# EXPLORING MI'KMAQ WOMEN'S EXPERIENCES WITH PAP SMEAR SCREENING IN NOVA SCOTIA

by

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#### **DEDICATION PAGE**

This dissertation is dedicated to all the Mi'kmaq women and healthcare providers who have graciously shared their time and Pap smear screening stories with me. These women taught me about resiliency and triumph in the face of adversity. Without them this research would not have been possible.

I also dedicate this research to my loving daughter Madison, born at the beginning of this PhD journey. You helped me stay balanced by taking me away to play, read, draw, and blow bubbles when I needed it most. I believe that God sent you to help me succeed in this endeavor.

To Dana, my life partner, who believed and encouraged me when I lost faith in myself, I dedicate this to you.

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# **Table of Contents**

LIST OF TABLES	vii
LIST OF FIGURES	viii
ABSTRACT	ix
LIST OF ABBREVIATIONS USED	X
ACKNOWLEDGEMENTS	xi
Chapter 1: Introduction	1
Introduction to Mi'kmaq People	7
Purpose of the Study	9
Research Questions	10
Significance of the Study	10
Chapter 2: Literature Review	13
Introduction	13
Historical Context	14
Aboriginal women's traditional roles.	21
An Overview of Aboriginal Women's Health Status	23
Impacts of Historical, Economic, and Social Contexts on Health	27
Aboriginal women and healthcare services.	32
Aboriginal women's encounters with the healthcare system	34
Healthcare system barriers to Pap smear screening.	36
Aboriginal women's experiences in healthcare systems.	38
Aboriginal Women and Pap Smear Screening	43
Summary	48
Chapter 3: Theoretical Perspectives, Methodology and Methods	49
Postcolonial Feminist Theoretical Perspectives	50
Introduction	50
Critiques of postcolonial theoretical perspectives.	54
Understanding concepts of culture, Othering, race, and racialization	56
Indigenous Knowledge and Epistemology	60

Indigenous principles.	62
Qualitative Research Design	64
Participatory action research principles.	66
Principles of the participatory action research process	67
Data Collection Methods	69
Community settings.	69
Gaining community access: Participatory approaches.	70
The study participants.	77
Data collection.	79
Data Analysis	83
Trustworthiness of the Data	86
Dissemination of Research Findings	91
Ethical and OCAP Considerations	93
Personal Reflection: Locating Myself in the Research	95
Summary	96
Chapter 4: Findings and Interpretation: Mi'kmaq Women's Perspectives	98
Finding Our Way	100
"Taking care of our health."	100
"Spreading the word with family and community."	109
Summary	113
Our Understanding and Perceptions about Pap Smear Screening	114
View of the body and self: "It's sacred."	114
"Paps: Important or not."	120
Pap smear screening:"Feeling violated."	126
Summary.	132
The Impact of History on Our Health and Healthcare Experiences	133
"The scar has been placed."	133
Socioeconomic factors.	145
"There are a lot of issues on Aboriginal women's plates."	150

Summary.	154
Healthcare Providers' Encounters: "Making a Difference in Our Path to Paps"	154
Relationships:"The fabric of our being."	155
Healthcare providers' practices and encounters: "Making it or breaking it."	162
Healthcare providers' education: "Our community as teacher."	172
Summary	181
"The Healthcare System is Complicating Our Going for Paps"	182
Confidentiality and privacy issues: "I don't want anybody knowing."	182
Healthcare system accessibility: "We need more services."	188
Summary.	192
Chapter Summary	192
Chapter 5: Findings and Interpretation: Healthcare Provider's Perspectives	195
Understanding the Realities of Aboriginal Women's Lives	
History	
Socioeconomic and political factors.	
Fostering Aboriginal Women's Access to Pap Smear Screening	
Trusting relationships	
Cultural safety in practice.	
Confidentiality issues.	
Optimizing processes to improve experiences	226
Chapter Summary	
Chapter 6: Overview, Study Strengths, Limitations, Implications and Conclusion	
Overview of the Study and Study Findings	
Study design and methodology	
Overview of Major Findings	
Historical and social contexts shaping Pap smear screening.	
Mi'kmaq women's understandings of and experiences with Pap screening	
Mi'kmaq women are accessing Pap smear screening.	248

Healthcare providers are influencing Mi'kmaq women's access	249
Healthcare systems are influencing Mi'kmaq women's access	250
Overview of Healthcare Providers Perspectives	251
Study Strengths and Limitations	252
Implications for Healthcare Practices	253
Individualize Pap smear screening.	254
Building relationships.	254
Creating safe spaces.	255
Educating women	256
Violence and trauma-informed care	256
Culturally safe practices.	259
Going step-by-step.	260
Offering consistent and convenient screening.	261
Forming a Pap smear screening committee.	261
Healthcare providers should.	262
Implications for Healthcare Education	263
Healthcare providers should.	265
Implications for Research	266
Researchers should	267
Future Research	268
Implications for Health Policy	269
Reflections and Personal Learning	271
Conclusion	272
References	274
Appendix A Information Letter to Community Facilitators	316
Appendix B Community Facilitator Agreement	318
Appendix C Letter of Information to Mi'kmaq Women Participants	319
Appendix D Letter of Information to Healthcare Participants	321

Appendix E Informed Consent for Interviews/Talking Circles for Mi'kmaq Women	323
Appendix F Informed Consent for Interview for Healthcare Providers	328
Appendix G Semi-structured Interview Guide for Mi'kmaq Women Participants	333
Appendix H Demographic Information Sheet for Mi'kmaq Women Participants	335
Appendix I Semi-Structured Guide for Healthcare Providers	337
Appendix J Demographic Data for Healthcare Providers	339
Appendix K Transcriptionist Agreement of Confidentiality	340

# LIST OF TABLES

Table 1 PAR Principles and Strategies	68
Table 2 Mi'kmaq Women's Demographic Characteristics	78

# LIST OF FIGURES

Figure 1 Thematic Analysis Process	. 84
Figure 2 Themes and Sub-themes: Mi'kmaq Women's Experiences with Pap Smear	
Screening	. 99

#### **ABSTRACT**

Mi'kmag women in Nova Scotia are reported to have lower rates of Papanicolaou (Pap) smear screening and have higher rates of cervical cancer compared to non-Aboriginal women. Much of the cervical cancer literature reflects mainstream values and tends to essentialize Aboriginal women as one at-risk homogenous group lacking knowledge about cervical cancer prevention. The primary purpose of this qualitative participatory study was to explore Mi'kmaq women's and primary healthcare providers' experiences with Pap smear screening and to consider the broader historical, economic, and sociopolitical contexts that shape those healthcare experiences. Mi'kmaq women's experiences accessing Pap screening services, their encounters with healthcare providers and the health care system, and women's past experiences with Pap smear screening were also explored. This inquiry was grounded in postcolonial feminist perspectives and Indigenous principles in a two-eyed seeing approach. Community facilitators were identified to assist with recruitment and the research process. Women participated in talking circles to learn about and shape the study. Sixteen Mi'kmaq women and five healthcare providers participated in two semi-structured interviews. Five themes were identified from the women: a) Finding Our Way, b) Our Understanding and Perceptions about Pap Smear Screening, c) The Impact of History on Our Health and Healthcare Experiences, d) Healthcare Providers' Encounters: "Making a Difference in Our Path to Paps," and e) "The Healthcare System is Complicating Our Going for Paps." Two themes were identified from healthcare providers: a) Understanding the Realities of Aboriginal Women's Lives and b) Fostering Aboriginal Women's Access to Pap Smear Screening. This research contributes to an understanding of the continued impact of wider historical, political, and socioeconomic conditions that have resulted from colonialism, residential schools, and assimilation on Pap smear screening. It reinforces the importance of not essentializing women's views or experiences and recognizing that some are accessing Pap smear screening regularly in spite of challenging circumstances. Mi'kmaq women have been underrepresented in the previous Pap smear screening literature. It is critical that healthcare providers understand how they can improve access to Pap smear screening and the screening process itself.

## LIST OF ABBREVIATIONS USED

AAHRP Atlantic Aboriginal Health Research Program

ANAC Aboriginal Nurses Association of Canada

CIHR Canadian Institutes of Health Research

CNA Canadian Nurses Association

CRNNS College of Registered Nurses Association of Nova Scotia

HIV Human immunodeficiency virus (HIV)

HPV Human papillomavirus (HPV)

NAHA National Aboriginal Health Association

NAHO National Aboriginal Health Organization

NWAC Native Women's Association of Canada,

OCAP Ownership, Control, Access and Possession

PAHO Pan American Health Organization

Pap Papanicolaou

PAR Participatory Action Research

STIs Sexually Transmitted Infections

WHO World Health Organization

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# Chapter 1:

#### Introduction

Aboriginal women are often considered the "life givers" of their communities; a gift bestowed to them from the Creator (Morgan & Wabie, 2012). Reproductive health is foundational to honoring this gift and to the well-being of Aboriginal women's families, communities, and Nations (Native Women's Association of Canada, 2007a). Nevertheless, Aboriginal women are confronted with sexual and reproductive health conditions such as cervical cancer. Papanicolaou (Pap) screening has been effective in decreasing the morbidity and mortality rates of cervical cancer (Canadian Cancer Society, 2012). Despite its efficacy however, Aboriginal women continue to have lower rates of Pap smear screening than other Canadian women, and higher rates of cervical cancer (Johnson, Boyd, & MacIsaac, 2004; Public Health Agency of Canada, 2012; Zehbe, Maar, Nahwegahbow, Berst, & Pintar, 2012). In Canada, it is estimated that cervical cancer rates are 1.8 to 4.0 times higher for Aboriginal women in comparison to non-Aboriginal women (Letendre, 2008; Young, Kliewer, Blanchard, & Mayer, 2000), with mortality rates approximately 2.5 to 10 times higher among Aboriginal women (Hislop et al., 1996; Letendre, 2008; Young et al., 2000). This situation is particularly concerning in Nova Scotia where women in general are known to have the highest incidence of invasive cervical cancer nationally (Province of Nova Scotia, 2007). In Nova Scotia, Aboriginal women are reported to have the lowest rates of Pap screening, yet higher rates

<sup>&</sup>lt;sup>1</sup> Aboriginal is a collective name for the original peoples of North America and their descendants. The Canadian constitution recognizes three groups of Aboriginal people: First Nations, Métis and Inuit. These are three distinct peoples with unique histories, languages, cultural practices and spiritual beliefs (Indian & Northern Affairs Canada, 2009).

of cervical cancer in comparison to non-Aboriginal women in the same region (Johnson et al., 2004).

The extent to which Pap screening is accessed by Aboriginal women is related to wider issues often related to marginalization and racialization in healthcare, and to the decontextualized societal discourses addressing Aboriginal women's risks for cervical cancer (Bottorff, Balneaves, Sent, Grewal, & Browne, 2001; Browne & Smye, 2002; Browne & Varcoe, 2006; Elias et al., 2011; McGibbon & Etowa, 2009; Reimer-Kirkham & Anderson, 2002; Tang & Browne, 2008). Most of the research related to Aboriginal women and Pap screening focuses on epidemiological data (i. e., stressing the high rates of cervical cancer morbidity and mortality) with little recognition of the sociopolitical, cultural, cognitive, psychological, and socioeconomic factors that have constrained women's access to Pap screening (Amankwah, Ngwakongnwi, & Quan, 2009; Black, 2009; Browne & Smye, 2002; Clarke et al., 1998; Hislop et al., 1996; Johnson et al., 2004; Peters, Johnson, Bear, & Thompson, 1989; Roberts, 2005; Tjepkema, Wilkins, Senecal, Guimond, & Penney, 2009; Wilson, 2002).

Aboriginal women continue to demonstrate major health discrepancies in comparison to other Canadian women, along with inequities in social determinants that contribute to this disparity (Dion Stout, Kipling, & Stout, 2001; Loppie-Reading & Wien, 2009). In reality, reasons for the high morbidity and mortality rates attributable to cervical cancer and low Pap smear screening rates are multifaceted and layered in historical and economic conditions that have negatively impacted women's health status and shaped their experiences with healthcare systems (Battiste, 2000; Black, 2009;

Bourassa, McKay-McNabb & Hampton, 2004; Browne, 2007; Letendre, 2008; Smye, Rameka & Willis, 2006; Warry, 2007). Consequently, there is an urgent need for research and healthcare discourses to situate the epidemiology of cervical cancer and the barriers Aboriginal women confront when accessing Pap smear screening services within these contexts (Browne & Smye, 2002).

The healthcare literature in general, epidemiological literature in particular, reports Aboriginal women as having higher rates of cervical cancer compared to non-Aboriginal women, attributing these differences to high-risk behaviors such as having unprotected intercourse with multiple sex partners, lower rates of screening, high rates of sexually transmitted infections (STIs), and early onset of sexual activity (Gerberding, 2004; Health Canada, 2002; Johnson et al., 2004; Reeves, 2008; Sheets, 2002; World Health Organization [WHO], 2006). In so doing, the literature reinforces stereotyping of Aboriginal women as reckless, unsafe risk-takers, while constructing them "in ways that reflect popularized negative stereotypes" (Browne & Varcoe, 2006, p. 161). Lifestyle and personal choice are positioned as the issues without examination of broader sociopolitical factors (Browne, 2007). This literature is powerful in constructing and reinforcing colonial images of Aboriginal women's identity in mainstream society and framing Aboriginal women's health and health behaviors negatively (Adelson, 2005; Browne et al., 2011).

The lack of contextualization of epidemiological and healthcare service discourses has alienated, marginalized, and stigmatized some Aboriginal women (Browne, 2005, 2007; Browne & Smye, 2002; O'Neil, Reading, & Leader, 1998; Smye et

al., 2006; Tang & Browne, 2008). For example, when the high rates of cervical cancer among Aboriginal women are attributed to certain risk factors, Aboriginal women are labeled as being "high risk in terms of their reproductive health" (Browne & Smye, 2002, p. 32). There are many factors that have impacted the health status of Aboriginal women and shaped their experiences with healthcare systems and services. These include historical trauma<sup>2</sup>, the removal of children from their homes to residential schools, appropriation of their lands, the creation of reserves, discrimination and racism (Battiste, 2000; Bourassa et al., 2004; Browne, 2007; Dion Stout, 2012; Gregory & Harrowing, 2012; Smye et al., 2006; Warry, 2007). Furthermore, healthcare systems predominately reflect a mainstream view of health and illness that has not always been effective for meeting the healthcare needs of Aboriginal people (Sherwood & Edwards, 2006; Smye & Browne, 2002). Western healthcare systems and services have been narrowly constructed in a biomedical model of health based upon individualism and conceptualization of disease and illness, which may directly contrast with relational approaches emphasized in Indigenous perspectives to health and healing (Azetsop & Rennie, 2010; Battiste, 2000).

Individualism refers to the choosing of health behaviours and poor health is attributed to exposures to health risks that the individuals have decided not to avoid (Azetsop & Rennie, 2010). This approach disregards the role of social, economic, and political conditions that structure the array of risk factors that individuals are supposed to

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<sup>&</sup>lt;sup>2</sup> Historical trauma is cumulative emotional and psychological wounding and suffering, over the lifespan and across generations, emanating from massive group trauma (Brave Heart & Daw, 2012). Residential school experiences have been identified as an important part of the cultural and identity loss referred to as historical trauma by Aboriginal researchers (Warry, 2007).

avoid and fails to explain how social inequalities cause poor health outcomes and access to healthcare (Azetsop & Rennie, 2010). Mainstream healthcare systems tend to conceptualize health and illness as stemming from lifestyle, cultural difference, or biologic disposition (Browne & Dion Stout, 2012; Loppie-Reading & Wien, 2009), which situates the problem of illness primarily with the individual. Healthcare policies and strategies aimed at helping Aboriginal people, but based upon Western models of healthcare delivery and on disease-based discourses, may perpetuate racism, social exclusion, marginalization, and inequitable access to healthcare (Barton, 2008; Martin, 2012; Paradies, Harris, & Anderson, 2008; Sherwood & Edwards, 2006; Tang & Browne, 2008). This may result in the negating and bracketing out of the importance the sociopolitical contexts of healthcare and healthcare encounters premised upon professional socializations that value egalitarian discourses and White middle-class values (Aboriginal Nurses Association of Canada, 2012; Browne, 2007).

Cancer-care literature also continues to reflect the mainstream values and beliefs of a Western healthcare system upon which cancer-care and prevention modalities have been structured. This perspective of healthcare negates sociopolitical and historical contexts of Aboriginal women's experiences with healthcare and devalues their traditional ways of knowing, philosophy, and medicine (Battiste, 2000; Loppie-Reading & Wien, 2009). The ethnocentric perception which dominates Western healthcare suggests that one set of values and beliefs are used as the standard for all healthcare, disregarding other ways of knowing and doing.

Many of the traditional ways of knowing, such as Indigenous knowledge and traditional healing practices of Aboriginal people, have been socially and culturally disrupted by Western medicine, colonization, residential schools, and government policies of assimilation (Browne & Dion Stout, 2012; Dion Stout, 2012; Martin, 2012; Vukic, Gregory, & Martin-Misener, 2012; Waldram, Herring, & Young, 2006;).

Furthermore, a history of internal colonization<sup>3</sup>, unjust laws, and economic and political disadvantage have negatively impacted health outcomes, broadened an existing gap of health inequities, and marginalized Aboriginal women (Adelson, 2005; Browne & Fiske, 2001; Browne & Smye, 2002; Warry, 2007). Inequities exist in social, economic, cultural, and political influences on health and accessibility to equitable healthcare for Aboriginal women (Adelson, 2005; Black, 2009; Browne, 2007; Browne et al., 2011; Dion Stout, 2012; Warry, 2007).

There is a critical need for nurses and other healthcare providers to situate the analysis of Aboriginal women's health. In this study the focus is Pap smear screening within broader sociopolitical, economic, and historical contexts. This recontextualization requires shifting the focus of the issue of low Pap smear screening rates from decontextualized epidemiological and healthcare discourses to consideration of the broader social structures and inequities in healthcare systems to understand why Aboriginal women may or may not be participating in Pap smear screening services. By situating Aboriginal women's health and access issues in a broader context of

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<sup>&</sup>lt;sup>3</sup> Internal colonization is the process of encroachment and subsequent subjugation of Aboriginal peoples since the arrival of the Europeans. From the Aboriginal perspective, it refers to loss of lands, resources, and self-direction, and to severe disturbance of cultural ways and values (LaRocque, 1993).

Aboriginal women's experiences of accessing Pap smear screening services and the wider historical and social contexts that reinforce disparities (Adelson, 2005; Browne, 2007). This knowledge will potentially assist healthcare providers and policy makers in the promotion of respectful and effective Pap smear screening services for Aboriginal women.

In keeping with Indigenous principles and informed by participatory action principles, a "two eyed seeing" approach, and post-colonial feminist theoretical perspectives, this qualitative study illuminates the broader sociopolitical, economic, and historical contexts that shape Aboriginal women's healthcare experiences. Including Aboriginal women's experiences and comprehending the historical, political, and socioeconomic contexts that impact their choice to access Pap screening services will inform policy, practice, and future research, and hopefully, increase Pap screening rates.

#### **Introduction to Mi'kmaq People**

The Aboriginal women who participated in this study are of Mi'kmaq descent, the main population of First Nations peoples in Nova Scotia. The term "Mi'kmaq" is a more modern term than the previous term, "Micmac," and means "people" (Steckley & Cummins, 2008, p. 51). The Mi'kmaq people's territory encompasses parts of Nova Scotia, Western New Brunswick, Prince Edward Island, the Gaspe in Quebec, Anticosti Island, and Newfoundland (Steckley & Cummins, 2008). Although the participants in

the study are Mi'kmaq women, it is possible that some may have some other tribal affiliation (e. g., Maliseet) as well.

Mi'kmaq people's culture was traditionally embedded in the principles of "the supremacy of the Great Spirit, respect for Mother Earth and people power" (Paul, 2006, p. 7). They had a deep appreciation for the Creator, Mother Earth, and living the principles of a democratic society in harmony with each other in a healthy, flourishing, and nonviolent social environment (Paul, 2006). Food was bountiful and they lived in harmony with the seasons that provided nutritional fish, game, and fowl (Paul, 2006). Mi'kmaq society was based on equitable human rights principles and free expression and language was valued. Storytelling was a primary source of education, entertainment, and used for the passing on of traditional ways (Battiste, 2000). Health was considered a communal responsibility and Elders and ill community members were continually cared for by others in the community (Paul, 2006). But with the arrival of the Europeans, colonization changes in Mi'kmaq communities occurred with the loss of lands, cultures, and traditions (Sable & Francis, 2012).

Like many Aboriginal groups across Canada, Mi'kmaq people in Nova Scotia are still attempting to settle land claims and treaty rights. In the later part of the 1990s, all 13 First Nations communities in Nova Scotia formed the Mi'kmaq Rights Initiative which conducted negotiations between the Mi'kmaq of Nova Scotia, the Province of Nova Scotia, and the Government of Canada. The Initiative was developed by the Mi'kmaq, for the Mi'kmaq, for the purpose of addressing land claims and treaty negotiations, with the hopes of finally implementing treaty rights signed by their ancestors in the 1700s

(Mi'kmaq Rights Initiative, 2005). On June 2<sup>nd</sup>, 2002 an agreement was signed to enable all three parties to work collaboratively to resolve the issues of treaty rights and land claims.

As of February 2007, there was also a framework agreement signed by the Nova Scotia government through the Assembly of Nova Scotia Mi'kmaq Chiefs to commence formal negotiations to address issues of definition, recognition, and implementation of Mi'kmaq land rights and land titles in Nova Scotia. There was also agreement to address other broader issues of land such as natural resources and governance. Currently, there are plans to review the entire process to determine the successes and shortcomings with an aim to developing a final accord that will pertain to the future relationship of the government and the Mi'kmaq of Nova Scotia with regards to land claim and treaty settlements (Mi'kmaq Rights Initiative, 2005a).

## **Purpose of the Study**

The primary purpose of this qualitative study was to explore Mi'kmaq women's and primary healthcare providers' experiences with Pap smear screening in two rural Mi'kmaq First Nations communities in Nova Scotia, and to consider the broader historical, economic, and sociopolitical contexts that shape those healthcare experiences. Aboriginal women's experiences accessing Pap screening services, their encounters with healthcare providers and the health care system, and women's past experiences with Pap smear screening were also explored. This expands the focus of women's lack of participation in Pap smear services from individual or cultural differences to a fuller

understanding of the importance of including historical, economic, and sociopolitical contexts that construct Aboriginal women's experiences. This study may lead to the development and implementation of healthcare practices and procedures, programs and policies that promote more respectful and culturally safe Pap screening approaches for Aboriginal women. The hope is that it could potentially contribute to increased screening rates and eventual decreased cervical cancer morbidity and mortality.

