provider was not raised by any other participants in this study, and for the two participants that were questioned regarding gender, their responses contradicted one another. Recognizing that this was the researcher’s personal bias of a possible barrier to CCS participation and not necessarily reflective of the women’s perceptions of their experiences, this study concurs with Risendal et al. (1999), who suggest that other related factors, such as knowledge or beliefs, better explains screening behaviour.

5.1.1.4 Sharing Information Across the Generations

5.1.1.4.1 Patterns of Communication

Findings from this study revealed a pattern of communication across the generations that varied from the pre- research assumptions of the researcher. Prior to the study, the researcher held a preconception that information was passed down from generation to generation, originating from the elders. The researcher remained aware of this presumption throughout the study in an attempt to avoid imposing this bias on the participants or the data. As a result, it was revealed that information was shared across generations, albeit originating from the childbearing generation rather than the elders. The elders were more likely to follow traditional ways and less likely to share information about, or participate in, CCS. The women in childbearing years were the most open and comfortable with discussing as well as participating in CCS. These women were willing to take the youth and elders ‘under their wings’ and provide support. Furthermore, information regarding CCS was passed on from the childbearing generation down to the youth and also up to the elders. However, this shared information stemmed from the women’s personal experiences and had a propensity to convey a reactive stance. Thus, findings from this study once again align with findings from available studies that emphasize the need for health promotion and prevention focused CCS educational programming (Clarke et al., 1998; Foxall et al.; Johnston et al., 2004; Wilcox & Mosher, 1993). Findings from this study coincide with Michielutte et al. (1999), who identified a general lack of knowledge concerning the Pap test, especially among older women. However, recommendations of this study are in contrast to those of Michielutte et al. (1999) who suggested that educational programming be developed targeting older women past child bearing years. Although women beyond childbearing age should be included, the patterns of communication found in this study suggest women in their childbearing

years should be the main target group for CCS education. Educating Aboriginal women about CCS and cervical cancer may be more effective at reaching all generations if nurses provide comprehensive education to and recruit mentors from those women in their childbearing years.

5.1.1.4.2 A Community Oriented Approach

All of the participants in this study shared a vision of informing the community, specifically the youth, about CCS. The women recognized and expressed that knowledge about CCS was not present in their community and that the current form of information sharing by “word of mouth” was producing more fear. Each of the women suggested a more formal community oriented approach to CCS education. There was an expressed need for a nurse to visit the community to provide comprehensive education on CCS while focusing on its benefits in order to ease general fear. Similar to the results from another study, participants recommended having more visual aids that are accessible and non-threatening (Clarke et al., 1998). Some suggestions for visual aids included pamphlets and posters at the health station, articles in the health station newsletters, and slideshow presentations with pictures at community health sessions. It was also recommended by the women that the nurse should collaborate with community health station employees and a local Elder who is open to this topic. Risendal et al. (1999) suggest “future efforts must have active community participation in all phases to ensure the relevance and effectiveness of cancer prevention and control programs” (p. 517). There is a need for this collaboration to host community health sessions on CCS for women that will include support persons such as parents or spouses. Another recommendation made by the women was to have a support team of community members that educate women and their daughters about CCS. This recommendation coincides with the researcher’s previous

recommendation to recruit and educate women in their childbearing years to become mentors in cervical health.

5.1.2 Summary

Accurate and complete information regarding CCS and cervical health is not reaching this population early enough and unfortunately, at times, not at all. Knowledge deficit was identified as the main barrier to regular CCS. As knowledge is often referred to as power, in this case, it is the key to empowerment for these women. The few women, who chose to become regular CCS participants, chose to do so for their own benefits and attributed this transition to gaining knowledge and understanding about CCS. With this in mind, it is crucial for health care providers to ensure comprehensive education is provided to these women prior to them experiencing a Pap test. Another factor positively associated with screening behaviour was having trust and a long-standing relationship with their health care provider. Cervical health is naturally a sensitive topic and traditional ways increase this sensitivity. Health care providers need to not only build genuine rapport with these women, but must do so in a culturally sensitive manner.

It is also important to educate and engage women beginning in their youth and to continue to engage them into their elder years. Participation in CCS was irregular to non-existent among the majority of the women, especially youth and elders. The women associated CCS with reproductive health interventions, such as prenatal care; hence the slight rise in screening rates among women in their childbearing years. Findings in this study indicate communication patterns for the topic of CCS originate from the childbearing generation. Rather than merely reiterating suggestions from previous studies to focus on the youth and elders for education programs, this study further recommends that establishing mentors from the childbearing

generation would be beneficial and perhaps more effective in reaching all age groups in this population.

A community focused approach to educating women and their support persons about CCS may result in increased screening rates. It was recommended by the women to approach educating the community with a formal health session hosted by a collaborative team consisting of a nurse, health station employees, and an Elder. In addition to the health session, the nurse should provide a more focused education on cervical health promotion and prevention to women in their childbearing years who are willing to become mentors and members of a support team for CCS.

5.2 Reflections on Methodology

5.2.1 Strengths of Qualitative Methodology

The qualitative and exploratory nature of this inquiry provided an opportunity for Standing Buffalo First Nation women to voice their experiences with CCS. Another strength of this qualitative study is that the importance of cultural competence emerges as a very important issue in developing awareness on CCS and creating women's empowering conditions. The findings of this naturalistic inquiry included common themes concerning Aboriginal women's experiences with CCS. These common themes provide an understanding and illuminate new findings, which add to the limited available literature on Aboriginal women and CCS. Finally, they provide guidance for health care providers working with this population and direction for further exploration.

5.2.2 Limitations of Qualitative Methodology

Although this study was carried out under the supervision of an experienced group of nurse researchers, the interviews were conducted by a novice investigator. The principal

investigator's inexperience may have resulted in a less than optimal interview technique as well as difficulty in obtaining the richest data possible. Secondly, the interviews were audiotaped, which may have affected the quality of data gathered. The participants' constant awareness of the tape recorder may have affected content and how they shared their experiences. As mentioned earlier, often once the interview was complete and the tape recorder was turned off, participants would relax and talk more freely and naturally. The researcher recorded these conversations as additional notes to the participants' transcripts. All of these extra conversations pertained to the importance of a community oriented approach in addition to asking the researcher, who is a Registered Nurse, about CCS procedures or general health questions. A third limitation involves the sampling criteria, sampling strategy, and sample size. The sampling criteria required that participants were fluent in English, thus non-English speaking women with expertise may have been excluded. The sampling strategy assumed that the Director of Health was the best person to identify and recruit women with expertise on this topic. Findings are limited by the small sample size and characteristics of the sample. There were eleven participants in total, all Dakota First Nation women living on reserve land. Finally, the participants' comfort level with the researcher and the topic at hand may have been the most prevalent limitation. The researcher, a registered nurse, is a non-Aboriginal woman and an outsider to Standing Buffalo First Nation community. Throughout the entire research process, the researcher followed appropriate Aboriginal research protocol and treated each participant with utmost respect, while attempting to avoid any sense of power differentials between the participants and herself as well as between the community and herself. However, CCS is a sensitive topic and, it may have been difficult for participants to discuss and share their personal experiences, especially with an outside researcher.