# **Research Questions**

The specific research questions of the study are:

- 1. What are Aboriginal women's experiences with Pap smear screening?
- 2. What is Aboriginal women's awareness and knowledge about Pap smear screening?
- 3. What are some of the factors influencing Aboriginal women's access to Pap smear screening?
- 4. What are participants' perceptions of the reasons why some Aboriginal women are not participating in Pap smear screening?
- 5. What sociopolitical, economic, and historical factors shape Aboriginal women's participation in Pap smear screening services?

# Significance of the Study

To date, research involving the population of Aboriginal women, particularly Mi'kmaq women in Nova Scotia, has been minimal in most aspects of health. Notably absent from the research literature are Aboriginal women's voices in relation to their

experiences accessing Pap smear screening services, and an analysis of the historical and sociopolitical contexts that impact access to Pap smear screening services. Critical analyses of how mainstream healthcare systems and some healthcare providers may be inadvertently perpetuating inequities in access to Pap smear screening services are absent in the literature.

The significance of this research began with providing Aboriginal women a platform to give voice and validation to their experiences and to highlight factors influencing their access to Pap screening services. Using participatory action research approaches adds to the significance of the study by enabling a context in which women were encouraged to share in-depth contextualized accounts of their Pap smear screening experiences. This study generates recommendations about Pap smear screening that are intended to assist healthcare providers and policy makers to provide Aboriginal women with more equitable access.

This study builds upon current research by critically analyzing the perceptions of Aboriginal women and healthcare providers about the reasons why Aboriginal women are and are not participating in screening services. This study adds to the awareness and critical consciousness found in the literature about issues of culture, colonial and historical contexts, inequities in healthcare, economic and social conditions, as well as discriminatory policies and procedures perpetuated in some healthcare system discourses and by some healthcare professionals (Browne, 2007; Browne et al., 2011; Browne & Varcoe, 2006; Dion Stout, 2012; Gregory, 2005; Smye et al., 2006).

This research complements one of the World Health Organization's (2008) mandates focusing on the renewal of primary healthcare for the purpose of reducing inequities in healthcare and the development of "reforms that ensure that healthcare systems contribute to health equity, social justice and the end of exclusion, primarily moving towards universal access and health protection" (p. xvi). This research may also augment the current cultural competence guidelines for the delivery of primary healthcare (Nova Scotia Department of Health, 2005) by expanding upon how guidelines address inequitable access to healthcare and by situating inequities in access within broader sociopolitical, economic, and historical contexts of disadvantage. This in turn could provide knowledge to front-line staff, management, administrative staff, and policy makers in primary healthcare services that can address issues related to inequities for Aboriginal women accessing Pap smear screening. In addition to Aboriginal women, communities and organizations may also use these research findings to disseminate knowledge and inform policies regarding Pap smear screening. Knowledge sharing potentially creates the capacity for communities to make informed decisions that acknowledge the importance of Pap smear screening. Furthermore, findings from this research may provide a foundation for future research pertaining to Aboriginal women and their experiences with Pap smear screening services.

## Chapter 2:

#### **Literature Review**

#### Introduction

An extensive review indicated a dearth of research literature exploring Aboriginal women's experiences with Pap smear screening. No peer-reviewed journal articles were found that specifically pertained to Mi'kmaq women and Pap smear screening. To date, much of the existing research has been based primarily on epidemiological data that focuses on high rates of cervical cancer mortality, while other data attributes the low rates of Pap screening to emotional, cultural, cognitive, and socioeconomic factors (Amankwah et al., 2009; Black, 2009; Browne & Smye, 2002; Burhansstipanov, Gilbert, LaMarsa, & Krebs, 2001; Clarke et al., 1998; Elias, Hall, Hong, Kliewer, 2012; Johnson et al., 2004; Letendre, 2008; NAHO, 2010; O'Brien, Mill, & Wilson, 2009; Roberts, 2005; Steven et al., 2004; Wilson, 2002). Epidemiological research findings have reinforced the need for health education campaigns and Pap smear screening programs specifically targeting Aboriginal women (Black, 2009; Browne & Smye, 2002; Johnson et al., 2004; Letendre, 2008). However, researchers and healthcare providers tend to situate the issues of low rates of screening solely with the women, ignoring the social, political, economic, and historical disadvantages faced by some Aboriginal women and the inequities experienced when accessing Pap smear screening (Black, 2009; Browne & Smye, 2002; Letendre, 2008; Morgan & Wabie, 2012; Trees, 2008).

Not only is there a paucity of research that addresses cervical cancer screening among Aboriginal women in relation to historical, sociopolitical, and economic

disadvantages, the structural inequities that are produced and reinforced by healthcare services and discourses are not often addressed. Decontextualized discourses addressing women's risks for cervical cancer can perpetuate damaging images and negatively impact women's accessing of healthcare services (Browne, 2007; Browne & Smye, 2002). Access to healthcare services such as Pap smear screening should be located within broader domains of historical, economic, and structural disadvantage, and require a critical examination for understanding how healthcare is shaped for Aboriginal women (Brown, McPherson, Peterson, Newman, & Cranmer, 2012; Dion Stout, 2012; Loppie-Reading & Wien, 2009; Smye et al., 2006).

In order to provide a foundation for understanding Mi'kmaq women within broader historical, socioeconomic, and political contexts that potentially impact upon their experiences with Pap smear screening, the following literature review will address historical impacts of colonization, residential schools, and assimilation on Aboriginal women's health and healing practices. An overview of the literature related to Aboriginal women's traditional roles, health status, and current reproductive health, as well as their experiences with healthcare systems and healthcare providers will also be discussed.

#### **Historical Context**

Inequities in health should not be attributed to lifestyle, behavior, or culture alone, but rather, health should be viewed as the interplay between historical, socioeconomic, and political conditions which are known to influence health and healthcare access (Browne & Fiske, 2001; Garman & Doull, 2009; Haskell & Randall, 2009; Raphael,

2007). Colonization had, and to some degree continues to have, a profound and disruptive impact on the health of Aboriginal people in Canada (Bourque Bearskin, 2011; Brownridge, 2008; National Aboriginal Health Organization, 2003). Research validates that colonization and historical trauma radically influenced and continues to impact Aboriginal people's social determinants of health (Garman & Doull, 2009). According to Battiste (2000), "colonization was a system of oppression rather than a personal or local prejudice" (p. xvii) bringing disorder to the lives of Aboriginal people by impacting their language, social relations, and ways of thinking, feeling, and interacting in the world (Battiste & Henderson, 2000). This resulted in the loss of many of the traditional ways of knowing, language, cultural practices, and medicines for many Indigenous peoples (National Aboriginal Health Organization, 2003; Warry, 2007). Colonization also shaped the physical, emotional, spiritual, and mental dimensions of Aboriginal health (Letendre, 2008; Smylie, 2000). Henderson (2000) suggests that colonization created systematic colonialism and racism, alienating Indigenous peoples from their "beliefs, languages, families, and identities; that deprived Indigenous peoples of their dignity, their confidence, their souls, and even their shadows" (p. 29). Governments and social hierarchies were created by the colonizers that acknowledged Europeans as being superior to Indigenous people (Brown et al., 2012; Henderson, 2000; Warry, 2007).

Colonization involved the "domination" of individuals as the colonizers created conventional regimes that prevented Aboriginals' participation in political life, legislative law, and decision making. This resulted in oppression which is defined as "social processes which inhibit people to play and communicate with others or to express their

feelings and perspective on social life in contexts where others can listen" (Young, 1990, p. 38). Social conditions of oppression are often related to material deprivation or misdistribution and oppressed individuals experience, to some extent, inhibition of their ability to develop or exercise capacity and express needs, feelings, and thoughts (Young, 1990). Young (1990) contended that it is impossible to define a single set of criteria that will describe the conditions of oppressed groups. In Canada for example, Aboriginal women have experienced "oppression" in relation to "health disparities that are directly and indirectly associated with social, economic, cultural and political inequities" (Adelson, 2005, p. S45). This form of oppression has led to a disproportionate burden of poor health that is not only deeply rooted in historical trauma, but has historically mediated relations between Aboriginal and non-Aboriginal people (Adelson, 2005; Dion Stout, 2012). A number of researchers stress the significance of analyzing health disparities in relation to the context of inequalities that emerge with and through a traumatizing legacy of colonialism and racism, and the importance of examining the direct and indirect sources of health disparities from broader sociopolitical contexts (Adelson, 2005; Black, 2009; Browne, 2007; Browne et al., 2011; Dion Stout, 2012; Haskell & Randall, 2009; Loppie-Reading & Wien, 2009; Morgan & Wabie, 2012; Paradies et al., 2008). This also holds true when examining the inequities that Aboriginal women experience with accessing healthcare services, including Pap smear screening (Letendre, 2008; Roberts, 2005; Wilson, 2002).

Assimilation also impacted Aboriginal women's health. North Americans assumed that Aboriginal people would become "civilized" by embracing European

customs, values, language, government, and health practices (Warry, 2007). Assimilation negatively impacted the traditional healing practices and traditional medicines of many Aboriginal communities (Waldram et al., 2006). Indigenous medicines, traditional healing knowledge and practices were lost as a result of assimilation, resulting in a profound impact on traditional medicine; few Aboriginal healers remain (Waldram et al., 2006). Unfortunately, assimilation caused some Aboriginal people to deny their origins and traditional healing practices that promoted mental, physical, and spiritual well-being through ceremonies, spiritual rituals, counseling by community members, and the wisdom of community Elders (Battiste, 2000; Waldram et al., 2006; Warry, 2007). With the loss of Indigenous medicine and healing practices, some Aboriginal people were forced to rely on foreign medicines and healthcare systems that "medicalize social problems as arising from individual lifestyles, cultural differences or biological predisposition - rather than from impoverished social and economic circumstances, marginalization and oppressive internal colonial politics" (Browne & Smye, 2002, p. 29). Assimilation also disrupted the traditional passing along of teachings about the body and sexual health from Elders. Younger women were no longer educated about aspects of health and sexual health that contributed to wellbeing and strong family ties that previously were passed down generationally (Kinnon & Swanson, 2002). Consequently, for many Aboriginal women sexual health has become medicalized without acknowledgement of the social determinants that shape it (Boyce, Doherty, Fortin, & MacKinnon, 2003; Reeves, 2008).

Another example of assimilation disrupting traditional Aboriginal knowledge and practices about the body pertains to the medicalization of childbirth. Many Aboriginal women are using Western hospital birthing environments which promote the use of fetal monitoring devices, epidurals, medications to induce labour, and episiotomies (Lothian, 2001; Whitty-Rogers, 2006). Standard protocols for childbirth have been developed and implemented in hospitals that negate traditional Aboriginal knowledge and alternative methods of childbirth. Aboriginal women are leaving their families and communities to give birth in medicalized healthcare systems that disregard their traditional birthing ways (Savage, 2002; Whitty-Rogers, 2006). Prior to the implementation of hospital birthing practices, Aboriginal women gave birth at home with the assistance of women from their community, primarily midwives, and were surrounded by family (Savage, 2002; Whitty-Rogers, 2006). Childbirth was considered a powerful natural event and was not discussed as being painful, fearful, or complicated (Savage, 2002), but considered a gift from the Creator (Kinnon & Swanson, 2002). Traditionally, in some Aboriginal communities, knowledge about childbirth was communicated by way of storytelling from one generation to the next. Elders in the community were valued for their wisdom and knowledge and were often consulted for information about childbirth, menopause, and the time of coming to adulthood (Kinnon & Swanson, 2002; Reeves, 2008). The loss of traditional child birthing practices had profound cultural and spiritual consequences in many Aboriginal communities resulting in the loss of the cultural identity of many Aboriginal peoples (Couchie & Sanderson, 2007; National Aboriginal Health Organization, 2004). The medicalization of childbirth and use of technology in

healthcare systems has changed how women view their bodies, as it "transform(s) our relationship to our insides" (Birke, 2000, p. 9). Mainstream healthcare views of childbirth being painful and therefore requiring medical interventions and treatments conflicts with Aboriginal views of child birth being a natural and sacred process (Million, 2000; Whitty-Rogers, 2006). Traditional Indigenous holistic views of the body and health are distinct from Western perspectives of healthcare that separate the whole into individual parts to be examined (Gadow, 2000). These opposing ways of perceiving the body may impact Aboriginal women's accessing of mainstream healthcare services, including Pap smear screening.

It is widely acknowledged in current research that residential schools had a painful and scarring effect on Aboriginal people's access to health and healthcare services (Dion Stout, 2012; Martin, 2012; Morgan & Wabie, 2012; O'Brien et al., 2009). Trauma experienced in residential schools has led to mistrusting relationships with Western healthcare providers and healthcare systems (Dion Stout, 2012; Waldram et al., 2006) and has shaped Aboriginal women's access to mainstream healthcare services. Current research has also attributed the higher rates of cervical cancer and low rates of accessing Pap smear screening services with the pain, suffering, and losses that resulted from residential school experiences (Black, 2009; Dion Stout, 2012; O'Brien et al., 2009).

The institution of residential schools by the Canadian government still has an impact upon some Aboriginal people today. Being forced to relinquish their cultural identity, beliefs, values, religion, and language, and being separated from their families

and communities resulted in a number of social consequences such as physical and sexual abuse, family violence, addictions to drugs and alcohol, and sexually transmitted infections (Department of Justice, 2005; Health Canada, 2004; Loppie-Reading & Wien, 2009; National Aboriginal Health Organization, 2002). Mancini (2007) contends that families and communities were torn apart by the abuse experienced in residential schools, and as a result, future generations of violence have been perpetuated. For instance, statistics indicate that Indigenous women are three times more likely than non-Indigenous women to experience spousal abuse and eight times more likely to be killed by their partners than non-Indigenous women (Mancini, 2007; Statistics Canada, 2011). Furthermore, Indigenous women, after separating from their partners, are more likely than non-Indigenous women to be forced into prostitution and contract HIV (Mancini, 2007). Researchers confirm that racist and sexist attitudes toward Indigenous women still occur in Canadian cities, impacting women's health and well-being and their access to mainstream healthcare services (Amnesty International, 2004; Black, 2009; Bourque Bearskin, 2011; Browne et al., 2009). Furthermore, abuse and violence has been linked to how Aboriginal people relate to each other and it shapes their sense of trust with mainstream healthcare providers when accessing Pap smear screening and other healthcare services. Aboriginal women's reticence to access Pap smear screening services is clearly not based on individual or cultural differences; rather it is rooted in complex historical events and contexts that continue to exert an effect on Aboriginal women's experiences with and access to Pap smear screening.

# Aboriginal women's traditional roles.

Traditional roles of Aboriginal women in the community have changed significantly. Prior to colonization, many Indigenous cultures were matriarchical or semi-matriarchical. They valued equality, power and honour of women, and equitable distribution of goods and unity (LaRocque, 1994; Warry, 2007). According to Moore (2002), Aboriginal women assumed positions of authority and were pivotal in decisionmaking regarding the social and economic organization of the community. Women were viewed as powerful by their communities as they were the bearers of children, central in food preparation and preservation, and provided care for children and Elders. Some women were powerful healers with traditional knowledge of healing herbs and plants that were considered valuable to community members (Kinnon & Swanson, 2002). Historically, women were the center of the community and the family; gender relations were egalitarian and women's work was equally valued to that of men's work (Leacock, 1991; Warry, 2007). Aboriginal women were responsible for the establishment of all community norms whether they were political, economic, social, or spiritual (Flaherty, 1996; Reeves, 2008). Aboriginal women were held in the highest regard because they were able to have children and thus were viewed as being closest to Mother Earth and Creation, and the foundation of the universe (Morgan & Wabie, 2012; Status of Women Canada, 2005).

Colonization caused the disruption of Aboriginal women's roles, responsibilities, and positions in their community. Aboriginal "men began to move into areas that had previously been the province of women, adopting some of the white attitudes toward

women and treating them as inferiors rather than equals" (La Rocque, 1994, p. 13). Consequently, Aboriginal women were no longer viewed as central to the functioning of their communities or valued for their work, and were expected to perform multiple roles and responsibilities. Aboriginal women's leadership roles were eroded along with the social structures of the community and previously egalitarian gender relations (Waldram et al., 2006; Warry, 2007). Suppression of Aboriginal women's roles has resulted from the imposing of patriarchal legislation and government policies based on European ideals rather than traditional Aboriginal beliefs (Browne & Dion Stout, 2012; Browne & Fiske, 2001; Status of Women Canada, 2005). The eradication of traditional structures and deprivation of Aboriginal women's traditional roles and responsibilities has weakened Aboriginal nations, thus negatively impacting the health of communities (Status of Women Canada, 2005). Many researchers argue that as a result of the historical disruption and sustained legacy of colonization, some Aboriginal women experience social conditions that impact health negatively and create health inequities that are still prevalent today (Adelson, 2005; Battiste, 2000; Bourque Bearskin, 2011; Browne, 2007; Browne & Varcoe, 2006; Dion Stout, 2012; Native Women's Association of Canada, 2007a; Smith et al., 2010; Waldram et al., 2006; Warry, 2007). These inequities are compounded by issues of discrimination, gender, race, and paternalistic policies and procedures that shape how Aboriginal women are portrayed and treated in healthcare systems and in other institutions (Adelson, 2005; Browne, 2007; Browne et al., 2011; Native Women's Association of Canada, 2007b). This, in turn, can shape Aboriginal women's access to healthcare and other services, like Pap smear screening.

### An Overview of Aboriginal Women's Health Status

According to Philips (1995), "women's health involves women's emotional, social, cultural, spiritual and physical well-being, and is determined by the social, cultural, political and economic context of women's lives as well as by biology" (p. 507). Some Aboriginal women confront individualized and institutionalized discrimination on the basis of race, class, and gender when accessing mainstream healthcare services (Browne, 2007; Dion Stout, 2012; Kurtz, Nyberg, Van den Tillaart, & Mills, 2008). Their health status in Canada is frequently referred to as being substandard compared to non-Aboriginal women (Native Women's Association of Canada, 2007b); "Aboriginal women are one of the most politically, socially, and economically marginalized populations in Canada" (Haug & Prokop, 2004, p. 2). Aboriginal women experience greater health disparities than non-Aboriginal women, especially in relation to chronic diseases that are associated with economic, political, and cultural inequities that influence health status and access to equitable healthcare (Browne, 2007; Loppie-Reading & Wien, 2009). For example, Inuit women's life expectancy in 2017 is projected to be 73 years and First Nation and Metis women's life expectancy is 78–80 years, in comparison to 83 years for non-Aboriginal women in Canada (Statistics Canada, 2010).

Some Aboriginal women live in environments where substance abuse and spousal violence are widespread, experience higher incidences of depression, have high rates of smoking and sexually transmitted infections, all associated with the historical trauma caused by colonization (Adelson, 2005; Brownridge, 2008; Dion Stout et al., 2001).

Brownridge (2008) reinforced that much of Aboriginal women's violent victimization can be attributed to the historical roots of colonization of Aboriginal peoples.

Ramifications of the Indian Act transformed Aboriginal society into a patriarchal society, relinquishing women's roles as equal partners and classifying women as property of men or the community (Warry, 2007). Aboriginal women lost their political, legal, and property rights as a result of government intrusion and legislated control over their identity; economic, social, and political disadvantage have ensued (Bourassa et al., 2004; Warry, 2007). In general, Aboriginal women have lower quality housing, experience a lower socioeconomic status, and have lower levels of education, fewer opportunities for employment, and higher exposure to violence (Bourassa et al., 2004; Paradies et al., 2008; Smylie, 2001). Experiencing inequities in the social determinants of health predisposes Aboriginal women to ill health and health outcomes (Loppie-Reading & Wien, 2009; Native Women's Association of Canada, 2007b). Lack of access to education, economic and social disadvantage, and being an Aboriginal woman have all been documented to be directly associated with poor health outcomes and primary reasons for Aboriginal women's lack of access to Pap smear screening services (Black, 2009; Kurtz et al., 2008; Letendre, 2008).

Furthermore, when Aboriginal women access healthcare services, some experience negative stereotyping, institutional and personal discrimination, racism, and sexism which negatively influence their health outcomes and perceptions of cultural safety within healthcare environments (Bourassa et al., 2004; Browne, 2005; Browne, 2007; Martin, 2012; Paradies, Harris & Anderson, 2008). Browne (2007) reported that

discourses and assumptions about Aboriginal people, culture, and presumed difference are interwoven into routine clinical encounters. The importance of analyzing healthcare encounters with regards to wider sociopolitical and historical forces that can perpetuate racialization, culturalism, and "Othering" was highlighted. Othering is "written with an initial capital to denote a specific category and space to which 'non-western' people; constructed as inferior" (Anderson, 2002, p. 8). Othering is referred to as "the projection of assumed cultural characteristics, "differences", or identities onto members of particular groups" (Browne, Smye, & Varcoe, 2005, p. 21).

Similarly, an earlier study by Browne and Fiske (2001) argued that healthcare encounters are essential areas for research because they are reflective of the social, economic, political, and ideological relations between Aboriginal women and the mainstream healthcare system. These authors conducted interviews with 10 First Nations women who had accessed mainstream healthcare services and found that "encounters with discriminatory attitudes and behaviours were pervasive throughout participants' stories" (p. 135). Examples included lack of regard for personal circumstances, negative stereotypes of First Nation women, and experiences of marginalization in healthcare encounters. Such experiences create barriers to accessibility of health services such as Pap smear screening.

Importantly, there is little literature found about the resiliency of Aboriginal women in the face of historical trauma, poverty, racism, and the day-to-day realities they confront. According to Kirmayer, Dandeneau, Marshall, Phillips, and Williamson (2011), despite the devastating impact of colonization, residential schools, and forced

assimilation, in many communities Mi'kmaq people still speak their own language and continue with traditional and cultural ceremonies and practices. Further, traditional Mi'kmaq values embodying collaboration and cooperation have assisted Mi'kmaq people to be "able to respond to the challenges of colonization and maintain their sense of cohesiveness as a people for centuries" (Kirmayer et al., 2011, p. 86). The revitalization of language, culture, and spirituality are paramount to strengthening individual and collective resiliency of Aboriginal people, strengthening identity, and counteracting cultural discontinuity and dispossession resulting from colonization (Kirmayer et al., 2011).

In the preceding sections the broader historical, economic, and political contexts of Aboriginal women's lives were discussed to enable an understanding of the complexities and inequities they confront when accessing health care services such as Pap smear screening. The following sections discuss the impacts of these historical, economic, and social contexts on Aboriginal women's health status including their risk for cervical cancer. When viewed through this lens, risk factors that profoundly impact the health of Aboriginal women such as social and economic disadvantage, poor living conditions, and the reliance of some women on the sex trade for income are made explicit and are not attributed to lifestyle and personal choice (Browne & Smye, 2002; Elias et al., 2012; Guerin, 2010; Reeves, 2008).

# Impacts of Historical, Economic, and Social Contexts on Health

Sexual abuse, violence, and exploitation are effects that have resulted from colonization and residential schools. Nationally and internationally, sexual abuse, violence, and exploitation are considered prominent reproductive health issues for some Aboriginal women, resulting in increased incidences of sexually transmitted infections (STIs), depression, and internalization of feelings of guilt that undermine women's sense of self-esteem and self-worth (Dion Stout, 2005; Ralph, Hamaguchi, & Cox, 2006; Reeves, 2008). In Canada, the rates of spousal and non-spousal violence and sexual abuse are higher for Aboriginal women than non-Aboriginal women (Native Women's Association of Canada [NWAC], 2007b; Statistics Canada, 2011). Aboriginal women are more likely to have endured physical injury, received medical attention, experienced 10 or more episodes of violence, and experiences of fear that their life is in danger (NWAC, 2007b). These high rates of sexual abuse and violence are often linked to lower incomes, high levels of alcohol abuse, and the breakdown of the families and communities resulting from the impact of colonization on traditional values and beliefs (Bourque Bearskin, 2011; NWAC, 2007b; Statistics Canada, 2011).

Young and Katz (1998), conducted a survey in Winnipeg to determine the association between sexual behavior and cervical infections. From the 1003 women sampled, 368 (43.6%) were Aboriginal and 44.8% of the Aboriginal women in the study indicated they had been sexually abused compared to 30.1% of non-Aboriginal women. Findings indicated that some Aboriginal women had been sexually abused at a young age, had multiple partners, and had histories of STIs. Aboriginal women who

experienced sexual abuse tended to have more abnormal Pap smear screens than women who had not been sexually abused (Young & Katz, 1998). Sexual abuse was found to predispose both Aboriginal and non-Aboriginal women to smoking, STIs, and sexual relations with large numbers of partners, thus increasing the risk for Human papillomavirus (HPV) infection and subsequent cervical cancer. As a result of experiences with sexual abuse, some Aboriginal women may not access Pap smear screening services, especially from a male healthcare provider (Young & Katz, 1998).

Varcoe and Dick (2008) conducted an ethnographic study exploring the intersecting risks of violence and human immunodeficiency virus (HIV) exposure for 30 women, 11 of whom were First Nations and 4 from other Aboriginal groups. They found that the neo-colonial and racist context of Canadian society generates challenges for Aboriginal women. For Aboriginal women, poverty, gender, and rural living shaped their intersecting risks of violence and HIV exposure, and systemic racism within the neocolonial context of Canadian society compounded their risks for violence. Varcoe and Dick (2008) stated, "the consequences of this systematic racism have included poverty, disconnection from family and community, and feelings of despair" (p. 45). Many women interviewed in the study communicated experiencing multiple forms of racism and discrimination that impacted upon their employment and access to affordable housing, and caused a loss of language and parenting skill that contributed to community and family breakdown. Being disconnected from their families and communities with little access to social support programs made some Aboriginal women susceptible to further violence and exploitation. Despite the many challenges confronting these

Aboriginal women, they demonstrated perseverance and achieved what they considered to be some success "with cultural and spiritual reawakening in their communities" (Varcoe & Dick, 2008, p. 49) in their healing. The study's authors recommended that "comprehensive, locally developed community responses that address cultural identity, healing, safe social support, and meaningful employment are needed" (Varcoe & Dick, 2008, p. 49).

Brownridge (2008) examined Aboriginal women's elevated risk for violence relative to non-Aboriginal women using two large-scale representative samples of data collected from 1999-2004 in Canada. The study found that Aboriginal women experience intimate partner violence at four times the rate of non-Aboriginal women in Canada. Brownridge suggested that many of the risks associated with violent victimization by intimate partners can be associated with the colonization of Aboriginal peoples in Canada. Recommendations were made for future research examining violence at both the individual and community levels, and to determine whether "efforts to reclaim and enhance essential elements of Aboriginal culture would be important for reducing Aboriginal women's elevated risk of violent victimization" (Brownridge, 2008, p. 397). The author concluded that further research is required to provide direct evidence of a relationship between cultural loss and Aboriginal women's increased odds of experiencing violent victimization.

Although some Aboriginal women have experienced considerable adversity, many remain resilient and strong. This resiliency is evidenced by the forming of associations such as the Native Women's Association of Canada, an organization that is

working "at entrenching and protecting the rights of Aboriginal women and families" (NWAC, 2007b, p. 16). This association is the national voice for Aboriginal women and addresses issues pertaining to Aboriginal women such as violence and the social determinants of Aboriginal health. In addition, the association promotes equal opportunities for Aboriginal women, assists Aboriginal women's organizations and communities in the development of projects, and assists in empowering women by actively participating in the development and reform of legislation.

Several authors report that Aboriginal women have higher rates of sexually transmitted infections (STI's) such as chlamydia, gonorrhea, and HIV/AIDS (Health Canada, 2012; Pan American Health Organization [PAHO], 2006; Public Health Agency of Canada, 2007; Steenbeek, 2004). STI's, if untreated, can lead to the development of reproductive health issues such as pelvic inflammatory disease, infertility, ectopic pregnancy, spontaneous abortion, and debilitating chronic pelvic pain (Health Canada, 2012; McKay, 2004; National Aboriginal Health Organization, 2002; Public Health Agency of Canada, 2007). Some Aboriginal women may not access healthcare services for STI treatment due to fear of stigmatization and ostracism, embarrassment, and being labeled or expelled from their community (Waldram et al., 2006).

Nationally and internationally, the HPV is one of the most common types of sexually transmitted infections and is directly linked to causing cervical cancer (Health Canada, 2010). Approximately 70% of the Canadian population is estimated to have contracted at least one HPV infection in a lifetime (Public Health Agency of Canada, 2006a), and prevalence is similar among Aboriginal and non-Aboriginal women (Young

et al., 2000). That said, Aboriginal women in Canada have higher risks for developing and dying from cervical cancer than the general population (Canadian Cancer Society, 2012). The authors of a Canadian study found that First Nations women in Quebec not only had higher rates of cervical cancer, but more cervical cancer-related deaths than the rest of the population in the province (Louchini & Beaupre, 2008). In an earlier Ontario study, cervical cancer was found to be the second most common cancer among First Nations women and they were twice as likely to succumb to the disease as other Ontario women (Marrett & Chaudry, 2003).

Many deaths caused by cervical cancer can be prevented with regular Pap screening (Canadian Cancer Society, 2006; Elias, Hall, & Hong et al., 2012). There is evidence that Aboriginal women are not being screened at all or are being under screened for cervical cancer (Native Women's Association of Canada, 2013). Although cervical cancer is a consequence of HPV infection in women, regular Pap smear screening detects cervical abnormalities at an early stage that many times can be curatively treated (Canadian Cancer Society, 2010). Early detection and prompt management has survival rates for cervical cancer at over 90% (Canadian Cancer Society, 2010; Gerberding, 2004). Cervical cancer can be prevented by decreasing HPV transmission and educating youth about screening practices for HPV. Yet, nationally and internationally, cervical cancer rates are not only higher for Aboriginal women, but the disease tends to be diagnosed at an advanced stage (Black, 2009; Dion Stout, 2012; Letendre, 2008; Luciani & Winkler, 2006; Pan American Health Organization [PAHO], 2006; O'Brien et al., 2009).

To conclude, health issues and access to healthcare services such as Pap smear screening for Aboriginal women are located in the broader domains of historical, economic, and structural disadvantage underscoring the need for a critical examination to understand how healthcare is shaped for Aboriginal women (Browne et al., 2011; Dion Stout, 2012; Smye et al., 2006). The following sections review the literature related to mainstream and Indigenous conceptualizations of health, Aboriginal women and healthcare systems, encounters in healthcare systems and barriers to Pap smear screening.

# Aboriginal women and healthcare services.

Mainstream healthcare systems have been documented as not always being effective for meeting the healthcare needs of Aboriginal people (Barton, 2008; Browne et al., 2011; Dion Stout, 2012; Loppie-Reading & Wien, 2009; Martin, 2012; Paradies et al., 2008; Sherwood & Edwards, 2006; Vukic et al., 2012). Healthcare and healthcare delivery systems can be disembodying of Aboriginal people (MacDonald, 2008).

Narrowly constructed in a biomedical model of health based upon conceptualizations of disease and illness, the underpinnings of mainstream healthcare systems contrast with Indigenous beliefs and values about health (Battiste, 2000; Letendre, 2008). Mainstream healthcare systems often disregard other forms of healthcare that are holistic, interconnected, and contextually rooted in culture and traditions (Ellerby, McKenzie, McKay, Gariepy, & Kaufert, 2000). Mainstream healthcare systems tend to medicalize health and illness as stemming from lifestyle, cultural difference, or biologic disposition (Browne & Smye, 2002) inferring the problems of illness and its causes are individually

based. For example, Browne et al. (2011) conducted an ethnographic study exploring the experiences of Aboriginal people accessing primary care services at an emergency department located in a large Canadian city. Their findings indicated that many Aboriginal participants felt they were being judged on the basis of their identity as Aboriginal people living in poverty, as people with illegitimate issues with pain, and as people accessing the emergency department for inappropriate reasons. The authors concluded by stressing the importance of understanding the role of the emergency department and the wider primary healthcare sector in responding to the needs of Aboriginal people experiencing "poverty, racialization, marginalization, and other forms of disadvantage" (p. 344). Similarly, Barton (2008) using a narrative inquiry approach, explored the experiences of Aboriginal people living with Type 2 diabetes mellitus in a rural community, and stressed the importance of expanding our understanding of diabetes within a specific cultural context. The author explored diabetes from a cultural perspective based on the existential dimensions of time, place, body, and relationship. The importance of translating Aboriginal healing philosophy into healthcare practices was also highlighted.

There is a general consensus among Aboriginal people that health involves the physical, emotional, mental, and spiritual domains of an individual and that it is holistic, balanced, and interrelated, rather than separate or distinct from other parts of a person's life (MacDonald, 2008; National Aboriginal Health Organization [NAHO], 2003). Indigenous health also embodies a connection with family, community, environment, and the spiritual world and is based on the maintenance of quality of life, rather than pursuits

of cure (Battiste, 2000; Letendre, 2008; Smylie, 2001). Neglect in any domain of health results in disharmony and imbalance in an individual's life and illness (Battiste, 2002).

## Aboriginal women's encounters with the healthcare system.

There is an increase in the body of knowledge related to Aboriginal women and their encounters with healthcare systems and services (Adelson, 2005; Bourassa et al., 2004; Browne, 2007; Browne & Fiske, 2001; Browne & Varcoe, 2006; Haskell & Randall, 2009; Kurtz et al., 2008; McCall & Pauly, 2012; Sherwood & Edwards, 2006; Smye et al., 2006; Tang & Browne, 2008; Zehbe et al., 2012). It has been reported in some research that healthcare systems and some healthcare professionals tend to perpetuate stereotyping, racism, marginalization, Othering, and discrimination against Aboriginal women (Browne, 2007; Browne et al., 2011; Dion Stout, 2012; Fridkin, 2012; Morgan & Wabie, 2012). Browne (2005) explored the social and professional discourses that influenced nurses' knowledge and assumptions regarding First Nations women. She found indicated three overlapping and interwoven discourses that shape nurses' perspectives in relation to First Nations women—discourses about culture, professional discourses of egalitarianism, and popularized discourses about Aboriginal peoples. Nurses appeared to be strongly influenced by institutional practices and cultural discourses that focus on cultural practices, cross-cultural training, and conceptualizations of culture as something that they could identify and address during the provision of care. Nurses also tended to associate social problems such as violence and alcohol abuse with inherent cultural characteristics of First Nations people. Dominant discourses about

culture in nursing and in healthcare have embraced the notion of culture as being "a social construction of the learned patterns of behaviors and a range of beliefs attributed to a specific group" (Dreher & McNaughton, 2002, p. 182). This rigid conceptualization of culture infers that culture is static and unchanging, and is based upon beliefs, values, habits, and behaviors of a specific ethnocultural group (Browne & Varcoe, 2006). Rigid and narrow conceptualizations of culture potentially lead to notions of difference, inferiority, and Othering of groups of individuals from the dominant culture (Barton, 2008; Browne, 2007; Browne, 2005; Browne & Varcoe, 2006; Dion Stout, 2012) and can further reinforce stereotyping of some Aboriginal women and ignore "the broader structural, economic, and historical contexts that shape social and health issues" (Browne, 2005, p. 75).

Healthcare providers are urged to analyze and reflect on professional discourses of egalitarianism and the premise that by maintaining professionalism one can achieve egalitarianism (Browne, 2005). Browne (2005) reported that most of the nurses in a study they conducted communicated "that they were committed to treating all of their patients equally" (p. 76). This was viewed and reinforced as a professional responsibility, regardless of patients' social, historical, or gendered locations. Although treating all patients equally is important, many First Nations women require specific tailored services and care to meet their needs "to rectify past injustices and present inequities" (Browne, 2005, p. 77). Browne found that popularized dominant social discourses about Aboriginal peoples reinforce nurses' perceptions of First Nations peoples. Perceptions such as Aboriginal people getting everything paid for and having

dependency on alcohol and drugs were dominant societal discourses that played a role in shaping nurses' understandings of First Nations patients (Browne, 2005). When Aboriginal women encounter professionals with these conceptualizations, it may prevent them from developing a trusting relationship with healthcare providers and even prevent them from accessing healthcare services, including Pap smear screening. According to Dion Stout (2012), "interventions that draw on nahi, fairness, rather than tipi, equal" (p. 12) are required to transform the health of Indigenous people and be incorporated into healthcare paradigms and practices.

#### Healthcare system barriers to Pap smear screening.

Some of the existing literature has indicated that healthcare systems present a multitude of barriers for some Aboriginal women seeking Pap smear screening (Amankwah et al., 2009; Becker, Affonso, & Blue Horse Beard, 2006; Black, 2009; Clarke, Joseph, Deschamps, Hislop, Band, & Atleo, 1998; Johnson et al., 2004; Letendre, 2008; Morgan & Wabie, 2012; NAHO, 2010; O'Brien et al., 2009; Steven et al., 2004; Zehbe et al., 2012). These barriers include lengthy delays between screening and referrals for follow-up, difficulties with staff turnover, distrust with healthcare systems, lack of female healthcare professionals and difficulties in obtaining timely clinic appointments (Becker et al., 2006; Black, 2009; National Aboriginal Health Organization, 2006b; Zehbe et al., 2012). Moreover, there are jurisdictional issues regarding the delivery of preventative cancer screening practices for off reserve Aboriginal women that impacts upon their participation in healthcare (National

Aboriginal Health Organization, 2006a). Others report that the lack of participation by Aboriginal women in Pap smear screening is due to lack of knowledge, shyness, embarrassment, fears, and overall discomfort with talking about and undergoing the procedure (Amankwah et al., 2009; Becker et al., 2006; Black, 2009; Clark et al., 1998; O'Brien et al., 2009; Zehbe et al., 2012). Difficulty accessing cancer screening, knowledge deficits regarding cancer and Pap smear screening practices, and fears of having cancer are all barriers that impact Aboriginal women's participation in Pap smear screening practices (Black, 2009; O Brien et al., 2009). While the aforementioned barriers are important to consider, they tend to have a narrow focus on the issues and needs that the women themselves may have (Browne & Smye, 2002; Palacios & Portillo, 2009; Smye et al., 2006).

Kurtz et al. (2008) maintained that in healthcare experiences Aboriginal women's voices were often silenced when they accessed healthcare services and they often felt marginalized by the many assumptions and inequities they experienced. Black (2009) added poverty, lack of cultural safety, confidentiality concerns, paternalism, history of sexual abuse, availability of healthcare providers, and Pap smear screening not being a priority as additional barriers to Aboriginal women accessing Pap smear screening services. Further, Palacios and Portillo (2009) pointed out that to understand Native women's health requires an understanding broader than culture, lifestyle, and genetics, and includes the historical legacies and intergenerational heritage of injustices. These authors render visible the significance of inequities that shape access to healthcare services for some Aboriginal women (Browne, 2005; Browne, 2007; Browne & Smye,

2002; Browne et al., 2011; Browne et al., 2007; Dion Stout, 2012; Smye et al., 2006;). According to Letendre (2008), specific barriers to accessing Pap screening for Aboriginal women and how these barriers interact to produce an environment that women are less likely to participate in screening is an area not well developed in the current research.

## Aboriginal women's experiences in healthcare systems.

Although Aboriginal women have positive experiences in healthcare, much of the current literature is based on women's experiences with marginalization, Othering, racism and stereotyping in healthcare systems, and encounters with healthcare providers that negatively impact health conditions and outcomes (Bourassa et al., 2004; Browne & Varcoe, 2006; Dreher & McNaughton, 2002; Kurtz et al., 2008; Morgan & Wabie, 2012). Many mainstream healthcare policies and practices targeting Aboriginal people are oppressive and detrimental to the health and health outcomes of Aboriginal peoples (Sherwood & Edwards, 2006).

Marginalization infers the positioning of people based on their race, gender, and/or economic class on the margins of a dominant culture (Hall, 1999). Aboriginal women are marginalized by not being included in "decision-making structures that will determine how Aboriginal health resources are to be designed or distributed" (Bourassa et al., 2004, p. 26) and often excluded from policy development related to their health (Bourque Bearskin, 2011; Dion Stout, 2012; NAHO, 2010; Sherwood & Edwards, 2006).

Many Aboriginal women's voices have been silenced in healthcare experiences by what Kurtz et al. (2008) call "an act of structural violence" (p. 53). The authors

conveyed that the voices of Aboriginal women were silenced as they accessed healthcare services, and this resulted in either delays in seeking needed medical advice or acceptance of the status quo. Aboriginal women discussed "how colonial stereotypes and structures continue to be perpetuated within the current health care system" (Kurtz et al., 2008, p. 60) and how they experienced structural violence in the form of racism, discrimination, and the silencing of their voices when they accessed healthcare services. Ultimately, the health of Aboriginal women was put in jeopardy as they refused or delayed needed healthcare in an attempt to prevent subsequent acts of structural violence (Kurtz et al., 2008). The authors concluded that the elimination of structural violence requires Aboriginal people's voices in decision-making and improving relationships between healthcare providers, policy makers, and community members.

Othering of First Nations women was evident in the work of Browne (2007), who explored the clinical encounters between First Nations women and nurses in a Western Canadian hospital. This study revealed that several nurses involved in clinical encounters with First Nations women described how it was difficult not to view their First Nations patients as "different" and acknowledged that they changed their approaches and interactions in accordance to preconceived notions about group differences.

Bourassa et al. (2004) pointed out that Othering places Aboriginal women at cultural risk to assaults on their overall well-being, and that "the cumulative effects have painful material, social and health consequences" (p. 24). The authors provided an example of Othering imposed upon Aboriginal women by way of colonial legislation, namely the Indian Act, that transformed Aboriginal women's identity and resulted in

"colonization-based economic, social and political disadvantage" (p. 27). These cumulative effects of Othering impede the development of a healthy sense of identity and put Aboriginal women's health at risk by reducing their access to quality healthcare and social determinants of health.

It has also been well documented in recent literature that some Aboriginal women have experienced individual and/or institutional racism when accessing healthcare and in clinical interactions with healthcare professionals (Bourassa et al., 2004; Browne, 2007; Browne et al., 2011; Browne & Varcoe, 2006; Kurtz et al., 2008; Morgan & Wabie, 2012; Sherwood & Edwards, 2006; Smye et al., 2006; Tang & Browne, 2008). Racism for the purposes of this study is defined and constructed as "both interactive and communicative, and as located within the language of practices and discourses in society" (Augoustinos, Tuffin, & Every, 2005, p. 317). Accordingly, racism can be manifested through everyday language practices whereby "relations of power, dominance and exploitation become reproduced and legitimated" (Augoustinos et al., 2005, p. 317). Racism has been linked to contributing to poor health of certain disadvantaged groups (Bourassa et al., 2004) and leading to racial stereotyping of Aboriginal women as being dependent, unfit mothers, struggling with alcohol and drug addictions, and/or being incapable of caring for themselves (Brown, 2005; Browne & Varcoe, 2006; Kurtz et al., 2008).

Racism can be overt or hidden in discourses and everyday encounters within healthcare systems, and perpetuated in institutional policies and procedures (Tang & Browne, 2008). Kurtz et al. (2008) describe overt racism experienced by some

Aboriginal women with healthcare encounters whereby "the color of their skin determined the type of treatment they received" (p. 56). However, institutional racism, that is "the practices, policies, and procedures of various institutions, which may, directly or indirectly, consciously or unwillingly, promote, sustain or entrench differential advantage or privledge" (Henry, Tator, Mattis, & Rees, 2000, p. 56), may not appear to be so obvious. For example, mental health systems in Canada are primarily aligned with policies that are developed within a Western context and reflective of an illness service model, which directly contrasts with traditional Aboriginal holistic approaches to health and disregards the social, political, economic, and historical contexts of Aboriginal health (Kirmayer et al., 2011; Smye & Browne, 2002).

Tang and Browne (2008) examined some of the issues that shape healthcare access for Aboriginal people and emphasized how race and racialization operate in healthcare. They found that racialization occurring in healthcare "can shape the ways that healthcare providers 'read' and interact with Aboriginal patients" (p. 100) and that some Aboriginal patients do not access healthcare due to their preconceived expectations of how they will be treated. One example presented by the authors was an Aboriginal man who went to an emergency department with an excruciating headache. This patient experienced discrimination as he was labeled as a "drunk," even though the patient had disclosed that he was not. A brain scan was performed and findings were negative, so the patient was sent home with pills. However, the following day the patient's condition worsened, so he went to another emergency room where they found that he was experiencing bleeding in the brain and was sent to the operating room for surgery. Tang

and Browne (2008) analyzed the patient's perception that the reason healthcare providers did not take him seriously or question the diagnosis made in the first emergency room was due to his Aboriginality and their assumption that he was a "drunk Indian" (Tang & Browne, 2008, p. 115) The way the Aboriginal man perceived his treatment by healthcare professionals in the first emergency room exemplifies "how perceptions are reflective of the larger discursive context in which racialized images of Aboriginal people are constructed and in which many Aboriginal people negotiate everyday life" (Tang & Browne, 2008, p. 115) and profoundly impacts their access to healthcare.