5.3 Implications for Practice and Research

5.3.1 Nursing Implications

Findings from this study led to an understanding of Saskatchewan Aboriginal women's experiences with participating in CCS. Furthermore, they provide a description of their experiences of and feelings toward CCS as well as the factors affecting participation as perceived by Saskatchewan Aboriginal women. Results of this study increase awareness of the necessity for comprehensive education on CCS with a focus on health promotion and prevention. Nurses should provide education and information to these women starting at an early age and to continue providing this information as long as the women are in the recommended age group for CCS. The reminder letters sent out by the PPCC to individual women living in Saskatchewan was revealed as a favorable practice by the majority of the women, even those who were not regular CCS participants. The reminder letters were thought provoking and, eventually for some women, action provoking; therefore, it is highly recommended that the PPCC continue with this intervention. Additionally, nursing interventions need to be provided in a culturally sensitive manner. Ensuring genuine rapport and trust are established between women and health care providers may decrease anxiety and increase screening rates. Following traditional ways was found to increase the sensitivity that already exists in relation to CCS and to negatively impact screening rates; this was more evident among older women. Although this finding was not surprising, it reinforces the need to consider the role that tradition plays in screening practice. "Specific nursing interventions to promote cancer screening practices may include educating [Aboriginal] women about...cancer detection and treatment, and the demystification of fears related to screening" (Foxall et al., 2001, p. 736).

Nurses should collaborate with Standing Buffalo First Nation community members, including health station employees and Elders, to deliver non-threatening, culturally suitable information and education on CCS to the community. Community health sessions involving slideshow presentations, actual equipment used for a Pap test, and opportunities for shared dialogue are recommended by the women. This more formal approach to education from a health nurse, with the support and guidance of community members, is recommended to introduce the topic to the community as a whole. It is extremely important for the nurse to establish working relationships with community members and to have their involvement in all processes. Many cultural factors may be associated with CCS practices and, nurses must be aware of the importance of social support, including family and friends, in screening participation. For this reason, a support team consisting of women from the community should be established. A specific nursing intervention should include providing a more focused education on cervical health promotion and prevention to this support team, in hopes of having the members of the team act as liaisons between women in their community and nurses. Results of this study suggest that women in the childbearing generation should be targeted for becoming mentors on the support team. The participants in their childbearing years were the most comfortable with sharing information about and participating in CCS. Findings indicated that these women already had the desire to be role models for youth in their family and community.

The suggestions made above are based on the findings of this study and are representative of the experiences of the women who participated in this study. The goal of these suggestions is to increase awareness among nurses in regards to factors affecting screening behaviour among Aboriginal women and possible interventions to overcome barriers. Lastly and most importantly, with this new knowledge and follow through with appropriate nursing interventions, the end

result of these suggestions may increase CCS participation among Aboriginal women as well as enhance their experiences during screening.

5.3.2 Research Implications

The purpose of this study was to gain an understanding of Saskatchewan Aboriginal women's experiences with participating in CCS. A qualitative exploratory method was used to elicit Aboriginal women's perceptions of their experiences with and feelings toward CCS, as well as factors affecting their CCS behaviour. The qualitative approach complimented Aboriginal tradition of oral communication and allowed the participants to share their stories and experiences (Crazy Bull, 1997 as cited in Smith et al., 2004). New findings were revealed regarding communication patterns about CCS among the different generations within this community. These can assist in the development of education and prevention programs. The study findings, attributed to an exploratory approach, emphasize the importance of the voice of community members. Therefore, future studies should continue with qualitative approaches.

Findings indicated that increased perceived associations between CCS and STI, and CCS and cancer were a deterrent to screening participation for women in this study. Moreover, many misconceptions regarding who should participate in screening and a lack of knowledge about the benefits of CCS contributed to lower screening rates. Further research is needed to determine how Aboriginal women perceive cervical cancer risk, cervical health, and cancer prevention. There is a need for more research focusing on the ways in which culture influences how women perceive screening practice. In addition, influences of acculturation and its association with CCS participation should be considered and, exploration on the different generations, levels of acculturation, and their openness to Western values. Future studies may explore misconceptions of cervical health and cervical cancer in relation to cultural beliefs and practices. Also, specific

interventions for health care providers can be developed based on the findings from the current study and, researchers can evaluate these newly developed programs or interventions for effectiveness.

This study looked solely at participants who were Dakota First Nation women living on Standing Buffalo First Nation Reserve; thus, leaving a need for future research to look at other Aboriginal bands as well as urban Aboriginal populations. An interesting future study would include women living on several different reserves in Saskatchewan. Although findings from this study add to the current knowledge base of the experience of CCS for Aboriginal women, the knowledge base remains limited. Ultimately, more Aboriginal based research with a cultural focus is required.

Lastly, there were numerous other factors that this study did not look at and may be interesting to include in future studies. Some examples are: the role of the HPV vaccine in CCS participation among this population, the effects of cancer fatalities and cancer survival in the community, and history of abuse in relation to Pap testing.

5.4 Conclusion

Findings of this study suggest that improving knowledge about CCS and cervical cancer may increase CCS utilization. Emphasis on health promotion and prevention should be considered when designing education programs. Interventions designed to improve screening rates are more effective when community members are involved in each phase, ensuring cultural relevance. Improving knowledge about, experiences with, and stories shared regarding CCS among Aboriginal women may increase screening rates. It is known that Aboriginal women have higher incident rates of cervical cancer which leads to a higher mortality rate from cervical cancer than rates for non-Aboriginal women. Hence, increasing screening rates for this highly

preventable disease is vital to reducing the disease burden in this high-risk population (Risendal et al., 1999).

Aboriginal women generally are an under considered group in areas of screening and prevention, yet often over considered in the areas of illness. This study was merely the tip of the iceberg in regards to exploring Aboriginal women's experiences of CCS; however, it informs the potential and future emphasis for research and nursing interventions.