Another example described by Tang and Browne (2008) was the portrayal of fetal alcohol spectrum disorder as an Aboriginal women's health issue, thereby perpetuating negative societal and professional perceptions of Aboriginal women as being uncaring or careless. These perceptions and discourses are important to consider when conducting research with Aboriginal women accessing Pap smear screening services because dominant societal and professional perceptions, assumptions, and discourses relating to Aboriginal people permeate the contexts in which negotiation for healthcare access occurs (Tang & Browne, 2008). Thus, it was imperative throughout the conduct of this study to be conscious of the dominant social and professional perceptions and discourses about Aboriginality that impact upon healthcare access with regards to Pap smear screening.

# **Aboriginal Women and Pap Smear Screening**

There exists a paucity of literature regarding Aboriginal women and Pap smear screening, especially in relation to women's accessing of services. One earlier phenomenological study by Hislop et al. (1996) to understand First Nations women's perceptions of barriers experienced with Pap smears in urban British Columbia indicated that Aboriginal women felt embarrassed and uncomfortable, both psychologically and physically, when having Pap smear screening completed, particularly if a male physician performed the procedure. Women's feelings about Pap smear screening were profoundly affected by "being taught to be modest about 'the sexual part' of the body and not to expose themselves" (Hislop et al., 1996, p. 1705). Women also communicated that the healthcare provider's attitude, ability to provide understandable information, and the ability to establish trusting relationships influenced their experience with Pap smear screening (Hislop et al., 1996). Many of the women articulated the need for a positive approach to Pap smear screening by encouraging women's choices for staying healthy rather than preventing cancer because "prevention is not a meaningful concept for them" (Hislop et al., 1996, p. 1705). The promotion of one's health is in keeping with beliefs of balance and holism, and consequently has meaning for First Nations women. Even though this research has heightened awareness of the need for increasing health education programs and developing Pap smear screening programs for Aboriginal women, its attribution of cultural characteristics to variations in health-seeking behaviors is a limitation. This can result in portraying cultural characteristics and attributes as being independent of one another or being static when, in fact, they are interwoven in power

relations and economic, political, and historical contexts embedded in the inequities of access to healthcare (Bourque Bearskin, 2011; Browne, 2005; Browne & Smye, 2002). Furthermore, relying principally on culturally sensitive approaches to Pap smear screening and other healthcare services for Aboriginal women has had limited success as a means for increasing the use of services (Browne & Smye, 2002; Browne et al., 2005). Factors such as "sociopolitical issues related to poverty, lack of access to education, social disadvantages and individual and institutional discrimination" (Browne et al., 2005, p. 36) tend to be rendered invisible or separate from the structural inequities that produce them. Culturally sensitive approaches fail to alter the rigid patterns of colonization and colonial policies and practices from the past that continue to shape how some Aboriginal women are perceived and treated in current healthcare systems (Browne & Smye, 2002).

The authors of an earlier American Cancer Society (2004) study reported that among Native American women in the United States, only 60.76% of the women had a Pap smear and 39.3% reported having a mammogram in the previous 2 years. These rates are far below screening rates for non-Native American women in the United States where 78% have a Pap smear and 72% have a mammogram (Becker et al., 2006). Similarly, the authors of the National Aboriginal Health Organization (2006b) review of cervical cancer in North American First Nations women echoed this view by indicating that "getting Aboriginal women to screen for cervical cancer is problematic" (p. 10). Lengthy delays between screening and referrals for follow-up, high staff turnover, and difficulties with obtaining timely clinic appointments were cited as barriers in the

healthcare system preventing Aboriginal women from attending Pap smear screening services. Additionally, lack of culturally appropriate and accessible services, lack of awareness, discomfort in discussing and undergoing the procedure, and shyness were also cited as reasons for Aboriginal women not participating in Pap smear screening (Amankwah et al., 2009; Becker et al., 2006; Black, 2009; Clark et al., 1998; O'Brien et al., 2009; Zehbe et al., 2012). Discomfort with undergoing Pap smear screening was attributed to issues related to sexuality, modesty training, and past experiences with abuse (Amankwah et al., 2009; Black, 2009; Clarke et al., 1998). It was reported that Aboriginal women require affordable access to services such as childcare and transportation, as well as healthcare providers with awareness and understanding of the cultural meaning of cancer and cancer prevention, and sensitivity regarding cultural behaviors (Young et al., 2000). Although this literature adds to existing research, it situates the problem of Aboriginal women not accessing Pap smear screening in a narrow context. What is required is a shift in focus from the individual to finding and critiquing the broader oppressive structures that constrain Aboriginal women's health and healthcare access (Browne, 2005, 2007; Browne & Smye, 2002; Kurtz et al., 2008; Native Women's Association of Canada, 2007; Palacios & Portillo, 2009; Smye et al., 2006; Trees, 2008).

Black (2009) conducted a qualitative study focusing on awareness and current interventions to encourage Pap smear screening among Aboriginal women in British Columbia. Findings suggested increasing women's participation in screening by building Aboriginal community partnerships, educating women at a young age about the

importance of regular screening and HPV vaccination, developing educational materials that are reflective of Aboriginal women and dedicating a week or day for Pap smear screening. Also, bringing screening services to the community, offering convenient appointments, and using creative technology for hard-to-reach populations were included. In conclusion, the author suggested the importance of cultural safety and respect to build relationships with Aboriginal communities to foster future collaborations.

Elias et al. (2012) examined the potential influence of trauma/mental health histories and addiction on self-reports of Pap smear screening. Data from a sample of 1,707 First Nations women living in Manitoba were analyzed from the 2002/2003 Manitoba First Nations Regional Longitudinal Health Survey. The authors found that regardless of their trauma histories and addiction behaviors women did not reduce their participation in Pap smear screening. The authors recommended that culturally grounded research and knowledge translation were necessary to undo misconceptions about the impact of trauma/mental health histories and addictions on participation in Pap smear screening, and to support women to access regular screening.

Zehbe et al. (2012) employed a participatory action research approach using Ermines' (2007) ethical space of engagement as a "method to bridge the diversity of knowledge and positions between community stakeholders and the research team" (p. 44) when engaging First Nations women in the development of culturally safe human papillomavirus screening. Ethical space is created when two societies or groups with differing worldviews are poised to engage with one another (Ermine, 2007). The authors widened the ethical space of engagement by starting with informal conversations with

women and progressing to formal dialogue and a pilot research in the community. Next an invitation to dialogue with leaders at an all Chief's meeting, the development of research agreements with communities, and an invitation to dialogue with 10 communities at meet and greets occurred. Facilitating the creation of ethical space was instrumental to developing collaboration between the researchers and the Aboriginal community to conduct research on such a sensitive topic.

Other research related to Aboriginal women and Pap smear screening consisted primarily of epidemiological statistics indicating the high rates of cervical cancer mortality; the emotional, cultural, cognitive and socioeconomic factors for low rates of Pap smear screening; and targeted interventions designed specifically for the purpose of increasing Aboriginal women's Pap smear screening rates (Black, 2009; Browne & Syme, 2002; Clarke et al., 1998; Johnson et al., 2004; NAHO, 2010; Steven et al., 2004).

Browne and Smye (2002) explored how decontextualized discourses addressing risk factors for cervical cancer can perpetuate negative stereotypes of Aboriginal women and minimize or ignore the historical, social, and economic contexts of women's health risks. The authors demonstrated that dominant healthcare discourses shape the provision of health services for Aboriginal women. They also examined how the dominant discourses in published literature may reinforce negative colonizing images of Aboriginal women, and "can guide the delivery of health services in ways that reinforce, rather than counter, neocolonial tendencies in healthcare provided to Aboriginal women" (Browne & Smye, 2002, p. 31). By critiquing dominant healthcare discourses and policies related to Aboriginal women and Pap smear screening from a post-colonial perspective, the social

inequities in access and historical, economic, and social health risks are illuminated. This enables explanations for the low rates of screening to shift from the women's lifestyle choice and behaviors to the broader historical, social, political, and economic inequities of Aboriginal women that constrain their health and healthcare.

## **Summary**

Aboriginal women are reported to have lower rates of Pap smear screening and higher mortality rates from cervical cancer than non-Aboriginal women in Canada. From some of the literature it is evident that history, socioeconomics, and politics play a pivotal role in Aboriginal women's access to Pap smear screening and other healthcare services, but to what extent is unclear. Furthermore, some literature broadly reports that healthcare providers and healthcare systems also may influence Aboriginal women's access to healthcare services, but further analysis of how they may perpetuate inequities in access is required. Some Aboriginal women experience discrimination, racism, Othering, and stereotyping when accessing Pap smear screening. There has been no research specifically related to Mi'kmaq women and Pap smear screening. Therefore this research study was undertaken to explore Mi'kmaq women's and primary healthcare providers experiences with Pap smear screening in two rural Mi'kmaq First Nation communities in Nova Scotia, and to consider the broader historical, socioeconomic, and political contexts that shape those healthcare experiences. The next chapter will discuss the theoretical perspectives, methodology, and methods of this study.

## Chapter 3:

#### Theoretical Perspectives, Methodology and Methods

Although both Western and Indigenous knowledge systems differ in epistemological and ontological philosophies (Battiste, 2000; Brown & Strega, 2005; Castellano, 2000; Dion Stout, 2012; Green, 2007; Loppie, 2007; Ouellette, 2002; Pidgeon & Hardy-Cox, 2002; Wilson, 2001), principles from both can be blended into the research process to capture realities and diversities among Aboriginal people when accessing healthcare. For example, researchers using participatory action research (PAR) can incorporate Indigenous principles to obtain knowledge about human and contextual perspectives (Loppie, 2007). This blending of aspects of Western research and theoretical perspectives and Indigenous research principles strengthens the outcomes of Aboriginal research in a "two-eyed seeing" approach (Marshall, 2007). The term "twoeyed seeing" (Sesatu'k Etuaptmnkl) was used by Elder Albert Marshall of Eskasoni First Nation, Cape Breton. The use of two-eyed seeing means that traditional knowledge (Indigenous principles) and Western science and PAR are considered complementary knowledge forms that when used in combination advance humanity's shared goals (Marshall, 2007). Marshall explains that two-eyed seeing is the need to learn from one eye the strengths of Aboriginal traditional knowledge and from the other eye, the strengths of Western scientific knowledge. Learning to use both eyes together in projects and in our lives will benefit both Western and Indigenous people's health and lives. This qualitative research design using participatory action research approaches is grounded in

postcolonial feminist theoretical perspectives and Indigenous principles in a two-eyed seeing approach to explore Mi'kmaq women's experiences with Pap smear screening.

In this chapter I discuss each of the above theoretical and methodological perspectives that guided this study and the methods used for data collection, analysis, and strategies to enhance trustworthiness.

## **Postcolonial Feminist Theoretical Perspectives**

#### Introduction.

Postcolonial feminist scholarship has been increasingly influential for researching health inequities and critically analyzing the interwoven contextual complexities in Aboriginal women's health and the factors that tend to shape inequities in health and healthcare access (Anderson, 2002; Browne, Smye, & Varcoe, 2007; Lewis & Mills, 2003; Reimer-Kirkham & Anderson, 2002). Postcolonial theory has its roots in the humanities and social sciences. Scholars such as Anderson, (2002), Bhabba (1994), Ghandi (1998), Hall (1996), McConaghy (2000), Mohanty (1998), Narayan, (2000), Said (1978), and Young (2003) have been instrumental in recognizing the importance and influence of historical conditions and colonization on Indigenous peoples' political, social, and economic issues and inequities. Anderson (2000) argues that postcolonial feminist theory is an inclusive and comprehensive framework "that gives voice to racialized women who have been silenced" (p. 145) while providing an analytic lens for exploring how women's lives and health have been positioned and shaped by politics and history. Reimer-Kirkham and Anderson (2002) espouse that "postcolonial theory with its

interpretations of race, racialization, and culture offers nursing scholarship a set of powerful analytical tools unlike those offered by other social theories" (p. 9).

Postcolonial does not mean that colonialism is over or completed, nor is it related to a specific period in time, but in the words of McConaghy (2000), "the post in postcolonial refers to a notion of both working against and beyond colonialism" (p. 268). In this study, a postcolonial feminist theoretical perspective is employed to expand beyond the notion of mainstream feminism that highlights the oppression of women by men and patriarchal structures, to critique all forms of oppression including historical, socioeconomic, political, and healthcare systems. There is recognition of "specifically situated women" located within varying complex systems of power, rather than universal female experiences, which challenge Western feminist constructions (Chilisa, 2012).

Mi'kmaq women's agency and resistance to oppression and the power of women within their communities to celebrate motherhood, sisterhood, and friendship is also highlighted (Chilisa, 2012).

Postcolonial feminist theory-driven research is an alternative approach in nursing science to the predominant culturalist approaches that potentially increase the possibility of essentialism and categorization of individuals (Anderson, 2000, Mohanty, 1998; Reimer-Kirkham & Anderson, 2002). Culture, in the words of Reimer-Kirkham and Anderson (2002), "has become a widely used metonym for 'difference' within nursing scholarship, without an appreciation of the ways in which the concepts of culture and race operate in tandem" (p. 5). Importantly, by drawing on critical theories, nursing scholarship also expands beyond positioning ill health as lifestyle and personal choice to

examine the broader historical, economic, and sociopolitical contexts that impact health status (Browne & Smye, 2002; Reimer-Kirkham & Anderson; 2002).

With a postcolonial theoretical lens, everyday experiences of marginalized individuals are accessed and illuminated with a view to understanding how these experiences are structured by unequal power relations existing in mainstream society and within healthcare systems, and how these relations are shaped by the legacy of colonialism and the neo-colonial present (Browne et al., 2007; Weedon, 2002).

Postcolonial theory does not typically include a gendered analysis, as is the goal of feminist scholarship which uses a theoretical lens to examine and analyze issues of gender (Lewis & Mills, 2003; McConaghy, 2000; Narayan, 2000). Feminist scholarship is particularly useful in addressing "issues of gender from the perspective of the postcolonial female subject and exposes the multiple social and historical locations from which men and women speak" (Anderson, 2002, p. 9). The combining of postcolonial and feminist theoretical perspectives not only prompts an analysis of gender differences in the structuring of inequities in mainstream society, but also provides a catalyst for considering the intersecting impact of historical and socially mediated conditions that impact women's health (Browne, Smye, & Varcoe, 2005; McConaghy, 2000; Narayan, 2000). For example, some Aboriginal women experience lower education, poverty, and poorer health, and may experience disadvantages based not only on gender but on economic, political, and historical locations (Adelson, 2005; Battiste, 2000; Browne, 2007; Browne et al., 2011; Dion Stout, 2012; Letendre, 2008; Loppie-Reading & Wien, 2009; NWAC, 2007a; Waldram et al., 2006; Warry, 2007). By combining postcolonial

and feminist theoretical perspectives, insights from more than one location can be realized while inequities are made more explicit within the broader social, political, historical, and economic contexts within which they occur (Reimer-Kirkham & Anderson, 2002). Postcolonial theoretical perspectives enable an understanding of how race, racialization, difference, culture, and historical positioning intersect to shape Aboriginal women's health and healthcare access (Browne et al., 2007). Postcolonial feminism provides a broader lens to view oppression and contexts that exist in mainstream society and addresses issues of gender, differences in ethnicity, and life circumstances which also impact access to healthcare services (Lewis & Mills, 2003; Weedon, 2002). Use of postcolonial feminist perspectives enabled me to see Mi'kmaq women not as a gendered group but as individuals with distinct historical, socioeconomic, and political experiences (Lewis & Mills, 2003), and drew attention to relationships and partnerships in the research process while offering women a voice for expressing what shapes their experiences with Pap smear screening. Furthermore, postcolonial feminist perspectives informed the interpretation of the impact of history and gender on Mi'kmaq women's access to Pap smear screening and assisted in gaining an understanding of how power, privilege, socioeconomics, and race may contribute to inequities in access. Cultural safety, which is rooted in postcolonial feminist perspectives, was used as a lens to analyze healthcare providers' practices and encounters with Aboriginal women.

Few studies have explored Aboriginal women's access to Pap smear screening using postcolonial theoretical perspectives that reveal how history, socioeconomics, politics, and healthcare providers have shaped healthcare access or addressed inequities

to access for Aboriginal women. For the purposes of this research, a postcolonial feminist theoretical perspective was appropriate to use given the significance of the colonial past and neo-colonial present, socioeconomic and political contexts, and gender when analyzing and critiquing the multiple contexts that shape Aboriginal women's experiences when accessing Pap smear screening. This perspective assisted me in responding to the study research questions about the factors influencing Aboriginal women's access to Pap smear screening and the sociopolitical, economic, and historical factors that shaped Aboriginal women's participation in Pap smear screening services.

## Critiques of postcolonial theoretical perspectives.

Although use of postcolonial theoretical perspectives has been reported to be useful in "illuminating how racialized, classed, and gendered positioning, originating in the past and continuing in the present" (Browne et al., 2007, p. 128) shapes the choices and opportunities for Aboriginal women, there are some criticisms of it that require further scrutiny. Perhaps one of the most noted criticisms of postcolonial theoretical perspectives is the concern of a "postcolonial presumption of a single shared experience of colonialism" (Reimer-Kirkham & Anderson, 2002, p. 6). Browne et al. (2007) echo this view when they discuss Aboriginal women's health and the importance of considering "the potential for postcolonial discourses to inadvertently reproduce essentialized portrayals of women" (p. 129). Essentialism ignores diversities within groups and the unique experiences of each woman within a group, thus reinforcing the notion that a woman's cultural characteristics shape her socioeconomic, political, and

health disadvantages and ignoring the contexts of poverty, dependency, and abuse (Browne, 2005, 2007; Browne et al., 2007; Reimer-Kirkham & Anderson, 2002). Using postcolonial feminist perspectives to "permit generalization about shared experiences of racialization, economic marginalization, and other forms of oppression" (Browne et al., 2007, p. 129) and focus on differences and contextualization of women's lives addresses this issue.

In relation to Aboriginal health, it is imperative to take into account "the potential for postcolonial theorizing to revert to a politics of binary opposition that implies clearcut distinctions between the colonized and the colonizer" (Browne et al., 2005, p. 24) which downplays and makes invisible the social locations of Aboriginal peoples by categorizing and further marginalizing them.

Postcolonial theory has its roots in Western epistemology and discourses (Browne et al., 2005) and differs from postcolonial Indigenous knowledge (Battiste, 2000). In the words of Battiste (2000), postcolonial Indigenous knowledge "emerges from the inability of Eurocentric theory to deal with the complexities of colonialism and its assumptions" (p. xix) and is based upon Aboriginal peoples' pain and experiences. Postcolonial, as defined by Battiste (2000), is used "to describe a symbolic strategy for shaping a desirable future, not an existing reality . . . and is used to imagine a new form of society that they desire" (p. xix). Although postcolonial Indigenous knowledge is grounded in Indigenous epistemology, ways of knowing, and worldviews (Battiste, 2000), it can be used to inform postcolonial theory (Browne et al., 2005). Battiste (2000) rightly notes that postcolonial Indigenous knowledge is essential for transforming a just society that

will "engage with and react to multiple circumstances and shapes of oppression, exploitation, assimilation, colonization, racism, genderism, ageism, and the many other strategies of marginalization" (xxi).

# Understanding concepts of culture, Othering, race, and racialization.

In this study, culture, Othering, race and racialization were conceptualized within postcolonial perspectives and discourses (Anderson, 2002; Bourassa et al., 2004; Browne et al., 2011; Browne & Varcoe, 2006; Reimer-Kirkham & Anderson, 2002). Postcolonial discourses are focused on "the processes of dehumanization and human suffering through history, and give us a context for understanding health inequities" (Anderson, 2004, p. 240). In this study, postcolonial feminist perspectives were used for understanding and critically analyzing how culture, Othering, race, and racialization are interwoven to shape healthcare and Pap smear screening access for Aboriginal women. Postcolonial perspectives challenge the notion of "fixity of 'race' and culture" (Anderson, 2002, p. 13), while expanding culture beyond narrow conceptualizations and contesting representations of cultural essentialism in the form of "Other" (Anderson, 2002, p. 14). However, it is important to understand the meanings of postcolonial concepts such as culture, Othering, "race," racialization, and to contextualize how they shape and influence healthcare and healthcare access in mainstream society. Furthermore, postcolonial perspectives offer a theoretical lens for deconstructing the ways that healthcare professionals and researchers think about and understand culture (Anderson, 2002). Throughout this research study, I was cognizant of how culture, Othering, racism,

and rationalization shaped women's experiences with access to Pap smear screening. In the following section, I define and discuss each of these concepts.

Culture and "other." Culture tends to be narrowly conceptualized in healthcare and healthcare discourses. Traditionally culture has been described as relating to the beliefs, values, norms, and practices of a particular group of individuals which are normally shared and learned (Reimer-Kirkham & Anderson, 2002). Nursing scholarship reinforces this notion of culture and often it transcends into practice areas where culture is interpreted as being affiliated with a specific ethnic or religious group (Reimer-Kirkham & Anderson, 2002). Common, pervasive conceptualizations of culture in healthcare contexts and discourses tend to reinforce the notion that culture can be easily identified, assessed, and addressed during routine healthcare (Browne, 2005; Browne et al., 2011; Browne & Varcoe, 2006).

Culture is also viewed as being synonymous with difference. Using cultural characteristics in descriptions of a particular group can be problematic because it places them at risk for being labeled or stereotyped, and reinforces (Browne & Varcoe, 2006) the "simplistic views of particular ethnocultural groups as outsiders, as different, and as 'other'" (Smye & Browne, 2002, p. 45). Othering results in the projecting of "assumed cultural characteristics, differences, or identities onto members of a particular group" (Browne, 2005, p. 66). Bourassa et al. (2004) echoed this point by stating that Aboriginal "women who bear their 'otherness' in more than one way suffer from multiple oppressions, leaving them more vulnerable to assaults on their well-being" (p. 24).