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APPENDICES
Appendix A: Literature Review Charts

Article #1 Community-based Cultural Predictors of Pap Smear Screening in Nova Scotia

Source	Purpose	Design/Sample/Setting	Statistical Analysis/ Variables	Data Collection	Results	Limitations	Conclusions/ Implications	Comments
2004 Johnston, Boyd, & MacIassac	- To examine associations of the Pap smear screening history of women in Nova Scotia with community measures.	<p>- Quantitative Non-experimental</p> <p>- Secondary data analysis of results from the Provincial Cytology Registry</p> <p>Sample - identified by Maritime Medical Care</p> <p>N = 360,587 women (18 years and over)</p> <p>Participant criteria: - ♀ 18⁺ yrs - had a provincial health card number - resided in Nova Scotia between June 1998 and April 1999</p> <p>Setting - Nova Scotia, Canada - urban and rural</p>	<p>- Multivariate analysis and Logistic regression to assess relationship between: 1) recent screening status 2) dependent variable with each independent variable</p> <p>- Procedures appropriate for type of data</p> <p>- 1.1% did not have a postal code therefore were excluded from analysis</p> <p>Variables <u>Independent</u> – age, urban/rural, income, ethnic group <u>Dependent</u> – recent screening status (binomial – no = recent Pap smear, yes = recent Pap smear) *recent = Pap smear within previous 3.5 to 4.4 yrs</p>	<p>- data set was prepared for and funded by the Population Health Fund</p> <p>- Provincial Cytology Registry database used to determine screening status of Nova Scotia ♀</p> <p>- linked to provincial health card number database for personal identifiers</p> <p>- postal codes were linked to enumeration areas & then to 1996 Census data to determine community measures</p> <p>Consent/Approval - approval from Nova Scotia Dept of Health - consent not discussed</p> <p>Instrument - PCR, 1996 Census databases</p>	<p>Less likely to have had recent Pap smear if: - reside in rural area - reside in an Aboriginal or mixed-Black community - reside in a lower income area - older in age</p> <p>♀ between 30 and 44 yrs were most likely to have had a recent Pap smear</p>	<p>- Secondary analysis of data</p> <p>- Caution in assessing stat sign when confidence intervals approach 1.0 due to clustering</p> <p>- Aggregated data from enumeration areas instead of data from the individual ♀ may impose a conservative bias</p> <p>- Extension of the method used to other geographic areas will require review off census cultural measures</p> <p>- Census data is self-reported and may be skewed</p> <p>- enumeration areas for rural requires min. 125 dwellings which may cover several km² and distort data</p>	<p>- Methods used have potential application for use in studies regarding other health utilization, disease status, & well-being by ethnic groups</p> <p>- Extend health surveillance & program assessment in Canada to include analysis by cultural group and other community attributes</p> <p>- Provides supporting evidence for the relationship between ethnic group (ie. Aboriginal) and lower rates of screening history</p>	<p>- Main focus was not on Aboriginal ♀</p> <p>- Do not involve ♀'s perspective</p> <p>- Secondary analysis of data</p> <p>- Self-reported values for community measures</p> <p>- 1996 Stats Canada census shows 360,450 Nova Scotia ♀ 18⁺ yrs (comparable to N)</p> <p>- Accuracy of results for linking data to Census and enumeration areas are questionable</p>

Article #2 Reducing Cervical Cancer among First Nations Women

Source	Purpose	Design/Sample/Setting	Statistical Analysis/ Variables	Data Collection	Results	Limitations	Conclusions/ Implications	Comments
1998 Clarke, Joseph, Deschamps, Hislop, Band, & Atleo	<ul style="list-style-type: none"> - To identify factors that influence Cervical Cytology Screening Program (CCSP) participation among First Nations ♀ - To develop and implement demonstration initiatives that would improve CCSP utilization - To evaluate the demonstration initiatives 	<ul style="list-style-type: none"> - Qualitative Participatory Approach (part of a larger set of on/off reserve projects in BC) - Consistent with goal & objectives - Directly involved beneficiaries in all aspects of the research <p>Sample</p> <ul style="list-style-type: none"> - 30 Bands participating <p>N₁ = 11 First Nations ♀ (15 to 58 yrs), varying PST-related history (individual interviews)</p> <p>N₂ = 44 ♀ (participated in 3 com'ty meetings) invited through First Nations agencies</p> <p>N₃ = 12 health care practitioners (focus groups)</p> <p>N₄ = 9 ♀ (Com'ty Advisory Committee)</p> <p>Setting</p> <ul style="list-style-type: none"> - Vancouver, BC, Canada 	<ul style="list-style-type: none"> - constant comparative method used to find themes from qualitative data - field notes and meeting minutes to supplement findings - Ethnograph software used <p>Variables</p> <p>Research – participants perspectives on factors effecting Cervical Cytology Screening Program participation</p> <ul style="list-style-type: none"> - com'ty perception of project 	<ul style="list-style-type: none"> - all data audiotaped and transcribed - individual interviews conducted by a First Nations ♀ - 3 research members analyzed data, revised interview to reflect ongoing findings & validate and extend findings through com'ty and Com'ty Advisory Committee meetings <p>Consent/Approval</p> <ul style="list-style-type: none"> - approval and consent not discussed <p>Instrument</p> <ul style="list-style-type: none"> - semi-structured interview 	<p>Research component</p> <p>3 themes from data:</p> <ol style="list-style-type: none"> 1) knowledge of, reaction to & preparation for screening 2) inhibiting & facilitating factors for having screening 3) health practices & support <p>Demonstration</p> <p>3 areas for change to improve participation:</p> <ol style="list-style-type: none"> 1) knowledge 2) environment 3) health care providers <p>Eval & Outcomes</p> <ol style="list-style-type: none"> 1) print material successful 2) tear-off pad of anatomical illustrations suitable 3) clinic low # attending, accessibility issues?; culturally appropriate, informative, respectful 4) new provincial First Nations Pap Smear Testing program 	<ul style="list-style-type: none"> - Interview guide was not provided (examples of questions or topic of questions) - Long-term evaluation is needed to determine impact of the interventions - Details of method, sample, setting, etc. were vague, therefore trustworthiness and generalizability is questionable 	<ul style="list-style-type: none"> - Further research required in developing & testing frameworks & theories to guide dev't of culturally suitable nursing & health care - Nurses encouraged to seek the culturally specific print materials for use in practice (available through the Canadian Cancer Society) 	<ul style="list-style-type: none"> - Participatory approach is culturally suitable - Interviewer common gender & nationality = trust; > reliability and validity of data - Main focus was on Aboriginal ♀, directly involving their perspective - Specific findings - 1st PST during prenatal < embarrassed, intimidated < history of abuse < no First Nations influences at clinic < male doctor > reminders for next PST < social situations, smoking/drinking - obtain health info from friends/family

Article #3 Psychosocial Factors Related to Cervical Screening among Lumbee Women

Source	Purpose	Design/Sample/Setting	Statistical Analysis/Variables	Data Collection	Results	Limitations	Conclusions/Implications	Comments
1999 Michielutte, Dignan, Sharp, Blinson, & Wells	- To examine psychosocial factors related to cervical cancer screening among Lumbee women	- Quantitative, non-experimental (part of the larger North Carolina Native American Cervical Cancer Prevention Project - a 5 yr trial) - randomized intervention & control groups (Solomon four-group design) - only two groups used (pretest & intervention; no pretest & intervention) Sample N = 378 Participant criteria: - ♀ 18 ⁺ yrs - members of Eastern Band of Cherokee - living on tribal lands in western North Carolina - member of Lumbee tribe Setting - North Carolina, USA - interviews in ♀'s home	- Chi-square test for univariate assoc. b/t each independent variable and screening status - Logistic regression for overall assoc. b/t factor scores and dependent variable with & without controls for confounding variables Variables <u>Independent</u> – 11 predisposing factors & 6 enabling factors <u>Control</u> (<u>confounders</u>) – age, education, health insurance status, head of household, knowledge of cervical cancer, social support <u>Dependent</u> – screening status (binomial – no = no pap smear in past year, yes = had pap smear in past year)	- interviews conducted by a trained Lumbee ♀ - for each of the 17 factors, participants were asked if it was ever a factor in their decision to get a pap smear - two summary scores computed by adding positive responses to all predis and enabling factors named by each ♀ (predis range 0 to 11 factors mentioned; enabling range 0 to 6) - open-ended question at end asking for other factors; no other factors were identified by this question Consent/Approval - approval and consent not discussed Instrument - Pre-intervention interview	Predisposing: embarrassment, wait time to see provider, felt no need if no symptoms, fear of surgery - <i>discomfort: only factor significantly assoc with having had pap smear in past year</i> - <i>predis factors score significantly assoc with having had pap smear in past year</i> Enabling: cost, problems of getting time off work Confounding: age & education (highly correlated so only results by age shown): Older ♀ more likely - believe no cure - dislike male doc - transportation problems - problems finding someone to watch their kids	- list of factors not comprehensive & partially created by the 2 pretest groups - dependent variable was measured 1 yr after pretest interview and intervention (cannot test effect of intervention) - Caution with interpreting odds ratios as dependent variable is not a rare event - the intensity of feelings about each perceived barrier was not measured - barriers survey not administered to control groups - sample size small with moderate statistical power - sample not living on federal tribal land, not generalizable to those who do	- Emphasis on content of educational programs targeted to older ♀ Programs need to address: 1) general medical environment - physical & emotional access; option of choosing ♀ provider 2) for both ♀ & health care providers methods of reducing physical & emotional discomfort 3) a variety of barriers identified by assessment of target population	- Main focus was on Aboriginal ♀, involving their perspective on pre-made factors - Interviewer trained ♀ Lumbee = trust; > reliability and validity of data - American study: cost for health care is a factor - # of predisposing factors is predictive of screening - different factors and combos of these factors will be significant for individual ♀

Article #4 Pap Smear Screening among Urban Southwestern American Indian Women

Source	Purpose	Design/Sample/Setting	Statistical Analysis/ Variables	Data Collection	Results	Limitations	Conclusions/ Implications	Comments
1999 Risendal, DeZapien, Fowler, Papenfuss, & Giuliano	- To examine cervix cancer screening participation among American Indian women living in the urban Phoenix metropolitan area	<p>- Quantitative Non-experimental (part of the larger Healthy Native Women Project)</p> <p>- cross-sectional survey on knowledge, attitudes, beliefs, & behaviors (KABB)</p> <p>Sample N = 519 Participant criteria: - ♀ over 18 yrs - American Indian</p> <p>- study coordinator & interviewers contacted participants through door-to-door search (86% response rate)</p> <p>- stratified sample: sample proportional to # of eligible ♀ in each of the 3 geographic areas</p> <p>Setting - Phoenix, Arizona, USA - urban - 3 geographic areas: Guadalupe & Salt River Indian com'ties & metropolitan Phoenix area containing 5-11% American Indian women - interviews in home</p>	<p>- Stat Version 5.0 used</p> <p>- univariate & stratified analysis of categorical variables using chi-square test</p> <p>- backwards stepwise multivariate logistic regression to adjust for variables of interest</p> <p>- two-sided test ($\alpha=0.05$) power of 80% detectable odds ratio of 1.70</p> <p>Variables</p> <p><u>Independent</u> – participant KABB about cervix cancer, pap smears, and cancer screening, sociodemographic variables</p> <p><u>Dependent</u> – screening status (binomial - pap smear within last year, pap smear within past 3 yrs)</p>	<p>- face-to-face household interviews between Mar and Aug 1996 by trained American Indian ♀</p> <p>- study coordinator & interviewers called apt managers and visually toured routes within census tracts to target areas for door-to-door search</p> <p>- areas in metro Phoenix containing 5-11% American Indian ♀ were targeted</p> <p>Consent/Approval - approval from Human Subjects Committee at University of Arizona - written informed consent obtained from each participant prior to interview</p> <p>Instrument - questionnaire(166 q's) in form of interview; input from focus groups, pilot-tested with American Indian ♀ to ensure cultural competence</p>	<p>- only half had pap smear in past year</p> <p>Associations with pap smear utilization: - Increasing age was negatively assoc. - access to care was positively assoc. (self-report of recent routine checkups) - knowledge & beliefs about cervix cancer & screening were positively assoc. (specifically high perception of risk) - physician recommendation was positively assoc. - use of clinic > private doc</p>	<p>- Cross-sectional nature limits interpretations because unknown if factors assoc with screening preceded screening or are result of receiving the examination</p> <p>- screening frequencies were self-reported</p> <p>- more than one interviewer, validity not discussed</p>	<p>- Outreach efforts needed for older women</p> <p>- identification of factors specific to com'ties is critical in dev't of effective programs</p> <p>- improving knowledge about testing and perception of risk of cancer may increase pap smear utilization</p> <p>- interventions best directed through clinics where majority of population seeks services</p> <p>- future efforts need active com'ty participation in all phases to ensure relevance & effectiveness</p>	<p>- Main focus was on urban Aboriginal ♀</p> <p>- Surveys assigned #s, verified for completeness, 10% randomly checked for data entry & coding errors - 100% concordance</p> <p>- American study: cost for health care is a factor</p> <p>- Age distribution closely approx. 1990 US Census</p> <p>- Literature support was evident</p> <p>- self-reported screening rates</p>

Article #5 Factors Associated with Obtaining Health Screening among Women of Reproductive Age