Postcolonial scholarship offers an alternative approach to counter narrow conceptualizations of culture that tend to reinforce Othering and stereotyping. A broader conceptualization of culture challenges "the unitary notion of culture" (Anderson, 2002, p. 14) and counters the essentializing of cultural characteristics while positioning culture as being interwoven with structural, historical, political, and economic contexts (Anderson, 2004; Browne, 2005; Smye & Browne, 2002; Browne et al., 2007). According to Reimer-Kirkham and Anderson (2002) definitions of culture need to move beyond "static, homogenous, and having a biological basis" (p. 4) to a more comprehensive "network of meanings enmeshed within historical, social, economic and political processes" (Anderson & Reimer-Kirkham, 1999, p. 63).

"Race" and racialization. Traditionally, "race" was constructed in relation to "biological origin and physical appearance" (Reimer-Kirkham & Anderson, 2002, p. 4) and although this theory has been disproved, mainstream society continues to categorize individuals into certain groups based upon their distinct biological characteristics (Reimer-Kirkham & Anderson, 2002). Race is socially constructed, formed in and by the processes of social and political struggles, and tends to shape everyday relations and unequal power relationships in society (Reimer-Kirkham & Anderson, 2002; Tang & Browne, 2008). Earlier, Bannerji (1995) supported the notion that "racism is after all a concrete social formation" and race "cannot be independent of other social relations of power and ruling which organize the society, such as those of gender and class" (p. 128).

Societal assumptions based on the premise of egalitarianism support the view of everyone being treated the same in society regardless of race, and consequently "race" and other socially constructed differences are non-existent (Tang & Browne, 2008). Henry et al. (2000) explain that healthcare professionals and professionals in other institutions, may unknowingly and unintentionally contribute to racial inequality.

Reimer-Kirkham and Anderson (2002) communicate that in nursing scholarship race still remains and is evident in the "ways in which the concepts of culture and race operate in tandem, most often with race as silent subtext to discourses of culture" (p. 5). Also, Tang and Browne (2008) argue that race matters in healthcare, particularly when Aboriginal people access healthcare services and encounter "some hidden (and sometimes unconscious) processes of 'profiling' based on a person's racialized or ethnic background" (p. 118). Tang and Browne (2008) provide an example of healthcare provider profiling in the emergency department in the following quote:

skids, lower income, maybe can't take care of themselves too well, so as an ED staff person, you tend to have a vision of every Aboriginal person as having a drug and alcohol issue, coming from a fairly low socioeconomic background, and having skills to maybe cope in that background, but not necessarily to cope into seeking care or options outside there. (p. 119)

From this example, it is evident that dominant societal beliefs and perceptions of some Aboriginal people become transferred and reflected not only in the media, but also in some healthcare relationships and discourses (Browne, 2007; Tang & Browne, 2008). St. Denis (2007) contends that the concept of racialization "brings attention to how race has been used and is continually used to justify inequality and oppression of Aboriginal peoples" (p. 1071) and reinforces unequal power and privilege. Throughout this study, I

analyzed the significance of race and racialization in shaping Mi'kmaq women's experiences with Pap smear screening from Mi'kmaq women and healthcare providers stories.

### **Indigenous Knowledge and Epistemology**

Although no one universal Indigenous paradigm exists, there is agreement that there are multiple realities and that Indigenous epistemology is relational and shared with all of creation. Indigenous epistemology follows Indigenous ways of knowing which are non-linear, relational, and experimental (Kovach, 2005). Indigenous knowledge encompasses what can be observed as well as what can be thought (Battiste, 2002). Indigenous knowledge and knowledge systems are centered in the environment, and based on relationships that Indigenous people have with their environment as well as to people and objects (Henderson, 2000; Wilson, 2001, 2002). Accordingly, the eco-system informs Indigenous knowledge and teachings which are passed on from one generation to the next by way of storytelling (Battiste, 2002; Castellano, 2000; Henderson, 2000).

Battiste (2002) claims that Indigenous epistemology is located in theories, philosophies, histories, ceremonies, and stories as ways of knowing. Indigenous knowledge is often oral and symbolic and transmitted by Indigenous languages, modeling, practice, and animation rather than the written word. The guiding tenets of Indigenous epistemology encompasses a legitimate way of knowing, storytelling as a method for sharing knowledge, and the relationship between the researcher and participants as a natural component of the research process (Kovach, 2005). Indigenous

epistemology is derived from multiple sources including traditional knowledge from previous generations, empirical knowledge from careful observation, personal knowledge and experiences, oral transmission, holistic knowledge, and experimental knowledge (Castellano, 2000). However, Indigenous knowledge could be challenged by some researchers who value scientific knowledge and would not consider this knowledge to be authentic, verifiable, or controllable. Indigenous knowledge is considered to be in binary opposition to scientific or Western knowledge and dismissed as incapable of informing the assessment of the needs of the world (Battiste, 2000). Indigenous scholars have questioned the supremacy of Western thought and knowledge systems when they were unable to use Western knowledge to solve the challenges facing their people. Indigenous researchers and professionals returned to traditional knowledge and ways of knowing to re-establish control over Indigenous development and capacity building (Battiste, 2000). In order to authentically explore Mi'kmaq women's experiences with Pap smear screening, Indigenous principles were valued and incorporated into this research design. Throughout this study, Indigenous knowledge and epistemology were valued as a legitimate form of knowledge passed on in the stories of the Aboriginal women. Indigenous philosophy embodies the belief that knowledge cannot be owned or discovered but is relational (Wilson, 2001) and "a living process to be absorbed and understood" (Battiste, 2000, p. 15). Indigenous ways of knowing in the stories of Mi'kmaq women in this study encompassed holism (physical, mental, emotional, and spiritual components), interconnectedness, circularity, personalism, and relationality (Battiste, 2000; Struthers & Peden-McAlpine, 2005).

### **Indigenous principles.**

Indigenous principles provide the foundation for theoretical development and are fundamental to conducting honourable and respectful research with Aboriginal people that is based in Indigenous reality and ways of knowing (Weber-Pillwax, 2001, 2004). This research study was shaped by the Indigenous principles of relationality, respect, reciprocity, relevance, and responsibility (Battiste, 2000; Kirkness & Barnhardt, 1991; Loppie, 2007; Weber-Pillwax, 2001; Wilson, 2002) to gain knowledge and understanding about Pap smear screening, a sensitive, but important topic for many Mi'kmaq women. Since relationships are fundamental when conducting Indigenous research (Battiste, 2000; Loppie, 2007), I developed trusting and respectful relationships with community members by visiting the health centre and attending community events prior to initiating this study. I also met with the healthcare directors in both communities as well as the Chief in one of the communities. This was vitally important as I attained knowledge about the communities and community members, community norms, expectations of me as a researcher, and it was also a good opportunity to gauge if there was interest in the research. The talking circle was another way of developing relationships as I introduced myself to the women and informed them about the study. They also told me about themselves and their thoughts about Pap smear screening. During the interactions with women I was cognizant that the sharing of knowledge was a reciprocal, respectful, and non-hierarchical process and I was engaged in learning with and from the women. I also used active listening skills and acknowledged the importance of valuing multiple and

individual perspectives on the topic by nodding my head and leaning forward when women were telling their stories. Women were also provided ample time to pose questions and ask for clarification on the information that I shared.

Battiste (2000) maintains that knowledge is transmitted by way of language and is embedded in culture with spiritual connections to the earth, but can be learned for a specific time and purpose. Indigenous knowledge is "a learned way of looking at the world that may have very different forms of acquisitions, transmission and manifestation for Indigenous peoples" (Battiste & Henderson, 2000, p. 48). Traditions, ceremonies, and daily observations are all integral parts of knowledge (Battiste, 2000). I honoured traditional knowledge and made observations by attending some community Maiomi ceremonies and an official opening of one of the community health centers. Attending community ceremonies and events fostered relationships and I gained knowledge about culture and the community so that I would not disrespect or not abide by community norms and expectations.

Indigenous research must benefit and be relevant for the community and community members (Weber-Pillwax, 2004). Relevance was achieved by ensuring that the research topic of Pap smear screening was relevant for the communities by talking to women in the community. Aboriginal women in the study were actively engaged in directing the research process by assisting with recruitment of participants, providing input about the interview guide and themes arising from the analysis, and planning how to disseminate the findings. Reciprocity was accomplished by the Mi'kmaq women and myself through actively engaging in knowledge sharing throughout the research process

in a safe space that was built on relationships. There was also a provision of food at talking circles and a gift of \$20.00 for participating in each of the interviews, as an attempt to ensure reciprocity.

Responsibility is the final "R" of Aboriginal research. Weber-Pillwax (2004) asserts that it is the researcher who is responsible for the effects of the research project on the lives of Indigenous people. Responsibility was assured by adhering to the Canadian Institutes of Health Research Guidelines for Health Research Involving Aboriginal Peoples (2007) and Schnarch's (2005) OCAP principles (Ownership, Control, Access and Possession). Responsibility was also assured by adhering to my professional standards of nursing practice (College of Registered Nurses Association of Nova Scotia [CRNNS], 2012), code of ethics (Canadian Nurses Association [CNA], 2008) and cultural competency and safety in nursing education guidelines (Aboriginal Nurses Association of Canada [ANAC], 2009) and by seeking ongoing participation and engagement of study participants. Employing Indigenous principles enabled women to share their wisdom about sexual health, Pap smear screening, and their experiences with accessing Pap smear screening. Further, there was acknowledgement by the researcher of multiple realities and ways of knowing and the valuing of historical and cultural meanings within the context of Aboriginal women's experiences.

#### **Qualitative Research Design**

Qualitative research involves "an interpretative, naturalistic approach to its subject matter" (Denzin & Lincoln, 2000, p. 2). One of the primary goals of qualitative

research is to interpret and document the entire phenomenon, from the individual's viewpoint or frame of reference (Gillis & Jackson, 2002; Streubert-Speziale & Carpenter, 2003). Qualitative researchers attempt to understand, describe, and give meaning to human behaviours within the context of individuals' lives (Gillis & Jackson, 2002; Schwandt, 1994). Orlikowski and Baroudi (1991) pointed out that "understanding social reality requires understanding how practices and meanings are formed and informed by the language and tacit norms shared by humans working towards some shared goal" (p. 14). The intent of qualitative research is to attain an understanding of the world from the participants instead of deriving an explanation of the world (Green & Thorogood, 2009). By using a qualitative research design for this study, the multifaceted aspects of Aboriginal women's lives from historical, political, economic, and social contexts were included in relation to their accessing of Pap smear screening services. This qualitative research study provided a means for analyzing and interpreting how the colonial past and the current sociopolitical and economic climate impacts Aboriginal women's access to Pap smear screening. Also, women told stories from their contextualized social, economic, political, and historical realities and elucidated hidden voices to give meaning and illuminate invisible experiences. Hence, my use of this qualitative research design reflects the values of subjectivity, individualism, holism, relativism, and interpretation (Streubert-Speziale & Carpenter, 2003); all are significant principles in keeping with Aboriginal philosophies. A qualitative research design using PAR and Indigenous principles was used in this study to guide the research process and further understanding

within broader contexts as to the reasons why some Aboriginal women may not be accessing Pap smear screening services.

## Participatory action research principles.

In this qualitative study I used the naturalistic inquiry processes of participatory action research approaches. PAR is used for research that explores social issues with marginalized populations and is therefore instructive for conducting research with Aboriginal women. According to Loppie (2007), PAR "is intimately linked to Indigenous philosophies through the valuing of local participation, learning through action, collective decision-making, and empowerment through group activity" (p. 278). My use of PAR also supported the participation of individuals with diverse capacities including physical, psychological, emotional, social, and spiritual (Loppie, 2007). This is particularly important for this study, given that researchers conducting PAR engage in a reciprocal process involving both the researcher and the participants in decision-making, non-hierarchical relations, and the sharing of stories. Knowledge generated from women's experiences with Pap smear screening was valued equally as expert knowledge. By using participatory approaches I ensured that research proceeded in a manner that was "culturally sensitive, relevant, respectful, responsive, equitable and reciprocal, with regard to the understandings and benefits shared between the research partner(s) and the Aboriginal community(ies)" (Canadian Institute of Health Research [CIHR], 2007, p. 3).

PAR approaches are also intimately linked to health and the health promotion of individuals and communities. PAR principles of equity, social justice, democratic,

collective decision-making and reciprocity (Koch, Selim, & Kralik, 2002; Loppie, 2007; MacDonald, 2012; Ortiz, 2003; Vollman, Anderson, & McFarlane, 2004) were used throughout this research. These principles were upheld by enabling the participation of community members, acknowledging that all participants' viewpoints were valued, using collaborative decision-making regarding the research process and dissemination of findings, and developing relationships and fostering open communication. Since PAR is grounded in practical problems and health issues of people in a given community, the research topic was identified with the community by developing collaboration between myself (as a researcher) and the community. I worked closely with both Mi'kmaq communities to identify individuals who acted as community facilitators within their respective communities.

#### Principles of the participatory action research process.

There are a number of principles of the PAR process from Selener (1997) and Ortiz (2003) that guided this research. However, it is important to note that although these look prescriptive, linear, and static, they occur at different times and are interwoven and interconnected in the research process. Table 1 illustrates the principles of the PAR approach and strategies that were implemented throughout the research process.

Table 1

PAR Principles and Strategies

Principles of PAR	Strategies
Acknowledged that the topic originated in the community itself and is defined, analyzed and solved with the community.  Collective decision-making, equity, social justice, democratic, and reciprocity	The communities have identified that for some women there are low rates of Pap smear screening. In keeping with PAR principles, Aboriginal women and community facilitators were active participants in all phases of the of the research, including input regarding research questions, participant recruitment, data collection and analysis, interview guide modification, and the dissemination of findings. Thus, the participants were considered co-investigators throughout this study (Gillis & Jackson, 2002).
Community members are the primary beneficiaries of the research.  Collective decision-making, equity, social justice, democratic, and reciprocity	This study provided an in-depth understanding of the broader impact of cultural, historical, political and economic contexts that influence Aboriginal women's lives and their experiences accessing of Pap smear screening services and the role that the healthcare system and healthcare providers play in shaping women's access to relevant Pap smear screening services. Findings used to inform future policies and curriculum related to Pap smear screening.
PAR involved the full and active participation of the community members throughout the research project.  Collective decision-making, equity, democratic, reciprocity	Community facilitators, community members and Aboriginal women were active participants in this study.
The ability to create a greater awareness in individual's own resources that can mobilize them for self-reliant development.  Democratic	Some Mi'kmaq women benefited from the opportunity of coming together and sharing common experiences and understandings related to the screening of women for Pap screening. They said that they increased their knowledge and awareness about Pap screening and some would now access Pap smear screening regularly.

Principles of PAR	Strategies
PAR is more than a scientific method in that community participation in the research process facilitates a more accurate and authentic analysis of social reality.  Equity, democratic, reciprocity.	The goal of this emerging program of research is to promote more equitable access to effective health care that is responsive and respectful of the contexts of Mi'kmaq women's lives.
In PAR, the researcher is a committed participant, facilitator, learner in the research process.  Collective decision-making equity, democratic, reciprocity.	The collaborative nature of the research process involved the researcher in facilitating sharing and moving discussions forward to generate new knowledge that is relevant and practical for this population.

In keeping with participatory principles, Aboriginal women and a few other community members were active participants in different phases of the research project. They provided input regarding research questions, participant recruitment, data collection and analysis, interview guide modification, and the dissemination of findings. Thus, the participants were considered co-investigators throughout this study (Gillis & Jackson, 2002).

## **Data Collection Methods**

# Community settings.

Qualitative research is primarily conducted in the natural surroundings of the participant (Gillis & Jackson, 2002; Strubert & Carpenter, 1995). The settings for this study included two rural Mi'kmaq First Nations communities in Eastern Nova Scotia.

The rationale for choosing two Aboriginal communities was to provide richer data by obtaining an in-depth range of perspectives and diversity in Aboriginal women's experiences with Pap smear screening, while protecting anonymity of the participants. I also chose these communities for my study as they were illustrative of the characteristics of other Aboriginal communities in Nova Scotia with respect to language and access to healthcare services. Some Aboriginal communities in Nova Scotia have kept their language while some communities have not. One of the First Nation communities is an example of a traditional community that has kept the Mi'kmaq language alive and children in the daycare in this community are even taught words and phrases in Mi'kmaq. In the second First Nation community there are few individuals that speak Mi'kmaq and children are not provided opportunities to learn to speak the language. Although both communities have a healthcare centre, they differ in how they offer Pap smear screening services. In the first community there is a fulltime healthcare provider who provides Pap smear screening. In the second community, there is a healthcare provider who visits for 1 day once every 6 months and completes the Pap smear screening on occasion. Some women may go to a healthcare provider outside of their communities. There are plans for the community health nurse in the second community to be trained in the future to complete Pap smear screening in the health centre.

#### Gaining community access: Participatory approaches.

Living close to an Aboriginal community, attending church in the community, and knowing some of the community members, I assumed that gaining access to conduct

this research would be relatively easy. I did realize that there would be some challenges to gaining access to the communities and in one of the communities in particular, as I had very few pre-existing relationships and there was already a lot of research being conducted there. Gaining access proved to be one of the biggest challenges I confronted during the research process and I now realize it was one of the most important components of the research process. However I now understand that gaining access is not about just walking into a community and conducting research. It begins with locating one's self in the research and relationship building, even before taking a research idea to the community. According to Absolon and Willett (2005), a fundamental principle of Aboriginal research is for the researcher to locate themselves by identifying "the location from which the voice of the researcher emanates" (p. 97) in the research process. Therefore, I knew I needed to take some time to reflect as to why I wanted to conduct this research, who would benefit from the research, and where I was located in this research. I was looking for a process of gaining access to the communities which was not recorded anywhere. Smith (1999) cites when conducting research with Indigenous communities that "in many projects the process is far more important than the outcome. Processes are expected to be respectful, to enable people, to heal and to educate. They are expected to lead one small step further towards self-determination" (p. 128). I visited the communities and the community health centers initially just to develop relationships without even verbalizing ideas about the possibility of conducting research in the communities. I requested that one of the community members I knew in each of the communities take me around and tell me about the community. I learned about

community needs, strengths, issues, education, economics, politics, and language. I began to realize the subtle differences between each of the communities. I also inquired about Pap smear screening and they said that this was a topic that was not commonly talked about in the community and that needed to be addressed. A few of the women told me stories about relatives they knew who had died of cervical cancer or how they had experienced abnormal test results themselves. Women then started to ask me questions about Pap smear screening, particularly about test results and the frequency of getting them done. I then casually revealed that I would be interested in doing some research in this area and some of the women expressed interest in being a part of the research. I then knew it was time to formally communicate my research interests. Some of the community members were in agreement with having Pap smear screening research conducted in their community. I then set up formal meetings with the Chief and the directors of each of the health centers to discuss the possibility of conducting Pap smear screening research with Aboriginal women and healthcare providers in their communities. During meetings with the Chief and directors they suggested that I have an individual from the community or healthcare provider working in the community health centre assist me with navigating the community, helping with the research process and recruiting women to the study. The Chief and directors identified that this research needed to be done and would be valuable for both Aboriginal women and healthcare providers.

I wanted to be respectful of the community members and protocols. I had read an abundance of literature pertaining to non-Aboriginal researchers being disrespectful and

not honoring or involving communities in the research process and Aboriginal communities not benefiting from the research. When I did meet with one Chief, we spent 2 hours talking about the community. He shared insider knowledge about health, education, politics, and the burden of residential schools prior to talking about the research. Then he spent some time talking about the ethics of conducting Aboriginal research and that there were formal CIHR and Mi'kmaq Ethics Watch guidelines that I was expected to follow. I, in turn, talked about the guidelines as well as current literature about Aboriginal women and Pap smear screening and the importance of cervical cancer prevention. He then gave written permission to conduct the research in his community. This proved to be a reciprocal learning process which mirrored the PAR principles of respect, reciprocity, relationality, sharing of stories, and collaboration. The Chief and the director in another community gave verbal agreement to conduct the research and the Chief had the healthcare director in his community provide a written letter of consent. I also spent time reflecting on the fact that I was a privileged, White, educated woman and researcher going to an Aboriginal community to conduct research with the community. I reflected upon my own biases and read everything I could find that pertained to Aboriginal health and conducting Aboriginal research.

The role of the community facilitator. Israel, Schulz, Parker, and Becker (1998) recommend that having successful partnerships in a participatory approach requires "a community organizer who is able to bring together people in the community, who has a history of community involvement" (p. 186). In this study community facilitators

organized the talking circles, assisted with recruitment of participants, acted as a community liaison for the research, provided feedback regarding the interview guide and research process, and reviewed themes throughout the analysis.

Respectful of PAR principles, I talked with community members about who might be interested and helpful in conducting this research. Based on this consultation, a community health nurse and a community member were invited and agreed to be the community facilitators. I met with each of the community facilitators to talk about the study and discuss any significant details or potential issues related to the study. Discussions ensued about community protocols, when and where to conduct the research, having talking circles to explain the study and to get to know me, obtaining consent, collecting data via storytelling interviews, and how to disseminate study findings. They also talked about who should participate in the study including the diversity that was important to have in women participants (e. g., education, employment, economic status) for the study. The community facilitators reviewed and provided feedback to a letter of introduction explaining the study that I developed (Appendix A). Following discussion about their roles, each facilitator signed a Community Facilitator Agreement (Appendix B).

**Recruitment of Mi'kmaq women.** Participants were recruited using purposeful and snowball sampling. Purposeful sampling involves the "selecting and interviewing or observing participants who have experienced the phenomenon of interest" (Gillis & Jackson, 2002, p. 712). In snowball sampling, research participants are asked if there is

anyone else in their community who might be interested in the study (Gillis & Jackson, 2002). Community facilitators in each of the communities contacted by phone or in person 20 to 30 Mi'kmag women and invited them to participate in the proposed study. As agreed with the community facilitators and in consultation with women participants, two talking circles were planned. The first one was to introduce and talk about the study with women who were potentially interested in participating, and the second one was for dissemination of the research findings. Traditionally a talking circle is intentionally structured for the purpose of permitting all participant voices to be heard (Tompkins, 2002). All those participating in the talking circle take turns speaking and are not interrupted or judged by others (Wilson & Wilson, 2000). There was no formalized guide developed for the talking circles. Topic(s) for discussion during the talking circles were fluid and both the researcher and participants were involved as active participants (McNiff & Whitehead, 2006; Wilson & Wilson, 2000). The talking circles were premised on the PAR principles of respect, shared decision-making, reciprocity, and relationality. The community facilitators invited potential women to attend the first talking circle that was held in their community for the purpose of discussing the study and introducing myself. A letter of introduction explaining the study was distributed to all in attendance (Appendix C). Aboriginal women willing to participate in the study could either provide informed written consent after the talking circle or contact me later to arrange a time and a place to meet for signing the consent form (Appendix E). After obtaining consent for participation, storytelling interviews using a semi-structured guide specifically developed for the study with input from the community facilitators

(Appendix G) were arranged and a demographic information sheet (Appendix H) was completed with each of the women at a convenient time and place.