Source	Purpose	Design/Sample/Setting	Statistical Analysis/ Variables	Data Collection	Results	Limitations	Conclusions/ Implications	Comments
1993 Wilcox & Mosher	- To examine health screening rates of women of reproductive age and determine the characteristics associated with the screening rates	- Quantitative Non-experimental - Secondary data analysis of results from the 1988 National Survey of Family Growth Sample Sample drawn from households that participated in the NHIS (Oct '85 to Mar '87) (convenience) N = 8,450 Participant criteria: - ♀ aged 15 to 44 yrs - from civilian population 82.5% response rate Setting - USA - geographic areas not identified	- Examined effects of characteristics on screening rates in bivariate cross-tabs and in multivariate, logistic regression - percents shown are weighted national estimates (accurate for most purposes) - Procedures appropriate for type of data Variables <u>Independent</u> – age, race, gravidity, education, current/recent pregnancy, family income, oral contraceptives, marital status, sexual activity, PID/vaginitis treatment, family planning visit, hx of hypertension <u>Dependent</u> – 3 dep vars: recent screening status for 1)pap test, 2)breast examination, & 3)blood pressure test (each binomial – no screening within past 12 months, screening within past 12 months)	- based on data from the 1988 National Survey of Family Growth Consent/Approval - approval and consent not discussed Instrument - personal interviews conducted by ♀	- overall rates of screening 67% for pap test, 67% for breast exam, 82% for BP test More likely to have received screening: - ♀ in their 20's - high levels of education & income - married - sexually active - obtained clinical family planning services in past year - current users of oral contraceptives - recently pregnant Less likely to have received screening: - Asian/Pacific Islander descent & American Indian least likely to received all forms of screening Predictors for receiving screening: - clinical family planning visit - current or recent pregnancy - use of oral contraceptives - hx of PID or vaginitis	- Secondary analysis of data - American Indian sample size too small, insufficient power to detect stat significance in large differences in rates b/t American Indians & non-Hispanic whites (therefore, only White or Black as ethnic groups were examined in detail) - Family hx of disease was not collected in the 1988 survey - Major predictors not applicable to high risk women beyond reproductive age - more than one interviewer, validity not discussed	- Complements earlier national studies of screening - Findings suggest that likelihood of screening is more closely assoc. with access than risk status - Special studies of minority ♀ are needed - ♀ who are minority, low income or education, sexually inactive, may require special attention in screening programs - Interventions to increase access may be more efficient than separate interventions directed to specific conditions	- Main focus was not on Aboriginal ♀ - Secondary analysis of data from a national study - Screening included pap, breast and BP - Aboriginal sample size too small - American study - self-reported screening rates

Article #6 Ethnic Influences on Body Awareness, Trait Anxiety, Perceived Risk, and Breast and Gynecologic Cancer Screening Practices

Source	Purpose	Design/Sample/Setting	Statistical Analysis/Variables	Data Collection	Results	Limitations	Conclusions/Implications	Comments
2001 Foxall, Barron, & Houfek	- To examine body awareness, trait anxiety, perceived risk, and breast and gynecologic cancer screening practices among four ethnic groups of women (Caucasian, African American, Hispanic, & American Indian)	- Quantitative Non-experimental - Comparative, descriptive secondary analysis Sample N = 233 (12% were American Indian) Participant criteria: - ♀ 19+ yrs - not pregnant or breastfeeding - no personal hx of breast or gynecological cancer - able to speak & understand English - physically & mentally able to participate - Random sampling from residential mailing list - Convenience sampling through ethnic church & com'ty health organizations Setting - a midwestern state, USA - urban and rural - questionnaires completed in home or com'ty setting	- Descriptive stats for sociodemographic, perceived risk, and screening practices - ANOVAs (analysis of variance) with independent and dependent variables (general linear models, group means using least-squares, Pearson to determine relationships, $\alpha=0.05$) - Procedures appropriate for type of data Variables <u>Independent</u> - ethnicity (categorical: Caucasian, African American, Hispanic, & American Indian) <u>Dependent</u> - four variables: body awareness, trait anxiety, risk perception, & breast & gynecologic cancer screening practices	- random sample given intro letter and follow-up phone call - convenience sample approached in person or by phone - questionnaires completed in home or com'ty setting - ♀ were given cash honorarium Consent/Approval - approval from university institutional review board for human subjects' participation - informed consent obtained prior to data collection Instrument - Screening practices: 4 item open-ended coded questionnaire - Body Awareness Questionnaire: BAQ 18 item, 7pt Likert type scale - Trait Anxiety Subscale: TAI 29 item, 4pt Likert type scale - Perceived risk: 2 continuous items, 7pt Likert type scale - Background Data From: demographic data	- BSE frequency: Hispanic & American Indian ♀ > Caucasian & African American ♀ - Mammogram use: Hispanic & American Indian ♀ < Caucasian & African American ♀ - increased body awareness was related to fewer gynecologic exams for American Indian ♀ - Aboriginal ♀: perceive an increased risk for cancer, have increased anxiety, lower rate of pap testing	- Secondary analysis of data - lack of random sampling for majority of ethnic sample (possible selection bias) - convenience sample limits the generality of the findings - Ethnic groups not homogenous, caution not to stereotype when interpreting data - Self-reported screening practices may have participant response bias - majority of Hispanic & American Indian ♀ from rural - questionnaire at grade 8 level (may be too high and influence responses) - BAQ and TAI scales not designed specific for breast & gynecologic cancer screening	Nursing: - need for ethnic & culturally specific nursing interventions - interventions include assessment of frequency of practice (be aware of over-reporting) - target Hispanic & American Indian ♀ for screening programs - consider role of body awareness with American Indian ♀ & decreased screening Research: - need to determine how ♀ perceive cancer risk & culture - examine ♀'s criteria for BSE - large #s of ethnic groups need to be included in - should incorporate in-depth interviews, better understanding for ethnic differences	- Main focus was not on Aboriginal ♀ - ♀ were given cash honorarium - Secondary analysis - Self-reported screening practices - Screening included BSE, clinical breast exam, mammogram, gynecologic exam - Addressed gap in literature

Article #7 Development and Implementation of a Culturally Sensitive Cervical Health Survey: A Community-Based Participatory Approach

Source	Purpose	Design/Sample/Setting	Statistical Analysis/Variables	Data Collection	Results	Limitations	Conclusions/Implications	Comments
2004 Smith, Christopher, & McCormick	<ul style="list-style-type: none"> - To examine Apsaalooke women's understanding and beliefs about cervical health - To develop and implement a culturally sensitive survey to guide the program and benefit the community - To understand the cervical health educational and related needs of the community through the survey and steer the course of the project 	<ul style="list-style-type: none"> - Community-based participatory research where there is com'ty participation in all phases of research - Mixed methods: quantitative and qualitative - Non-experimental (initial phase of the larger Messengers for Health 4 yr project) <p>Sample N = 100 Participant criteria: - Apsaalooke ♀ 18+ yrs - living on or near reservation - no mental handicap, illness, or incapacitated elderly woman</p> <p>Computer generated random sample from tribal list of all eligible</p> <p>Setting - Apsaalooke reservation, Southeastern Montana, USA</p>	<ul style="list-style-type: none"> - Descriptive data: selected frequency percentiles from the baseline data - Analysis not in-depth <p>Variables <u>Independent</u> - risk factors, barriers to screening, screening rates, etc. included in survey - questions on survey were not discussed in detail</p> <p><u>Dependent</u> – Apsaalooke ♀'s response (not explicitly stated)</p>	<ul style="list-style-type: none"> - advisory board, project consultants & coordinator created survey - ♀ approached by interviewer and information regarding study was explained - structured face-to-face interviews conducted by trained Apsaalooke ♀ - participants with questions were provided follow-up assistance from either the project coordinator, principle investigator, or a ♀ physician <p>Consent/Approval - approval and consent not discussed</p> <p>Instrument - advisory board, project consultants & coordinator (to create survey) - 121 item survey, in form of interview, with both closed- and open-ended questions</p>	<ul style="list-style-type: none"> - screening rates are low (63% had pap test in past year) - 30% not know of a test to check for cervical cancer - low rates on knowledge of risk factors - low rates of exposure to cervical cancer info - childcare & transportation seen as barriers - uncomfortable topic to talk about with family, friends or co-workers 	<ul style="list-style-type: none"> - self-reported screening rates (may reflect higher rate than actual) - wording/reading level of questions may be too high ie) "Have you heard of a test to check for cervical cancer?". Reading level was not discussed - past research atrocities may have made ♀ feel motivated to give "correct" responses - differing ethnic backgrounds on research team may have caused lack of shared meaning & values when choosing items for the survey - more than one interviewer, validity not discussed - findings not generalizable to population off reserve or other tribes 	<ul style="list-style-type: none"> - Findings will guide the education & intervention programming & help to avoid making stereotyped generalizations - Mixed-methods helped to gain a richer perspective of their understanding & beliefs - researchers must be skilled to incorporate cultural components into research design - researchers need to recognize some survey items will never be culturally sensitive, need gentle, well-trained interviewer - CBPR for survey research is critical for success, validity & giving back to com'ty 	<ul style="list-style-type: none"> - Main focus was on Aboriginal ♀, involving their perspective - CBPR approach - open-ended questions helped to support traditional means of communication - Interviewers trained Apsaalooke ♀ = trust; > reliability and validity of data - American study - self-reported screening rates

Article #8 Cervical Cancer Screening in Ethnocultural Groups: Case Studies in Women-Centered Care

Source	Purpose	Design/Sample/Setting	Statistical Analysis/Variables	Data Collection	Results	Limitations	Conclusions/Implications	Comments
2001 Bottorff, Balneaves, Sent, Grewal, & Browne	<p>- To identify and describe critical elements of women-centered care within the context of providing cervical screening to three ethnocultural groups in Canada: Asian, South Asian, and First Nations</p> <p>- Aim to determine factors that influence full implementation of women-centered care.</p>	<p>- Qualitative Collective Case Study</p> <p>Sample 3 specialized cervical cancer screening clinics for case studies</p> <p>Case study #1 (South Asian): N = 20 clients, 5 key informants</p> <p>Case study #2 (Asian): N = 15 clients, 4 key informants</p> <p>- Case studies #1 & #2 purposeful sampling of ♀ who received pap test from family docs, gynecologists, or the specialized clinics with a variety of ages and immigration history; key informants were nurses/physicians working in the clinics, program developers, & docs in community</p> <p>Case study #3 (First Nations): N = 5 key informants - key informants had been involved in development & operation of the clinic</p> <p>Setting - urban setting in western Canada</p>	<p>- all interviews were translated & transcribed verbatim</p> <p>- thematic analysis led to coding for use in computer software program</p> <p>- cross-case analysis by comparing & contrasting issues & contextual factors influencing ♀'s & providers' experiences</p> <p>Variables Research – clients' experiences & views concerning pap testing & their expectations & preferences for screening - key informants' perspectives on screening women from ethnically diverse communities</p>	<p>- trained ♀ interviewers from appropriate ethnocultural community</p> <p>- interviews conducted in language of participant's choice</p> <p>- all interviews were translated & transcribed verbatim</p> <p>Consent/Approval - approval and consent not discussed</p> <p>Instrument - open-ended interviews</p>	<p>- ♀ desired thorough explanations, comfortable settings, ethnocultural values, ♀ providers, and opportunity to address a range of health concerns with ♀ providers at the clinic</p> <p>- 3 key elements: 1) respectful & culturally appropriate interactions b/t ♀ & health providers 2) importance of providing acceptable alternatives for ♀ 3) need for comprehensive health services</p> <p>First Nations clinic barriers: - avoid seeking additional care due to marginalization or not a priority - uncomfortable - fears of social service intervention - mistrust of health systems - vulnerability (ie)abuse - location of clinic - clinic's exclusive focus on cancer screening - no mass of ♀ for informal advertising</p>	<p>- findings cannot be generalized to other settings & populations</p> <p>- First Nations clinic was closed at time of study so no data from these clients' perspectives were gathered</p> <p>- data gathered in more than one language, may decrease validity in translation</p> <p>- more than one interviewer, validity not discussed</p>	<p>- changes in health policy & structure of health services required for existing programs to fully implement elements of women-centered care</p> <p>- other models of providing health care to ♀ in ethnocultural groups should be evaluated</p> <p>- analysis informs understanding of women-centered care</p> <p>- other factors influencing ♀'s receptivity to pap testing need to be acknowledged</p> <p>- Increasing involvement of ♀ nurses/practitioners should > participation rates</p> <p>- particular efforts & affirmative actions needed for First Nations ♀ to regain trust in health care system</p>	<p>- main focus was not on Aboriginal ♀, did not participate due to closure of clinic</p> <p>- research team held extensive direct experience in providing pap testing to ♀ within each of the 3 ethnocultural groups enhanced the validity of the themes</p> <p>- 3 key elements are supported by existing literature</p>

Article #9 Breast and Cervical Cancer Screening Practices among American Indian and Alaska Native Women in the United States, 1992-1997