In one community there were 8 women and the community health nurse who attended the first talking circle, whereas there were 10 women, the community health nurse, and the director who attended the first talking circle in the other community. In one community the first talking circle was initially led by me. In the other community the community facilitator led the talking circle, introduced me, and invited me to talk about my study. In accordance with PAR principles, women posed questions, made comments, told stories, and provided suggestions regarding the interview questions and research process in both communities. There was a mutual exchange of information in a comfortable environment while sharing food that I had brought. Women suggested having the interviews at the community health center to eliminate the need for childcare or transportation. It was stressed that this talking circle was an information session only and that study participation was strictly voluntary with no obligation to participate in the study. If women were not comfortable talking in the talking circle they could contact me afterwards.

There were six women in one of the communities who informed me that they wanted to participate in the study after the talking circle, and two more contacted me afterwards to participate. In the other community there were five women that wanted to participate in the study after the talking circle and I contacted three more directly after the community facilitator told me they were interested in participating and provided me with their contact information. As suggested by the community facilitators, the Chief, and

women, a second talking circle was arranged in each of the communities in collaboration with the community facilitators to disseminate research findings to the community once the dissertation is completed.

Recruitment of healthcare providers. The community facilitators in each community provided me with names of potential healthcare provider participants. I wanted to contact the healthcare providers myself in case the community facilitators were not comfortable with contacting them and to balance power differentials that may have existed. I contacted four healthcare providers in person while visiting in healthcare centers and provided them with an information letter explaining the study (Appendix D). At that time I also answered questions, provided clarity, and determined their interest in the study. All four agreed to participate in the study as they believed it was a topic that was important in Mi'kmaq communities. I contacted another healthcare provider by telephone to explain and invite their participation. I set up a time and a place convenient to each of them to meet to discuss the study further, answer questions, and obtain consent (Appendix F).

#### The study participants.

*Mi'kmaq women.* To be included in the study women had to; 1) be a self-identified or status Aboriginal woman; 2) live in one of the Mi'kmaq communities; 3) be between 21 to 75 years of age; 4) have had a least one Pap smear screen; 5) be able to provide informed consent; and 6) be able to read, understand, and speak English. The

age parameters were based on Cancer Care Nova Scotia's Cervical Cancer Prevention

Program guidelines that propose that women should initiate regular Pap screening within

3 years of her first vaginal sexual activity or at age 21 and cessation of Pap smear screening may occur at aged 75.

Sixteen Mi'kmaq women were invited to be interviewed twice; 8 women from each of the two communities. Table 2 displays demographic information about the women. The numbers of women are in brackets before each of the characteristics.

Table 2

Mi'kmaq Women's Demographic Characteristics

Age Ranges in Years	Highest Education Attained	Employment Status	Relationship	Residential School	Accessing of Pap smear screening
(4) 21-29	(1) Elementary	(7) Full time	(5) Married	(2) Attended	(9) Regularly
(4) 30-39	(2) Junior	(3) Part-time	(4) Partner	residential school	()) 1108010111
(5) 40-49	High	(1)Unemployed	(2) Widowed	(11)	(7)Irregularly
(1) 50-59	(2) High School	(1) Retired	(5) Single	Relative attended	
(2) 60-69	Diploma	(1) Student	· / · · ·	residential school	
(0) 70+	(1) College	(3) Social			
	Degree	Assistance		(3) No	
				relative in	
	(5)			residential	
	University			school	
	Courses				
	(5)				
	University				
-	Degree				

Healthcare providers. The second group of participants in the study was healthcare providers working with Aboriginal women in either one of the two communities. There were five healthcare providers interviewed for the study; four from one community and one from the other community, aged 37 to 63 years. The healthcare providers' experience working in Aboriginal communities ranged from 2 to 38 years. Of the five, only two were employed full-time in the community. The healthcare providers were nurse practitioners, community health nurses, and physicians.

#### Data collection.

In-depth interviews with Mi'kmaq women. There have been various methods for data collection used in a PAR approach. It is customary that the researcher and participants collaborate to establish the appropriate methods of data collection for their specific issue or situation (McNiff & Whitehead, 2006). Interviewing is an appropriate method for collecting data regarding human experiences (Kvale, 1996). Interviews, for example, are methods used in PAR approaches that "enable participants to describe their situation" (Stringer, 1999, p. 68). The researcher explores a few general topics to assist in uncovering the participant's perspectives, but demonstrates the utmost respect for how the participant frames and structures the responses (Marshall & Rossman, 2006). For the purposes of this study, two in-depth interviews were completed to provide an opportunity for participants to tell their stories about Pap smear screening which was the process agreed upon by the community facilitators and some Mi'kmaq women. The purpose of the in-depth interview was to provide Mi'kmaq women with an opportunity to share

stories about their personal experiences, beliefs, attitudes, and issues with Pap smear screening. Aboriginal women were also invited to share personal experiences and challenges that they confront when accessing Pap smear screening services.

In keeping with PAR principles, women had a choice to participate in talking circles, interviews, or both. Interviews were conducted by me using a semi-structured interview guide developed with input from community facilitators and some women (Appendix G). Fifteen women agreed to be interviewed twice, and one woman chose to be interviewed once. The second interview took place following transcription of the first interviews and preliminary analysis of findings (at a time and place convenient to the participants). During the second interview women reviewed their transcripts and had an opportunity to clarify, confirm, or alter the data collected so that it accurately reflected their experiences with Pap smear screening. Women were asked to provide feedback on data interpretation, preliminary findings, and emerging themes. The second interview also permitted me to seek clarification on topics and generate insights as women expanded upon their experiences and stories (Kaufman, 1992). Prior to the interviews in a location chosen by the women, consent forms were signed after a full explanation of the study was provided and all questions were answered. One woman chose to have her interview in her home and the other 15 chose to have their interview at the health centre. Prior to the interviews women were also asked to complete a demographic information form (Appendix H). Both interviews lasted between 60 and 90 minutes, were audiotaped by me, and transcribed verbatim by a transcriptionist after signing a Confidentiality Agreement (Appendix K).

Healthcare provider interviews were also conducted by myself using a semi-structured guide specifically developed for the interview (Appendix I) and audio-recorded. The demographic sheet (Appendix J) was also completed at that time. A second interview took place after each initial interview was transcribed with all but one of the healthcare providers, for the purpose of reviewing transcripts and expanding and providing clarity on what they said in the first interview. One healthcare provider did not want to review their transcript or be interviewed by me a second time, explaining they had nothing more to say or expand upon.

Reflective journaling. Journaling has been described as a tool for personal and professional growth and is comprised of written accounts that promote expression of perspectives, ideas, and feelings (Gillis & Jackson, 2002). Journal writing is a form of self-expression, a recording of events, feelings, impressions, reactions, concerns, and ideas as well as a method for facilitating reflection on learning (Boud, 2001; Gillis & Jackson, 2002). According to Bunkers (2000), journaling provides learners with opportunities to describe, interpret, and analyze their own learning and perspectives while providing a means for making sense of the world. Throughout the research process, I kept a personal reflective journal of impressions about the research process, methodological issues, and insights. Journal notes also included personal reflections, observations, and impressions about interactions and behaviors of research partners, personal biases, and learning experiences.

**Field notes.** Field notes are records about the people, places, and things encountered during the research process (Streubert & Carpenter, 1995), and "attempt to capture, with as much accuracy as possible, descriptions and interpretations of individuals, interactions and events" (Gillis & Jackson, 2002, p. 230). After each interview I detailed my thoughts, observations, and reflections about what was said, how it was said, verbal and non-verbal communication, and the environment. I also detailed my insights, feelings, biases, and interpretations about the research process, participants, and the environment. I created a table with three columns: observational notes, methodological notes, and theoretical notes. For example, one woman was asked to describe her thoughts about Pap smear screening in the interview. In my observational notes I wrote that she appeared tense, clenching her hands and body rigid as she spoke about being absolutely mortified at 16 having her first Pap smear screening. In the methodological notes section I asked what and how she was taught about Pap smear screening with a follow up question for her next interview being why did she think she was not more informed about Pap smear screening? In the theoretical notes section I wrote my thoughts questioning stigmatization related to educating young Aboriginal women and noted research to support my thoughts. Some of these field notes assisted with the planning for follow-up questions in the second interviews and were helpful when interpreting the data.

# **Data Analysis**

The purpose of analysis is to "delineate the forms, kinds, and types of social phenomena and to document their existence" (Field & Morse, 1985, p. 104). To assist with the management and analysis of transcribed data, N-Vivo 8 qualitative software was used to classify, sort, and arrange information (QSR International, 2007).

DeSantis and Ugarriza (2000) emphasize that thematic analysis is a common sense approach for data analysis. Thematic analysis is the "search for common threads that extend throughout an entire interview or set of interviews" (Morse & Field, 1995, p. 139). Thematic analysis embodies a process of searching and documenting common concepts, principles, or themes that appear in the data (Polit, Beck, & Hungler, 2001). Themes are concepts indicated by the data, rather than participants' descriptions of entities, and they are often difficult to identify. Data analysis for this qualitative study was informed by thematic analysis approaches (O'Connor & Gibson, 2003; Sandelowski, 1995) with the goal of staying close to the data and providing "a comprehensive summary of events" (Sandelowski, 2000, p. 334) from "the complex world of lived experience from the point of view of those who live it" (Schwandt, 1994, p. 118). Conducting thematic data analysis permits the researcher "to capture all of the elements of an event that come together to make it the event it is" (Sandelowski, 2000, p. 336) and assumes that reality of human experiences is socially constructed and contextual, while allowing for shared realities (Sandelowski, 2000). The researcher is the means by which this reality of human experience is revealed and theories that emerge must be grounded in the data (Andrade, 2009).

For the purposes of this research inquiry the thematic analysis processes described by Sandelowski (1995) and O'Connor and Gibson (2003) were employed to identify themes from the participants' stories. Figure 1 provides a summary of the steps involved in the thematic analysis process and the interpretative approaches that were implemented when analyzing Aboriginal women's and healthcare providers' stories about Pap smear screening. Although these steps seem sequential, linear, and appear prescriptive, they were useful as a guide and modifications were made to ensure the best fit for the data (Sandelowski, 2000). Also, the steps cited below may be interwoven, not sequential, and involve more than one step at the same time.

### Figure 1

Thematic Analysis Process

# Getting to know the Data and Getting a Sense of the Whole:

- All audio-recorded interviews were listened to
- Transcripts were read and re-read after being transcribed with errors corrected
- Transcripts were imported into N-Vivo 8
- Transcripts were read while listening to audio-recordings
- Memo notes were also made using N-Vivo 8
- Journal notes written

# **Organizing the Data:**

- Data were organized using N-Vivo 8 after re-reading transcripts
- Each transcript was fully coded line by line

## "Open coding," Organizing Ideas and Concepts:

- Identifying salient themes, recurring ideas, language and patterns.
- Once frequently used ideas, language, concepts were identified then they are organized into codes or categories.
- As many headings were developed to describe all aspects of the interview content.
- Categories were freely generated and broad themes started to become evident.
- When ideas or concepts were identified, they were organized into nodes
- Chunks of text from each transcript were coded under a node(s) that represented that node.

## **Reducing Categories:**

- I surveyed the list of categories and groups together high-ordering headings, thus reducing the number of categories.
- Data under each node were then reviewed to determine if it represented the node label and node description.
- If there was inconsistency or the data did not seem to match a particular node, then node labels and descriptions were redefined or the data was moved to another node.

### **Removing Repetitious Headings:**

- I reviewed the new list of categories and sub-headings, removing repetitious headings.
- Repetitious nodes were collapsed when there was overlap between nodes
- The final coding consisted of overarching themes and several subthemes, which were organized in tree nodes.

• Tree nodes were then reviewed and collapsed according to labels.

#### **Inter-rater Reliability:**

- My co-supervisors and a colleague were asked to generate category systems without viewing my list to enhance validity of the categorizing method
- My co-supervisors and community facilitators reviewed the coding process of three transcripts and participated in the collapsing of categories to come up with themes and sub-themes.
- The themes and sub-themes were reviewed and agreed upon by some community members, community facilitators and co-supervisors.

### Finding Possible and Plausible Explanations of Findings:

• I made a summary of my themes and sub-themes and went to the literature to compare and contrast findings prior to writing up the findings.

#### **Trustworthiness of the Data**

Establishing trustworthiness of qualitative findings assures a study's applicability, consistency, and neutrality (Gillis & Jackson, 2002). Adhering to the participatory principles of relationality, collective decision- making, respect, and reciprocity provided a means to enhance trustworthiness of this study. Lincoln and Guba (1985) have developed an approach critical for ensuring validity and reliability in qualitative research. Trustworthiness encompasses credibility, dependability, confirmability, and transferability of the study findings. Each will be discussed below, as well as their relevance, which was a criterion for assessing the validity of this qualitative research study.

# Credibility

Credibility refers to the internal validity in research and involves "the accuracy of the description of the phenomenon under investigation" (Lincoln & Guba, 1985, p. 215). According to Gillis and Jackson (2002) "the portrayal of the reality must be faithfully represented and plausible to those who have experienced that reality" (p. 702). Credibility becomes enhanced with more interactions with the participants and the prolonged time the researcher invests in the setting during data collection, so that the multiple realities of the participants are reported as accurately and authentically as possible (Gillis & Jackson, 2002; Morse & Field, 1995).

I addressed the credibility of research findings by using member checking, recording field notes, forming partnerships with community facilitators, debriefing with community facilitators, and engaging in peer review and debriefing. Member checking is the collaborative process of involving participants in data analysis by verifying and refining data and research findings for congruency with their experiences and meanings (Gillis & Jackson, 2002, p. 216). Participants in this study had an opportunity to read and validate their transcribed interviews and reviewed a summary of potential themes with myself. This process provided each participant time to clarify, alter, or confirm that the data adequately reflected and was consistent with their stories and experiences (Creswell, 1998; Gillis & Jackson, 2002).

Another way to establish credibility is by maintaining field notes throughout the research inquiry. I kept field notes, records of what participants said and how it was said,

and the reactions of others to what was being said (Gillis & Jackson, 2002). I also documented my personal reflections about my attitudes, biases, values, and preconceived notions.

Forming research partnerships and debriefing with community facilitators is another example of how I tried to ensure credibility. The forming of partnerships was initiated prior to commencing the research by visiting the community, the Chief, and the health centers. Collaborative partnerships and community facilitator debriefings also assisted in improving the credibility of the research findings by verifying the effectiveness of data collection, providing ongoing feedback regarding the research process, providing feedback regarding the interview guide, and reviewing themes after completion of data collection.

Peer review and debriefing as an external check of the research process was also maintained in order to ensure credibility (Creswell, 1998). According to Lincoln and Guba (1985) the peer reviewer or debriefer is an individual who acts as a "devil's advocate" by ensuring that methods, meanings, and interpretations are accurate; reviewing transcripts to ensure accuracy of themes; and asking difficult questions about the research inquiry when necessary for clarification purposes. For this study, consultations with community facilitators, participants, and with my dissertation supervisors for peer review and debriefing occurred throughout the research process.

# **Dependability**

Dependability refers to "the quality and appropriateness of the inquiry process" (Lincoln & Guba, 2000, p. 243) and can change with conditions and time (Gillis & Jackson, 2002). Dependability substantiates that another researcher with knowledge in the field being studied would have similar findings from data collected and analyzed (Creswell, 1998; Gillis & Jackson, 2002). This was addressed by consulting my PhD committee members to ensure accuracy of the interpreted findings and by maintaining an audit trail outlining the methods and sources of data generation and decisions made regarding data analysis throughout the research process.

An audit trail ensures that another researcher should be able reach comparable conclusions given the same setting (Gillis & Jackson, 2002). I also debriefed and consulted with my committee members about the research process, including reviewing transcripts, coding of data, development of themes, and methodology.

#### Confirmability

Confirmability is the extent to which the study findings are shaped by the participants and not by the researcher's motivation, bias, or interest (Lincoln & Guba, 1985). Thus, others can follow the process of the study and agree with the meanings and interpretations that emerged from the data collected and analyzed. Establishing confirmability for this study included examining the participant's "data, findings, interpretations, and recommendations" (Lincoln & Guba, 1985, p. 318). Confirmability of this research process and data findings were addressed by having the community

facilitators, the participants, and my PhD committee supervisors review my data collection and data analysis processes, and acknowledge agreement with themes and subthemes. I also kept details by journaling about personal reflections regarding the research process and the process of data coding.

### **Transferability**

Transferability provides the reader with an opportunity to make assumptions regarding the application of the data to other settings, populations, and contexts (Guba & Lincoln, 1985). Transferability involves a process whereby the researcher provides rich contextual descriptions of the participants and setting where the research occurs (Creswell, 1998; Lincoln & Guba, 1985). Transferability enables researchers to ascertain whether or not the research findings can be transferred to settings with similar characteristics (Erlandson, Harris, Skipper, & Allen, 1993). Every attempt was made to ensure transferability throughout this research inquiry by providing a contextual account of participants and describing their demographics, describing Mi'kmaq culture and historical contexts, and using detailed descriptions of the participant selection and analysis techniques used. This will provide other researchers with sufficient information and an opportunity to determine the transferability of these study findings to similar contexts and settings.

#### Relevance

Mays and Pope (2000) argue that "research can be relevant when it either adds to knowledge or increases the confidence with which existing knowledge is regarded" (p. 50). Relevance has been conceptualized by Anderson (2001) in terms of the potential for solving a research problem and requires consideration when conducting Aboriginal research. Relevance of the importance of Pap smear screening in their communities was acknowledged by community facilitators, the Chief, healthcare directors, Mi'kmaq women, and healthcare providers. Knowledge developed from this research will hopefully improve the healthcare of Aboriginal women by providing greater understanding about the broader historical, economic, and sociopolitical issues influencing Mi'kmaq women's access to Pap smear screening services. The findings from this research will be disseminated to Mi'kmaq communities, healthcare professionals, university healthcare educators and students, and healthcare authorities, and policy makers to inform healthcare practice, policies, and education.

#### **Dissemination of Research Findings**

The findings from this research will be disseminated with the permission of the participants which adheres to the OCAP (ownership, control, access, and possession) principles of the National Aboriginal Health Association (NAHA) (2004). The OCAP principles are considered self-determination applied to research with Aboriginal people and "a political response to the tenacious colonial approaches to research and information management" (Schnarch, 2005, p. 1). The ownership principle involves the relationship

of a First Nations community to its knowledge, data, and information. Thus, the community owns the information similarly to the manner in which an individual owns their personal information (Schnarch, 2005). With regards to control, Aboriginal people have the right to control all aspects of the research and any information processes that may impact them. Access ensures that Aboriginal people have access to all the information and data regarding themselves or their communities. Thus, Aboriginal people have the right to make decisions regarding the access of information and the management of information (Schnarch, 2005). According to Schnarch (2005), "possession (of data) is a mechanism by which ownership can be asserted and protected" (p. 2), particularly when there may be trust issues between the researcher and participants. The OCAP principles were respected in this study by informing the women about the entire study and their participation, ensuring an informed consent form was signed and given to the participants, discussing anonymity and confidentiality with the participants, and discussing the findings with some participants as well as discussing the possible dissemination of study findings.

As requested by the Mi'kmaq women, community facilitators, and the Chief, a verbal presentation of the findings will be presented by way of a talking circle. A copy of the dissertation will be given to the Mi'kmaq College Institute, Cape Breton University, Nova Scotia, and Atlantic Aboriginal Health Research Program (AAHRP). The study findings will be disseminated in journal publications, conferences, workshops, brochures, and future research projects for the purpose of increasing awareness and knowledge regarding Aboriginal women's experiences with Pap smear screening. The findings of

this research will be disseminated to influence policies pertaining to current Pap smear screening practices. Consequently, these research findings will be presented to the Chiefs and Band Council members in both communities, members of the Nova Scotia Gynecological Screening Program, Nova Scotia Department of Health and Wellness, Cancer Care Nova Scotia, and First Nations Inuit Health of Health Canada.

#### **Ethical and OCAP Considerations**

Ethical approval for this study was obtained from the Dalhousie University Health Sciences Human Research Ethics Committee and the Mi'kmaq Ethics Watch Committee of Nova Scotia. This research was guided by the OCAP (ownership, control, access, and procession) principles of the National Aboriginal Health Association (2004) and the Canadian Institute of Health Research (2007) guidelines for health research involving Aboriginal people. Permission was also obtained from the appropriate individuals in both Aboriginal communities in the form of letters after meeting individually with them and explaining the study in detail.

Participants' health records were not accessed nor was any information regarding the treatment of individual participants from healthcare professionals. All those interested in participating in the research signed a consent form prior to entering any of the study phases. The consent form was explained and signed prior to participating in a talking circle or being interviewed. The participants were assured that they could withdraw from the study and have their data removed at any time up until the time data analysis has occurred, and that participation in the study was strictly voluntary.

Additionally, the researcher informed the participants that they could refuse to answer any questions during the interview and could make comments or ask questions regarding any aspect of the study at any time.

Anonymity was maintained during the interviews by using pseudonyms that were selected by the participants and no participant names or identifiers were used in any of the documents. I informed the participants that I could not guarantee that other women participating in the talking circles would keep comments confidential or maintain anonymity of others. I requested that all information in the talking circles remain confidential prior to starting and requested that the privacy of others be respected.

The participants were informed that all study notes and data were secured in a locked filing cabinet accessible only to me and that all audio-recordings would be destroyed upon completion of the study. All transcripts and other written materials pertaining to the study will be kept in a locked cabinet and destroyed 5 years after the study is completed as required by the Dalhousie University Health Sciences Human Research Ethics Committee. If any of the participants felt they needed to talk to a counselor about emotional or physical trauma at any time during the study, a name was provided to them.

In one Mi'kmaq community the health nurse agreed to be consulted and talk with women about any issues relating to social or physical trauma they may have previously experienced or the nurse could consult a Family Healing Centre or mental health services at the local hospital. In the other Mi'kmaq community an Aboriginal woman and a clinical therapist agreed to be consulted if women in the study required counseling

services related to previous emotional or physical trauma and mental health services. In accordance with Indigenous tradition, participants and community facilitators were given an honorarium (thank you gift) to acknowledge their participation in the research.

## **Personal Reflection: Locating Myself in the Research**

I was always interested in learning about Aboriginal culture, beliefs, and traditions from the time I was a child. My cousin is an honorary Chief in one of the Aboriginal communities close to my home, and my mother was a substitute teacher in that same community. I had often heard stories from my mother about events in the community and educational practices. I have been privileged in my previous oncology clinical practice to provide nursing care for some Aboriginal women experiencing cervical cancer and other cancers. Many of these women had presented with advanced stages of cancer upon admission to hospital. The women seemed hesitant to interact with healthcare professionals or inquire about care or treatment modalities. This resulted in what seemed to be the delivery of cancer treatment with little expectation of cancer care. Given that this was contrary to my experience as an oncology nurse, I began to also observe the interactions of non-Aboriginal women. There was a distinct uniqueness in how the two groups of women communicated with healthcare professionals, inquired about their care, and engaged in questioning treatment plans for cervical cancer. I had the opportunity to listen to Aboriginal women's stories about their lives, their challenges, and the issues they confronted in our mainstream healthcare system. I learned about Aboriginal cultural practices, beliefs, traditions, as well as the historical trauma

experienced because of residential schools and assimilation policies. I realized that our mainstream policies and procedures were not culturally appropriate and did not address Aboriginal patients' needs or beliefs. I became aware of my lack of knowledge for providing culturally competent care to Aboriginal patients which motivated me to become more educated about Indigenous ways of knowing and cultural and historical trauma. I began researching Indigenous ways, culture, beliefs, and values only to find very little literature pertaining to Aboriginal women and cancer, particularly gynaecological cancers. Therefore, I became motivated to pursue further education and research pertaining to Aboriginal women and Pap smear screening.

### **Summary**

This qualitative participatory research approach, grounded in postcolonial feminist theoretical perspectives and Indigenous principles in a two-eyed seeing approach, fostered the valuing of Mi'kmaq knowledge and beliefs and created ethical spaces for reciprocal information sharing and relationship building. Every effort was made to have women's voices heard throughout the research process and to honor them as co-researchers. Efforts were also made not to frame Mi'kmaq women or their experiences in negative or pathologizing ways and to maintain the ethical integrity of the study and study findings by adhering to research, community, and my professional protocols (codes of ethics, standards of practice, and cultural competency and safety guidelines). Mi'kmaq women and healthcare providers were respected as experts of their own knowledge. The women and the healthcare providers expressed a genuine interest in

telling stories about their experiences with and perceptions about Pap smear screening. The following findings and interpretation chapter will discuss themes and sub-themes arising from the interviews with Mi'kmaq women.

# Chapter 4:

### Findings and Interpretation: Mi'kmaq Women's Perspectives

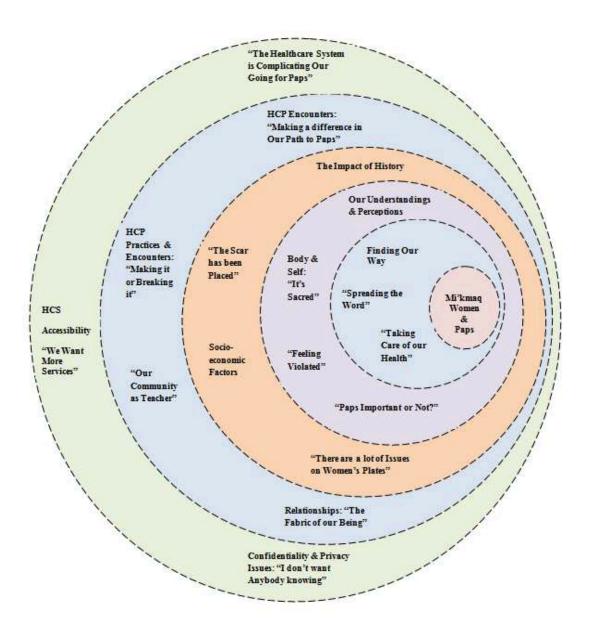
This chapter discusses findings from stories about Pap smear screening from 16 Aboriginal women in two First Nation's communities in Nova Scotia. This qualitative study design was informed by participatory action research approaches using Indigenous principles and post-colonial feminist perspectives. They are reflective of the study purpose, which was to explore Aboriginal women's and primary healthcare provider's experiences with Pap smear screening, and to consider the broader historical, economic, and sociopolitical contexts that shape those Pap smear screening experiences.

The themes presented are interrelated and are presented in no particular order or priority, which is consistent with Indigenous principles and beliefs (Battiste, 2000; Loppie, 2007). Smylie (2001) suggests that a circular concept or cycle represents phenomena as interrelated parts of repeated sequences; therefore, the themes depicted in the following cannot be viewed as separate entities or explained individually. Thus, throughout the findings chapters in this dissertation linkages between themes and subthemes will be identified.

Five major themes were identified from Mi'kmaq women's stories: a) Finding Our Way; b) Our Understanding and Perceptions About Pap Smear Screening; c) The Impact of History on Our Health and Healthcare Experiences; d) Healthcare Providers' Encounters: "Making a Difference in Our Path to Paps"; and e) "The Healthcare System is Complicating Our Going for Paps." These five themes are comprised of a series of sub-themes depicted in Figure 2.

Figure 2

Themes and Sub-themes: Mi'kmaq Women's Experiences with Pap Smear Screening



The findings and interpretation of the findings are interwoven in a relational and personal manner that gives voice and represents Aboriginal women's stories in an attempt to minimize the fracturing of knowledge passed on orally (Brown & Strega, 2005; Smylie, 2001). Indigenous knowledge and the transfer of knowledge are not considered a product to be owned, divided, or controlled, "but a living process to be absorbed and understood" (Battiste, 2002, p. 15). Throughout the presentation of the findings, relevant literature will be incorporated to support or counter study findings.

### **Finding Our Way**

The theme, "Finding Our Way" with two sub-themes identifies how Aboriginal women are finding their way by paying attention to and taking care of their health, and the health of their families and communities. The sub-themes are: a) "Taking Care of Our Health" and b) "Spreading the Word with Family and Community Members."

Women described being committed to taking care of their health by seeking knowledge and becoming educated and by sharing knowledge with family and community members.

### "Taking care of our health."

Many women explained the importance of taking care of their health by taking action to address some of the determinants of health, even though they were confronted with considerable historical, economic, and social disadvantage and adversity. Some women talked about taking the initiative to take care of their health by getting educated, being employed, and implementing early childhood learning. Other women told stories

about returning to cultural and traditional ways, revitalizing their language, and passing along parenting skills. Still other women talked about seeking knowledge about healthcare as a way of taking care of their health. Some women talked proudly about returning to school for upgrading or to attain a diploma or degree so that their lives and the lives of their children would be enriched. For example, Charity, who attended a residential school, continued with her education at university and then became employed in her community. She accomplished this despite having been in a residential school and having witnessed a lot of abuse and neglect by educators.

I went to university, I was in a residential school for about 11–12 years, I'm what you call a lifer, I did life there from the time I was 4 'til the time, well I got out of there 2 years before the school closed, so they still considered me as a lifer. . . . But when I came back I came back as the education counselor.

Continuing on with post secondary education and obtaining employment was a way that several women described as being able to take care of their health. Muriel talked about being a mother of two children, graduating from university, and then taking a job at the health centre in her community so that she could provide for her children and their health. Taking care of her children and their health was talked about as an extension of taking care of her own health. Muriel stated "I want a good life for my children . . . and to take care of our health."

Another demonstration of women taking care of their health was exhibited by women taking action to return to their cultural and traditional ways and language. A few women provided examples of how they were keeping their culture and traditional ways alive by using traditional medicines, organizing ceremonies in the community, and participating in the development of a First Nation museum. A few women made visible

the link between keeping their traditional ways and culture alive with assisting women to take care of their health and the health of their community members. Aaden spoke about her mother, a residential school survivor, who used to be embarrassed about some traditional ways. Nevertheless, she decided to return to her traditions by doing bead work, picking herbs and traditional healing plants, and using traditional medications which affected her sense of well-being.

My mom was embarrassed of like traditional things. But she's goin' back into that [traditional ways] now so, she does bead work and she does do baskets. No she doesn't do baskets, she does bead work. She's been recently just usin' Indian meds and she picks the medicine, so she's like pickin' it all back up again . . . She seems so much more alive now.

A few other women acknowledged that they were returning to their culture by either organizing or attending traditional ceremonies such as sweats, sweet grass ceremonies, naming ceremonies, and sun dances in their communities. It was important to some women to keep traditional and cultural ceremonies so that community members would be strong and healthy. Grace described how she was keeping her traditional and cultural ceremonies alive by organizing sweats in her community and teaching her children about their culture. She provides details about the types of cultural ceremonies that she facilitates in her community which she attributes to being important in taking care of herself, family, and community.

Spiritually, I run sweats for the community, I teach my kids a lot about culture and getting ready for different ceremonies 'cause we have different ceremonies, it's not just a sweat, we have new moon, we have sun dance, we have fasting, we have naming ceremonies, and Thanksgivings and so a lot of that takes a lot of work, so that's what I do with my family, with the community, or anybody that's looking for guidance in that area.

Charity, an Elder who attended residential school, explained about being active in keeping her culture alive. She was participating in the development of a First Nation museum which she believed would educate others about her culture and keep the traditions strong and vibrant and thus keep her community healthy.

The importance of good parenting and the passing along of parenting skills was another way that a few women were taking care of their health. Women told stories about being committed to their children and family as Aboriginal women were traditionally. Charity indicated the importance of being committed to parenting and educating parents so that they will be able to educate their children about life and health.

So you see that ripple effect happening. You're committed to your family, you're committed to your children. That's a traditional way; you take care of them. . . . I think if you can educate the parents, I think the parents should be able to educate the children, and that's the cycle you're striving for. Because then half your work is done as you're going along. Then you call that a success rate, if it continues on.

A few women demonstrated taking care of their health by making sure their own follow-up appointments for test results and treatments were made and keeping track of dates for healthcare appointments, such as Pap smear screening. While some indicated that a phone call reminder from the health centre assisted them in accessing Pap smear screening, a few others indicated that they did not rely on a phone call from the health centre, but instead kept track of appointment dates themselves. For example, Aaden stated, "I know when my appointments [for Pap smear screening] are due, usually I'll remember, and I keep track."

Many women also cited examples about obtaining educational information and knowledge about Pap smear screening from multiple sources such as printed materials,

videos and television commercials, and educational sessions and workshops by healthcare professionals in order to take care of their health. However, generally women disclosed that many of these educational materials were not developed specifically for Aboriginal women. According to Nakita, "you don't really see a lot of pamphlets with an Aboriginal woman on it; it's usually White women or Black women or Chinese." Only a few women had seen pamphlets and posters developed specifically for Aboriginal women, which they perceived to be motivators for some women to attend Pap smear screening. Aaden told about some Aboriginal women dressed in traditional regalia from her community being on a Pap smear screening poster. Although the poster was written in English and not in her Mi'kmaq language, it still made an important point to Aboriginal women about the importance of accessing Pap smear screening. Charity also told about the importance of having educational tools and pamphlets developed specifically for Aboriginal women that prompt women to think about or to access Pap smear screening. Having more Aboriginal women included in educational materials and on posters empowers other Aboriginal women to take care of their health because women can relate to other women with similar life contexts and traditions. According to Desiree, "sometimes people know those people [on the poster], so it's like wow; they got it [Pap] done, so should I."

The importance of women recruiting other women to take care of their health by accessing Pap smear screening was also echoed in some of the women's stories. Giselle spoke about herself as being an ambassador for Pap smear screening and she recruited everyone she could to have Pap smear screening completed.

Well anybody I talk to and I'm able to have that conversation with I tell them go for it [Pap screening] and I tell them it's not so bad, but that's just anybody I can have the conversation with.

Likewise, Desiree demonstrated the importance of telling her sisters about taking care of their health and then their friends would be told as well. This highlights the importance of women informing other women about the importance of taking care of their health.

Inherent in some women's accounts were examples of the importance of taking action to address Mi'kmaq language loss and the implementation of early childhood learning, as ways of taking care of health. Some women identified that the revitalization of their Mi'kmaq language or "mother tongue" was very important in bringing back their culture and traditions to restore health and collective pride. Women able to speak and read their language spoke about teaching their children the language at home and communicating to their children in Mi'kmaq.

Gisell: In my own community, I didn't speak the language with my friends, but determined I learned the language . . . My husband is full Mi'kmaq speaker, and so I'm getting after him to talk to the kids in Mi'kmaq, my kids speak English because of the dominant figure, me, which is a shame, when they mostly been with their father. I been going to school, but there is that dominancy of me in there, so I really regret it, now I'm embarrassed.

Aaden says that her mother was in residential school and lost her ability to speak Mi'kmaq. However, after returning to her community and realizing the importance of her language, started speaking Mi'kmaq again. Also, Aaden has a 3-year-old niece speaking Mi'kmaq fluently because her grandmother is teaching her the importance of speaking her language. Aaden says "My niece speaks Mi'kmaq fluently. She's 3."

Many of the women in this study were making efforts at restoring and taking care of their health by taking action to address some of the social determinants of health by

getting educated, being employed, implementing early childhood learning, returning to cultural and traditional ways, revitalizing their language, passing along parenting skills, and seeking knowledge about healthcare. Social determinants influence health, healthcare access, health inequities, and health outcomes for Aboriginal individuals, families, communities, and nations (Loppie Reading & Wien, 2009). When people experience a lack of access to the basic essentials of life such as food, safe shelter, and education, their health is compromised (McGibbon & Etowa, 2009).

Findings from this study offer a counter balance to much of the existing epidemiological literature that implies, perhaps unintentionally, that Aboriginal women do not take care of their health or make personal efforts to take care of their health. Much of the existing research focuses primarily on women's low rates of Pap smear screening, high rates of cervical cancer, barriers to accessing healthcare services, strategies to improve Pap smear screening rates, and the current reproductive health issues confronting Aboriginal women (Black, 2009; Clarke et al., 1998; Hislop et al., 1996; Johnson et al., 2004; NAHO, 2010; O'Brien et al., 2009; Peters et al., 1989; Steven et al., 2004; Young et al., 2000). Graham and Stamler (2010) reported that epidemiological statistics solely do not impart a complete representation and reality of the current state of Aboriginal health, and "are not sufficient evidence on which to base effective intervention and health programming" (p. 8). Much of the existing epidemiological data and statistics have the propensity to focus on the deficits of Aboriginal health and neglects to highlight the strengths and resiliency of Aboriginal people and their communities. Some of this epidemiological research tends to place

blame on the women and infers that personal and lifestyles choices are reasons for their low rates of accessing Pap smear screening or having poor health. It neglects to consider broader perspectives or to research the efforts and strategies that Aboriginal women are implementing to take care of their health by accessing Pap smear screening services.

Deficit-focused findings may potentially construct and reinforce stigmatizing and colonial images of Aboriginal women that can impact negatively upon knowledge about Aboriginal women and their health behaviors (Dion Stout, 2012; O'Neil et al., 1998).

Epidemiological research needs to be balanced with other types of research that considers factors and contexts of Aboriginal people's lives such as the social determinants of health, history, abuse, and politics that impact access to healthcare and inequities in healthcare services for Aboriginal people. For example, Brown et al. (2012), drawing on findings from a community-based qualitative study, demonstrated that the dispossession of land and language threaten the well-being and health of First Nation people and can worsen existing illness.

Although there are women in this study that did not have enough knowledge about Pap smear screening; others indicated that women are not only seeking knowledge and information about Pap smear screening, they are communicating it to their daughters and other women in the community. This is incongruent with much of the existing literature that portrays Aboriginal women as lacking knowledge about health, particularly Pap smear screening (Amankwah et al., 2009; Clarke et al., 1998; Hislop et al., 1996; NAHO, 2010; O'Brien et al., 2009; Steven et al; 2004). Such a portrayal is not reflective of all Aboriginal women and their life contexts. The literature primarily focuses on the

lack of knowledge from the women's perspective, and often does not consider the reasons for the lack of knowledge from broader historical or socioeconomic contexts. This situates ownership of obtaining knowledge solely on the women, and not on healthcare providers or the healthcare system. Women in this study are communicating that many researchers and healthcare providers are saying that Aboriginal women are lacking knowledge, yet they are not asking women what they want to know or the types of knowledge that would be appropriate for them. Furthermore, when women are provided healthcare literature it is not always culturally appropriate or representative of Aboriginal women and often literacy levels are not appropriate. How can healthcare professionals and researchers expect Aboriginal women to have knowledge when they are not being consulted to participate in knowledge development or knowledge translation? According to Browne and Dion Stout (2012), health research needs to be conducted in partnership with Aboriginal people and must include approaches that consider "critical analyses of root causes of health, social, and health-care inequities; generation of knowledge to mitigate health and health-care inequities; integration of Indigenous epistemologies and decolonizing perspectives; and decolonizing approaches to policy development" (p. 9).

Prior to colonization Aboriginal women were viewed as powerful by their communities as they provided care for children and Elders, and some women were considered powerful healers as they held traditional sacred knowledge about healing herbs and plant medicines that were considered extremely valuable to community members (Kinnon & Swanson, 2002). Due to assimilation, colonization, and residential schools, traditional medicines and healing practices that were previously passed down by

oral tradition were lost resulting in reliance on Western medicines and healing practices (Battiste, 2000; Waldram et al., 2006; Warry, 2007). Some women in this study acknowledged that they are returning to their traditional ways and ceremonies as a means of taking care of their health and the health and well-being of their community. According to Dion Stout (2012), there is a shift by Aboriginal people to achieve health and wellness by "adopting traditional perspectives, correcting power imbalances, and riding new waves such as health, social, and health-care equity are increasingly becoming part of the consciousness and health actions of Indigenous people" (p. 13). Aboriginal people are resilient and are channeling their energies towards a positive goal of healing, while reclaiming what was previously denied to them (Dion Stout et al., 2001).

# "Spreading the word with family and community."

This sub-theme represents the importance Aboriginal women placed on sharing knowledge and their wisdom about health and Pap smear screening with family, friends, and community members. Some women talked about the knowledge and advice they would share with healthcare providers and policymakers that could make Pap smear screening a more positive experience, and potentially increase access to Pap smear screening. A few women perceived sharing words of wisdom and advice about Pap smear screening to be their personal responsibility as women, mothers, aunts, grandmothers, and friends, as it was traditionally. This is supported by Moriah who stated that, "We learned about it [Pap smear screening] through word of mouth from

family," while Kayla stated, "We learned [about Pap smear screening] from family and friends' stories."

It was evident that some women in the community were taking on roles to enable more formal sharing of education such as being on posters or presenting at health conferences; this was seen as important for raising awareness and recruiting Aboriginal women to Pap smear screening. Faith passed on a story about an acquaintance who attended health conferences and appeared on posters sharing her knowledge about the importance of Pap smear screening and prevention of cervical cancer. She spoke in a loud voice and smiled as she spoke of her acquaintance and her accomplishments.

So I heard a little spiel from her, and that was probably the first time I ever really heard like cancer prevention associated with a Pap. She was going to a health conference. And they asked her to participate at the health conference 'cause she's like on the posters and stuff . . . I'd say that's probably the first time I really heard of it as cancer prevention, and that would've been like 4 years ago. I thought it was cool that she was involved.

When asked about whether seeing another Aboriginal woman on a Pap smear screening pamphlet or poster would encourage women to access Pap smear screening or not, Mya replied in an optimistic and similar manner as was mentioned earlier in the subtheme "Taking Care of Our Health," reiterating that it would make a difference. She replied that it would seem important for them to attend and they could relate to those women on the pamphlets.

Some other women talked about their informal sharing of knowledge and wisdom about Pap smear screening with other community members after they had a Pap smear screen completed. Mylynn, who had cervical cancer, communicated that she not only will talk to her own daughter, but also friends, cousins, and nieces about the importance

of having regular Pap smear screening. She even takes it upon herself to make appointments for other women who have not attended regularly, so that they will not experience health issues as she did in the past.

I do that [talk with] now with my friends. I even get mad at my nieces and my cousins. If I find out they haven't been to a Pap in over a year, I'll be on the phone making the appointment for them. But just because of my personal experience. Like, I will tell my story. And if I had to put a fear in them I would, because I wouldn't want anyone to go through what I went through.

Aaden, who lives in the community and works at the health centre, tells a story in a proud manner about noticing more women accessing Pap smear screening at the health centre. She communicated that prior to accessing Pap smear screening some Aboriginal women consult with her to ask questions and obtain knowledge that she has regarding Pap smear screening. She also suggests that she wants to alleviate women's fears about accessing Pap smear screening.

Aaden: Some women would come in and ask my opinion. They ask me well is it [Pap screening] good? How is she [healthcare provider], and I'll say oh it [Pap screening] doesn't hurt. She's pretty good you know. . . . I don't want them to be afraid when they're goin' in [for screening], Who wants a person to be terrified?

Again, this example illustrates the importance of verbally obtaining knowledge, and the valuing of wisdom and knowledge from a familiar female community member. In addition, this example also illuminates that alleviating fears is an important strategy for encouraging Aboriginal women to access Pap smear screening services. Not all women agreed that the sharing of knowledge and wisdom from a family member or friend would definitely make a difference in their accessing of Pap smear screening.

Faith: I don't know if it would make a difference, I don't know if I've ever asked my mom if she goes for them or not. I don't ever remember talking to her about it really.

Spreading the word about Pap smear screening to daughters and other community members was highlighted as being extremely important for encouraging women to access Pap smear screening. The sharing of wisdom and knowledge about healthcare, especially the accessing of Pap smear screening with family, community members, and healthcare providers demonstrated that Aboriginal women were making conscious efforts to take care of their health. Women in the study shared knowledge and wisdom about personal experiences by storytelling, and shared information attained from resources such as pamphlets, brochures, and healthcare providers. Traditionally, sacred knowledge and wisdom about health and healing was passed from one generation to the next by telling vivid accounts of experiences and sharing what was learned from those experiences (Barnes, Josefowitz, & Cole, 2006; Weber-Pillwax, 2004). According to some of the literature many of the traditional ways of knowing and the passing of knowledge and wisdom about the health and healing practices of Aboriginal people have been socially and culturally disrupted by Western medicine and colonization (Browne & Smye, 2002). Even though some women in this study agreed that there has been a loss of some traditional ways and knowledge, they are continuing to use storytelling with family and community as a path to taking care of their health and have suggestions for healthcare providers and policy makers for improving Pap smear screening access.