Source	Purpose	Design/Sample/Setting	Statistical Analysis/ Variables	Data Collection	Results	Limitations	Conclusions/ Implications	Comments
1999 Coughlin, Uhler, & Blackman	- To describe the breast and cervical cancer screening practices of American Indian and Alaska Native women in 47 states obtained by population-based probability samples from 1992 through 1997.	<p>- Quantitative Non-experimental</p> <p>- Secondary data analysis of results from the Behavioral Risk Factor Surveillance System</p> <p>Sample N = 4,961 (analysis of mammography & clinical breast exam use limited to 40yrs+ N = 2438)</p> <p>Participant criteria: - ♀ 18⁺ yrs - self-identified American Indian or Alaska Native - noninstitutionalized who have telephones - responded to Behavioral Risk Factor Surveillance System surveys</p> <p>- random-digit-dialing, multistage cluster sampling</p> <p>Setting - 47 states in the USA</p>	<p>- age specific & crude rates calculated for 6 yr period</p> <p>- bivariate associations with sig level using Pearson's chi-square (limited to age-adjusted rates)</p> <p>- SAS & SUDAAN to calc 95% CI & weighting of estimates</p> <p>- samples were weighted to compensate for unequal sampling probability</p> <p>- multivariate analysis of predictors of screening use by logistic regression & SUDAAN: backward stepwise, assoc at P<0.05</p> <p>Variables <u>Independent</u> – ever been screened, frequency, age, income, marital status, education, employment, seen physician, smoking, alcohol, general health status, etc. <u>Dependent</u> – # of participants responded</p>	<p>- data from Behavioral Risk Factor Surveillance System database for 6 yr period</p> <p>- state-based, computer-assisted telephone survey by trained interviewers</p> <p>Consent/Approval - approval and consent not discussed</p> <p>Instrument - telephone survey</p>	<p>Positive assoc with:</p> <p>1) Pap test: - higher education - having seen physician in past year - younger age - higher income - current smoking - marital status</p> <p>2) Mammography: - higher education - having seen physician in past year - poorer general health status - current alcohol use</p> <p>3) Clinical Breast Examination: - higher education - having seen physician in past year</p> <p>- ♀ from Alaska were more likely to have had a pap test</p> <p>- no significant trends over the 6yr period in screening rates</p>	<p>- Secondary analysis of data</p> <p>- only 47 state included; may not be generalizable to all ♀ in USA of same ethnicity</p> <p>- possible response bias, 15-20% contacted did not respond; excluded ♀ who do not have a telephone</p> <p>- more likely to represent urban areas due to incomplete telephone coverage in some rural areas</p> <p>- screening practices were self-reported, may reflect higher rate</p>	<p>- need for continued efforts to ensure this population of ♀ who are elderly or medically underserved have access to screening services</p>	<p>- Main focus was not on Aboriginal ♀</p> <p>- Secondary analysis of data from national studies</p> <p>- Self-reported screening practices</p> <p>- American study</p>

Article #10 Mammography and Pap Smear Screening of Yaqui Indian Women

Source	Purpose	Design/Sample/Setting	Statistical Analysis/ Variables	Data Collection	Results	Limitations	Conclusions/ Implications	Comments
1994 Gordon, Campos- Outcalt, Steele, & Gonzales	- To determine the use rates of Pap smear and mammography screening by Pascua-Yaqui women ages 35-65.	<p>- Quantitative Non-experimental</p> <p>- Secondary data analysis of results from the local neighborhood health center (NHC)</p> <p>Sample N = not discussed Participant criteria: - ♀ 35-65 yrs - listed on tribal roll & living in Pima County - received services at satellite or NHC</p> <p>2 groups: - eligible - active users (in past 3 months) (sub group of eligible)</p> <p>Setting - Pima County, Tucson, Arizona, USA</p>	<p>- individual yrs from 1986 to 1990 examined for pap test rates</p> <p>- total # of tests (separated by at least 9 months) for each ♀ for the 5yr period calculated</p> <p>- mammography only calculated for yrs 1989 to 1990 (test not available prior to 1989); rates calculated according to recommended frequencies</p> <p>- no in-depth detail on analysis provided</p> <p>Variables <u>Independent</u> – not discussed in detail <u>Dependent</u> – screening status (binomial – no/yes)</p>	<p>- data from local NHC computerized billing database</p> <p>Consent/Approval - approval and consent not discussed</p> <p>Instrument - computerized billing database</p>	<p>- tables were omitted from article</p> <p>- inadequate screening in older Native American ♀</p> <p>Pap smears: - over the 5yrs rate was 54% for eligible & 65% for active users for at least 1 smear - ♀ having received 2, 3, 4, or 5 smears decreased; only 1% received yearly smears for 5yrs - average rate per year was 35% for active users (about the same year to year)</p> <p>Mammography: - 67% received at least 1 test over the 3yrs - rates were lower for older ♀</p>	<p>- Secondary analysis of data</p> <p>- accuracy of billing records was dependent on radiology suite and lab</p> <p>- ♀ receiving health care elsewhere are listed as not having received services</p>	<p>- need to examine older Indian ♀ and underutilization factors</p> <p>- screening needs to be encouraged and continued on older population</p> <p>- need to research how changing from one health center to another impacts use of screening services</p> <p>- important to explore why many active users do not receive regular screening</p> <p>- studying & understanding nonfinancial barriers may help with challenge to recruit eligible who do not use services and increase regular use of active users</p>	<p>- Main focus was not on Aboriginal ♀</p> <p>- Secondary analysis of data from local health center</p> <p>- rates recorded by service providers</p> <p>- American study</p>

Appendix B: Information-Consent Letter

Title

Exploring Cervical Cancer Screening Behaviour: A Grounded Theory Study of Aboriginal Women's Decision-Making Experiences

Name of Researcher and Supervisor

Crystal Duchcherer
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Purpose and Procedure

The purpose of this research study is to gather information about what helps or keeps Aboriginal women from having Pap tests. This study will work with women from Standing Buffalo First Nation. The study involves two parts. For the first part, you will be asked to fill out a personal information form. This form asks questions about your background, such as your age and marital status. The second part of the research study is a tape recorded interview with the researcher. The interview will explore how you decided to participate in Pap testing. This part will take about 30 to 90 minutes of your time. There may be a second interview to confirm or change your information. All information collected from this study will be kept confidential.

Potential Risks

You may feel tired from the interview process. You are free to take breaks or stop the interview at any time. Because this is a sensitive topic, you may have negative feelings come up. (Name of Elder), a community Elder can be contacted at (phone number) or (Name of counselor), a counselor from the local health clinic can be contacted at (phone number) to discuss any issues that you may come across during or after this study. Also, you can reach the crisis hotline free of charge at (phone number) anytime of the day or night.

Potential Benefits

The benefits include, but are not limited to, offering you the opportunity to openly talk about your experience, giving a voice to Aboriginal women, the possibility of influencing nursing practice, and providing a foundation for future research.

Storage of Data

All of the information collected from this study will be kept in a locked cupboard at the College of Nursing, Regina site by the research supervisor for a minimum of 5 years. To ensure confidentiality, the consent form will be stored separately from the data collected.

Confidentiality

The overall results of this study will be provided to Standing Buffalo First Nation and local health care workers to help in planning and developing Pap test programs that will help women in your community participate in Pap testing. A copy of these results will be provided to each participant upon request. As well, the results of this research study will be used for my master's thesis. I will also use the information from this study to publish articles in journals and for presentations at conferences; however, your identity will be kept confidential. Although I may report direct quotations from the interview, you will be given a false name, and all identifying information will be removed from the report. However, if any illegal or incriminating information is provided, the researcher is obligated to report it.

Right to Withdraw

Your participation is voluntary, and you may withdraw from the study for any reason. You may do so at any time without penalty of any sort. The decision to withdraw will not affect the health services you receive. If you withdraw from the study, any data that you have contributed will be destroyed at your request.

Questions

If you have any questions about this study, please feel free to ask at any point or contact the researcher, Crystal Duchcherer at (306) 717-6198, or the research supervisor, Dr. Pammla Petrucka at (306) 798-1082. This study has been approved by Standing Buffalo's Chief and Council on (date) . This study has also been approved by the University of Saskatchewan Behavioural Research Ethics Board on (date) . If you have any questions regarding your rights as a participant you can call the University of Saskatchewan Research Ethics Office collect at (306) 966-2084.

Signature and Consent Form

(Exploring Cervical Cancer Screening Behaviour: A Grounded Theory Study of Aboriginal Women’s Decision-Making Experiences)

I have read and understood the information provided above; I was able to ask questions and my questions have been answered to my liking. I consent to participate in the study described above and understand that I may withdraw this consent at any time. A copy of this consent form has been given to me for my records.

(Name of Participant)

(Date)

(Signature of Participant)

(Signature of Researcher)

Appendix C: Demographic Form

Participant Information:

Date: _____ Code No.: _____

1. Age: _____ years

7. Employment:

- _____ Full time
- _____ Part time
- _____ Unemployed
- _____ Student
- _____ Retired

2. Aboriginal ancestry:

- _____ Dakota
- _____ Assiniboine
- _____ Cree
- _____ Sioux
- _____ Other (please specify): _____

8. Number of pregnancies: _____

3. Where do you live?

- _____ On Reserve
- _____ Off Reserve

9. Age at first Pap test: _____ years

4. Highest Level of Education Completed:

- _____ Less than Grade 12
- _____ High school diploma or GED
- _____ Some post-secondary education
- _____ Completed technical training program
- _____ Completed university degree

10. How often do you have Pap tests?

- _____ Every year
- _____ Every 2 years
- _____ Every 3 years
- _____ Every 4 or more years

5. Marital Status:

- _____ Married or Common-law
- _____ Divorced
- _____ Widowed
- _____ Single

11. Where do you get your Pap tests?

- _____ Standing Buffalo community health clinic
- _____ Other health clinic/doctor's office
- _____ Other (please specify): _____

6. Annual household income before taxes:

- _____ Less than \$19,999
- _____ \$20,000-\$39,999
- _____ \$40,000-\$59,999
- _____ \$60,000 or more

12. Who does you Pap test?

- _____ Doctor
- _____ Nurse
- _____ Other (please specify): _____

13. Reason(s) for getting Pap test:

Appendix D: Interview Guide

Date: _____ Code No. _____

What are your thoughts and feelings when you hear the words Pap test?

How did you decide to participate in Pap testing?

(prompts) What did you consider when making this decision?

(prompts) What do you think influenced this decision?

What motivates (would motivate) you to go back?

Could you tell me about your experience(s) with Pap tests?

(prompts) What lead you to participate in pap tests?

(prompts) What was the best part of your experience?

(prompts) What was the worst part of your experience?

What has made it easy for you to get your Pap test?

(prompts) What can others do to help you participate in Pap tests?

What advice might you give to another woman?

Is there anything you thought I would ask that I didn't?

Is there any thing else you would like to add?

Appendix E: Reflexive Journaling

Excerpt: Discovering New Communication Patterns

- (During earlier interviews with women from the childbearing generation and reading over transcripts) I've noticed a pattern where women in their childbearing years are offering advice and guidance to their children and other youth in the community. They have taken on the duty to help these young girls out with sexual and reproductive health issues. They state that their mothers did not share information with them while they were growing up and they don't want to see the future generations going through the same. Also, these women are telling their mothers about their experiences with CCS and encouraging them to consider participating in CCS.

- (Later interviews involving women from the elder generation) This is when the communication patterns involving CCS information were confirmed. Elder women were generally non-participants or had previously experienced only 1 or 2 Pap test in their lifetime. They discussed how this topic is not to be talked about in the open and they had difficulties with deciding to participate in CCS during their youth. They stated how their daughters had informed them about what a Pap test is. Their daughters shared their experiences of CCS and with other reproductive health issues.

- I've always assumed that in the Aboriginal culture information is always passed down from generation to generation, starting with the Elders. I believed from my own education and personal interactions that members of the community would go to their elders for advice and listen to their stories and wisdom. As this may be the case for other topics, I am finding this is not the case for CCS discussions and information. It is the childbearing generation that holds the key – these women pass on information down to the youth and up to the elders. Are women from the childbearing generation the knowledge brokers in regards to CCS? Should they be the target group for passing on information to the community?

Appendix F: From Codes to Themes

Transcripts	Code	Theme
then that's when I think I get <u>scared to know</u> , to know <u>what's wrong</u>	-scared what's wrong	fearing negative outcome
it's more a <u>fear of the unknown</u> , of what can happen	-fear of unknown	
I think people are afraid of, some people are <u>afraid of facing what they may have</u>	-afraid what may have	
there was <u>fear within me</u> to think that maybe yes there is <u>something wrong</u>	-fear something wrong	fearing cancer
<u>fear of getting cancer</u> and maybe there's <u>something else wrong</u>	-fear cancer; -fear something wrong	
just <u>scared</u> like <u>of cancer</u> or things like that	-scared of cancer	fearing disease
That'll <u>scare me</u> more than anything else, if you have to <u>tell me I had cancer</u>	-scared of cancer	
It's kind of a <u>fear</u> , because <u>who knows</u> what could be coming out of it like a <u>negative thing</u> . Some people who are very, very, very <u>sexually active</u> ...it's a fear that <u>they do</u>	-fear negative sexual outcome	fearing STI
when it's pap test I think of well, <u>sexually transmitted diseases</u> ...actually what use to make me <u>feel scared</u> is because I use to have many sexual partner	-scared of STI	
after I went for my third pap test, I got results back stating that <u>I had Chlamydia</u> and that's what started to scare me	-scared of STI	

Appendix G: Demographic Characteristics of Participants

n=11

Characteristics	Number of Participants
Age:	
Childbearing Years	5
Beyond Childbearing Years	6
Highest Level of Education Completed:	
Less than Grade 12	3
Some Post-secondary	5
Completed Technical Training Program	3
Marital Status:	
Married or Common-law	3
Widowed	2
Single	6
*Annual Household Income:	
<\$19,999	5
\$20,000-39,000	4
Employment:	
Full-time	5
Unemployed	3
Retired	3
Frequency of Pap tests:	
Every year	1
Every 2 years	1
Every 3 years	1
Every 4 or more years	5
Never	3