From this study it was evident that Aboriginal women are forced to seek knowledge primarily from Western sources about healthcare and healing which differ from their traditional knowledge and ways. Aboriginal women are relying on Western educational tools and materials that are not always representative or reflective of the

realities of Aboriginal women (Battiste, 2000; Sherwood & Edwards, 2006). The findings from my study indicate the use of brochures and educational materials that are reflective of Aboriginal women's lives for educational purposes positively influences Aboriginal women accessing Pap smear screening. Similarly, Black (2009) suggested the importance of Aboriginal role models, having the faces of Aboriginal women evident in printed materials and brochures, and the telling of success stories that reflect Aboriginal women. Having Aboriginal role models and faces of Aboriginal women on printed materials may assist in dispelling myths and misinformation regarding cervical cancer and heightening awareness about the benefits of prevention and Pap smear screening (Black, 2009; NAHO, 2010). This demonstrates the importance of having knowledge that is relevant and appropriate for Aboriginal women and encourages "the empowerment of Aboriginal women to take control of their own health care needs" (Black, 2009, p. 174). Interestingly, no one woman in my study talked about accessing the internet for information about Pap smear screening, despite the fact there were younger women in the study who would likely be more accustomed to using technology.

#### **Summary**

Women's stories acknowledged that they are making efforts to take care of their health, despite their life circumstances and statistical data that provides a grim picture of cervical screening rates among Aboriginal women. In some instances, women communicated stories about furthering their education, becoming employed, keeping their language alive, returning to their culture, and the passing along of parenting skills,

all of which they regarded as contributing to taking care of their health. A few other women took care of their health by keeping track of appointment dates and making their own follow-up appointments, while a few others relied on the physician's office or healthcare centre to assist them in taking care of their health by reminding them of appointments. Women disclosed that they were restoring their health by seeking knowledge about Pap smear screening, and some women communicated the importance of recruiting others in the community to improve their health.

### Our Understanding and Perceptions about Pap Smear Screening

In the second theme, Aboriginal women expressed a multitude of beliefs, experiences, and feelings about Pap smear screening. Women also described cultural ways of thinking about the body and self that impacted their experiences with Pap smear screening. The sub-themes are: a) View of the Body and Self: "It's sacred"; b) "Paps Important or Not?" and c) Pap Smear Screening: "Feeling Violated."

### View of the body and self: "It's sacred."

In this sub-theme Aboriginal women explained their views of the body and self through a cultural lens. Some described that Aboriginal views and conceptualization of the body and self were dramatically different from Western perspectives that tend to perceive the body as made up of independent parts (MacDonald, 2008; Gadow, 2000). For example, several participants described that an Aboriginal view of the body is holistic and encompasses physical, emotional, mental, and spiritual domains that are not viewed

as distinct or separate. Some women's perceptions and conceptualizations regarding the body and self were described as not only holistic, but rooted in culture and traditions.

This was evident when Faith stated, "the body is like you said, holistic, we're all one, not a piece here, piece there."

Although some of the women in the study talked about how they believed that Aboriginal and Western views of the body and self were different, others did not. As one woman indicated, "Not all First Nations people view the body and self in the same way" (Faith). In essence, the point was made not to essentialize all Aboriginal people as having the same view of the body and self; views differed depending on whether women were traditional or not.

Nakita: Well some people that are traditional, your body is your temple. You have to treat it good. But some Western people are just like, this is just my body for now. I'm not gonna be here forever, so there's no point in taking care of it. So people have different points of view of how they view their own body. First Nations view their bodies differently because it all depends too if they're into their culture or not.

Some women in the study expressed the importance of treating and talking about the body in a respectful manner and with pride. Most of the women did not use the term cervix when talking about Pap smear screening, even when I used the term, but instead referred to the area of the body where the Pap smear screening is completed as being a "private area." A few women added that, while a private area is where Pap smear screening is completed, they did not associate it with culture or being Aboriginal.

Desiree: Well, I think with every culture it is private. I don't really feel like there's a cultural thing, it's a private area and nobody is supposed to go looking down there.

A smaller number of women described it as being a "sacred area." Women who told stories of the area of the body where Pap smear screening is completed as being a sacred area tended to have traditional, cultural, or religious beliefs. Muriel, who identified herself as being very traditional and an active participant in cultural ceremonies indicated that Aboriginal women are considered sacred beings and as such should treat themselves and be treated by others with respect. She explained, "we view it [the body] like we're sacred, women are sacred beings, and we are to be treated respectfully, we're to treat ourselves respectfully."

One middle-aged woman told a story about the body and being on her moon-time (menstrual period) as being sacred.

Mylynn: Yes they are very sacred, and that nobody else should be there, but your significant other. . . . A period is your moon-time. We go by moon time. That's when mostly all women have their periods is during moon, full moon time. Your moon time is your menstrual cycle, but it fluctuates with the full moon, and that's when us women are on it and it's a sacred moment. And we don't involve ourselves with ceremonial stuff. You're not allowed, you're forbidden. It's a cleansing time for you. That's why it's so sacred.

Another woman viewed that part of the body as sacred because "that's where your baby's life comes through, of course it's sacred" [Giselle].

The belief that the body was sacred was not shared by all Aboriginal women. A few women revealed stories about being taught to be ashamed of their body and that the body was "dirty," especially with regards to their menstrual period.

Giselle: Because we were taught, well I know growin' up to hide myself. When I came to my grandmother's we grew up with seven, it was her daughter and seven sons, so we were brought up to be ashamed of our bodies, even the pads, we weren't puttin' them in the bathroom, and we weren't allowed to wear halter tops because of uncles so that made me grow up ashamed. . . . And I remember my grandmother, she always said don't invite trouble, so I think it was all

preventative measures. She was from the older generation and nobody touches you.

In this quote from Giselle, it may be inferred that her grandmother was attempting to protect her from being sexually abused or violated by teaching her to be ashamed and to hide her body so that she would not be as appealing to males. Giselle also talked about not having a "becoming a woman ceremony" as some other girls had in her community. This ceremony was considered a sacred celebration of girls' responsibilities when entering womanhood and their ability to bear children. Prior to colonization, Aboriginal cultures did not view the body in a negative context and women's bodies were respected and celebrated (Reeves, 2008). Women's bodies were honored in traditional ceremonies and violence against women was viewed as a social taboo to be punished (Kinnon & Swanson, 2002). With colonization came Euro-Christian values of patriarchy and White dominance that devalued women and women's bodies, which resulted in violence and abuse against women (Reeves, 2008). This is connected with the sub-theme "The Scar Has Been Placed" in theme 3, which further demonstrates the long lasting impacts of colonization and historical trauma on Aboriginal women.

Another topic that resonated in the stories of the women was whether or not Pap smear screening and "private" or "sacred" areas of the body were topics that should even be talked about. Most of the women acknowledged that it was a community norm that Pap smear screening and private or sacred areas of the body were not topics that were appropriate to talk about in their communities. Some women attributed culture as a reason for not discussing such topics and a few women related this reluctance to the legacy of residential schools and abuse. Past experiences as a child may have influenced

how women talk about the body as an adult. Past experiences served as a reference point to judge the appropriateness of speaking openly about anatomical body parts or Pap screening. The legacy of residential schools and past abuse were experiences that influenced how open or not women were about topics such as the body. A strict environment that was often abusive and did not provide for discussion of personal issues not only taught women to be silent about sexuality and female anatomy, but also influenced how these women then communicated to their own children about such topics.

Clara: It's not something [Pap smear screening] that you would talk openly about normally in our culture.

Giselle disclosed a somewhat different view indicating that culture was not the reason women did not use anatomical language saying:

I don't think anybody any culture sits down and actually has a talk about their cervix, really. I haven't heard any anyway.

On the other hand, a few women were in agreement that Pap smear screening and topics related to sexuality and Pap smear screening were taught and talked about in their homes. According to Clara, "When you're growing up in a certain house you're taught that type of stuff."

Traditionally, in Aboriginal cultures children were taught by their families and Elders about their bodies and how to take care of and respect their bodies (Kinnon & Swanson, 2002). However, due to residential schools and the fracturing of families, teachings passed down to children about the body were lost. Again, this can be linked with the sub-theme, "The Scar Has Been Placed" in theme 3, and further demonstrates the long lasting impacts of residential schools on Aboriginal women and families.

Several of the participants described women as being sacred due to their ability to have children and it was inferred that this made women powerful. Traditionally, it was thought that Indigenous creations and mother earth resulted from a female spirit which viewed them as being sacred and powerful (Gunn Allen, 1986). The ability of a woman to give birth and raise children positioned women in an esteemed, sacred, and respected role in Aboriginal culture (Carroll & Benoit, 2004; Gunn Allen, 1986; Kinnon & Swanson, 2002; LaRocque, 1994; NAHO, 2004).

Analysis of the findings from this study revealed that variations in women's views about the appropriateness of speaking about Pap smear screening and sexual organs were linked to past experiences and family role modeling. Study findings revealed that for some, Pap smear screening and sexual organs were topics that were not appropriate to be talked about in communities. O'Brien et al. (2009) found similar trends among Cree First Nation women. Several women in my study manifested reluctance to talk about sexuality including the genitalia and other pelvic body parts. However, in many Aboriginal cultures historically, teaching and knowledge acquisition about the body and sexuality was passed on from one generation to the next through oral traditions (Barnes et al., 2006) by way of narratives, storytelling, talking circles, and sharing circles (Weber-Pillwax, 2004). The body and sexuality were considered a gift from the Creator and not perceived as shameful or the body being dirty (Kinnon & Swanson, 2002; Reeves, 2008). Adults were responsible for teaching children in their communities openly about their bodies, the moon time, and other sexual and reproductive passages and ceremonies (Kinnon & Swanson, 2002; Loppie, 2007; Reeves, 2008). Further, birthing knowledge

was also considered important and no one was sheltered from birthing knowledge and teachings. European contact brought the destruction of traditional teachings about the body and sexuality. With the loss of traditional teachings about the body and sexuality came negative sexual health outcomes and abuse, and devaluing and shame about the body ensued.

None of the women in this study talked about the impact religious teachings, those of the Catholic church for example, may have had on their beliefs and values regarding how they view the body and self. Missionaries and priests were some of the first European people to sustain contact with Aboriginal peoples in Canada and attempted to convert Aboriginal people to Christianity (Waldram et al., 2006). In eastern Canada it is reported that elements of Catholicism were accepted by Aboriginal Peoples (Waldram et al., 2006). Aboriginal traditional healing and ceremonies to celebrate sexuality were condemned by Catholic missionaries and replaced with teachings about sex as sin and everlasting damnation (Fiske, 1996). One community in the study did have a Catholic church, but no one mentioned the church which was crowded on more than one occasion when I attended.

### "Paps: Important or not."

This sub-theme describes women's understandings and perceptions about the importance of Pap smear screening and the impact this has on their accessing of Pap screening services. Many women in the study communicated similar, yet at times diverse and conflicting perceptions, about the importance of Pap smear screening. Several

participants held the perception that Pap smear screening, although uncomfortable and at times embarrassing, was important. Kayla, when talking about her reasons for accessing Pap smear screening, stated, "I don't like it, but I know it's important to make sure health-wise everything is OK in your female area."

Several of the participants who were mothers talked about needing to stay healthy to care for their children, and for them Pap smear screening was "unpleasant, but necessary." For example, one woman expressed it this way.

Nakita: No, I don't really feel like it's [Pap screening] bothering me or anything like that, it's just I know that it's helping me [Pap] and then you know they're just doing it to make sure that I'm healthy, which is good because I have three kids to take care of. It was uncomfortable, but I just made sure that they got it done just 'cause I want to make sure I'm healthy.

More than a few women also talked about the importance of accessing Pap screening to prevent disease through early detection. Muriel, who views the body as "sacred," communicated that she went regularly for Pap smear screening, so that if there was anything abnormal it could be diagnosed and treated early.

I don't want to find out that I have cervical cancer, I want to make sure that I don't end up with any kind of disease . . . and if so they can get it early.

Mya indicated how it was important for her to not only attend regular Pap smear screening but for her to also be a volunteer for a healthcare provider in her community to practice the skill, so that the healthcare provider could become certified to complete Paps on other women in the community. Mya believed in being a role model for other Aboriginal women and that women should be offered Pap smear screening in their community. She also went on to speak in a serious tone about the importance of her and others being able to access a female healthcare provider for Pap screening.

Well I just started going to Pap smears in 2000 when we got that nurse practitioner. She needed volunteers 'cause she needed so many clients to get her certification, so I volunteered with her, I never went to a man again. I found it very easy when a woman does the Pap smear instead of a man . . . It will help other women to get for a Pap, if it is in our community.

While many women consistently reported their main reason for accessing Pap smear screening was to remain healthy, importantly over half of the women indicated their reason for accessing Pap smear screening was because they themselves had abnormal Pap results or a relative or a community member they knew had cervical cancer. This demonstrated that knowing someone or having had cervical cancer themselves was motivating for some women to access Pap screening.

May: I think it's [Pap smear screening] very important; like I hear of people dying of cervical cancer, and you know this lady had it, and she thought it was cured and all that but then it came back, and she passed away . . . that's why I now go.

A few women disclosed that having cancer themselves or finding out others had cancer was a reason for accessing Pap screening on a regular basis.

Nakita: But I had to deal with cancer cells now, so that's why I go to my Pap test all the time. Yeah the most recent one was my aunt, she passed away probably about 10 years ago maybe, and she just was one of those woman that just felt that there was no point of going [for Paps] until she found out she did have cancer [cervical], and then by the time then it was too late and then the cancer just spread through her whole body. That's why I go regularly.

In a few other instances, fears of having cervical cancer was perceived to be a reason for not accessing Pap smear screening. A few women spoke about how fears of being told that they had a disease, like cervical cancer, prevented some women they knew from accessing Pap screening.

Aaden: I remember this one woman. She was 46, 47 years old at the time, maybe older. She didn't go, it was her very first Pap test and she was terrified of having

cancer. She was terrified goin' in. She went in. She got her Pap done. She come out, it wasn't that bad she said. She was relieved.

Others, however, identified that not all women viewed accessing Pap smear screening as important, valuable, relevant, or necessary. They indicated this was the case with some older and many younger women in the communities.

Aaden: And probably the older women, I hear a few people say that they don't think it's important for them to go. They don't realize, you know, at any age that you're supposed to go for Pap smears.

Some women also perceived it to be important to access Pap smear screening services after starting to have sexual relations; others communicated the importance of having Pap smear screening so that they would be able to become pregnant as well as during pregnancy. However, Clara went on to describe that she believes that women should access Pap smear screening even when they are not pregnant or sexually active.

I think that everyone should do it at all times, like after, even if you're not pregnant or not sexually active.

Notably, one woman perceived that she felt it was important to attend Pap smear screening because she worked in healthcare. "Why do I participate, it's part of my job. I work in the healthcare field" (Mya).

The women identified a number of reasons why some women in their communities were not accessing Pap screening services. Other women identified that being shy was not necessarily a reason that prevented all women from accessing Pap services. This is supported by Kayla who said, "My mom, she doesn't really talk into details too much about anything and she's shy, but she does get Paps done."

Lack of knowledge or education about Pap smear screening was viewed by some as another primary reason why some women in their community did not access Pap smear screening.

Clara: I just wish it would be easier for people to understand, they shouldn't be afraid to ask questions about it [Paps]. It is a big topic. It's stuff [Paps] that we don't know about. Especially older women, they are all just quiet and timid, didn't really say much. I just think there's a lot that everyone can learn about this.

In one example, a woman revealed she did not agree with her aunts who did not access Pap screening. She explained that some of her aunts had never gone for Pap screening because they felt healthy and were practicing safe sex. Notably, another woman, a residential school survivor, attributed her experiences with regimes and routines learned while at residential school to be a primary reason for her regular attendance with Pap smear screening.

Charity: Because of this cyst, I made it a priority to go to have Pap smear, but that kind of regimen is just, like myself. I might not even be a good candidate for you because I would say that's something that comes from the residential school, repetition, you go do something, and you do it on a constant base, and so that's probably why I myself as an individual person did make a point of going to have Pap smears.

This differs from other women's perceptions of how residential school impacted Pap smear screening access, which is discussed and linked to the next sub-theme "Pap Screening: Feeling Violated."

It was evident from the women's stories that there were multiple understandings and perceptions about the importance of Pap smear screening and variation in women's reasons for accessing or not accessing Pap smear screening services. The variation in importance attributed to Pap smear screening and the reasons for accessing or not

accessing Pap smear screening can be linked to variation in how the historical and socioeconomic factors have impacted women, the various roles and responsibilities of women, and how they view their bodies which were discussed in previous sub-themes. Although many of the women in this study communicated Pap smear screening to be uncomfortable and considered Pap smear screening to be frightening, some continued to regularly access the service. Findings also indicate that some women accessed Pap smear screening to remain healthy to care for their children, to be able to have children, and when pregnant, to prevent cervical disease through early detection. The importance of a woman taking care of herself when she was pregnant or to be able to have children was also highlighted previously in the sub-theme "Cultural View of the Body and Self: 'It's Sacred.'" Furthermore, similar to what others have reported in studies with Aboriginal women (Black, 2009; Letendre, 2008; O'Brien et al., 2009), fears about having cervical cancer both prompted some women in this study to access screening and prevented others from doing so.

Reasons for not participating in Pap smear screening for some Aboriginal women in this study were that Pap smear screening was not perceived as necessary, valuable, relevant, or important. Another factor that impacted access was whether women had knowledge or education about Pap smear screening. Likewise, Black (2009) attributed the low participation of some Aboriginal women in Pap smear screening services to their lack of knowledge about the procedure, shyness, and overall discomfort with talking about or undergoing the procedure.

# Pap smear screening: "Feeling violated."

This sub-theme represents Aboriginal women's accounts of their negative experiences with Pap smear screening. Some women reflected back on their experiences with Pap smear screening and described explicit personal stories where they felt that Pap smear screening was violating. Some women who described "feeling violated" linked it to prior experiences of abuse; others did not articulate this experience. Six of the 16 women in this study disclosed being sexually abused.

The majority of women talked about feeling physically uncomfortable, psychologically embarrassed, and a few even disclosed feeling mortified during the procedure. The following excerpt described the feelings of being violated experienced by Avril during Pap smear screening which she attributed to the sexual abuse she had experienced as a child. She spoke in a quiet voice and looked at the floor as she relayed her story and described being afraid of going for Pap smear screening.

Like I said especially around a lot of the abuse and all of the everything that filters out of residential school because, and there's a lot of abuse and there was a lot of things like that happened, that makes Paps uncomfortable. You got people down there that's . . . no business [pointing to her genitals]. I don't like it [Paps], a part of it is because I was abused as a child. My abuser went to residential school. He wasn't the only one, but he's one [abuser]. . . . So I'm so uncomfortable and afraid with people down there [pointing to her genital area].

Avril is describing the abuse that has filtered down from residential school through her family and how it negatively impacts upon her Pap smear screening experience. Although she experienced sexual abuse and finds the procedure difficult, she attends Pap smear screening regularly so that she will remain healthy and be able to continue to care for her children.

A few other women also told stories about feelings of being violated during the Pap smear screening procedure and several of these women disclosed that they had experienced sexual abuse in their past. Giselle communicated that "Sexual abuse could be a reason for our women [Aboriginal] not to go [for Pap smear screening]. It could bring up bad memories from the past."

Giselle is describing that some women seemed to make a conscious choice not to access Pap smear screening as a way to protect themselves from feelings and fears originating from past sexual assaults or abuse.

Similarly, another young woman described how Pap smear screening was associated with sexual activity and sexual abuse.

Faith: You know sexual abuse is rampant in our communities and to me Pap smear screenin' is always been just so associated with sex. Like and I think that's kind of the message that's been drilled into our communities. Like that's all I ever remember doctors tellin' me about when I was a teenager, and I don't know if it's just 'cause we were teenagers or we were younger or if it was 'cause we're Aboriginal, but you know it was always like oh you gotta get this done if you're sexually active to prevent STDs. So, you know the whole prevention associated Pap testing with sex really. And a lot of my friends I think that's what they've always associated it [Paps] with sex too.

In this excerpt, this young woman described that Pap smear screening was linked to sexual activity. A message was conveyed that Paps were a punishment or consequence of sexual activity rather than a means to promote women's health.

The women who were never sexually abused conveyed stories about their first experience with Pap smear screening which was when they were teenagers and/or pregnant. They explained in detail about how they were terrified, tense, scared, lacked knowledge about Pap smear screening, and did not understand what was happening to

them. Aaden talked about feeling "completely terrified" and in pain when she had her first Pap screening. She recalled that she was 15 years old and pregnant with her first child and not informed about Pap smear screening. She also relayed that this first experience made her afraid of accessing Pap smear screening again. As she spoke of her first Pap smear screening experience, her body became tense and she squeezed her hand into fists, while leaning forward in her chair.

My very first Pap smear I was 15 years old. I was pregnant and a male doctor did it at the hospital and I seen this . . . The specula. I went what the hell is he doin' with that thing? I was terrified 'cause nobody explained to me and I was pregnant. I didn't know what he was gonna do with that thing. They [healthcare professionals] were tellin' me calm down, just relax. It was the most painful experience of my life. I was scared and then after that I was scared of Pap smears. . . . I was terrified.

A few other women talked about negative and violating first experiences with accessing Pap smear screening later in life. Clara talked about her first experience with Pap smear screening not being until she was in her 30s, after she had children and she went upon the advice of a male physician. She disclosed that she hated to go for Pap smear screening and recalled it as being a very painful experience, gritting her teeth at times as she spoke in a loud voice.

I hated going for it, [Pap screening] every time I hated going for it. For some odd reason, every time I went for a Pap smear it always hurt, and that was the big thing . . . that Pap smear thing is not a nice thing to do . . . it was terrible.

Muriel explains that although she knows Pap smear screening is good, it does not seem right to her that healthcare providers educated in Western society have the right to disrespect and "be in a sacred area of Aboriginal women." She referred to Western society continuing to do whatever they want and believe to be right to Aboriginal people,

even when it is intrusive and violating. This notion of Western society being intrusive to the body was also communicated by a few younger women as well as Elders in both communities.

Not knowing and understanding about Pap smear screening often led women to have negative experiences and feelings of being traumatized and fearful. For some Aboriginal women Pap screening generates distress and feelings of being traumatized because having the test triggers concerns that there is something wrong, especially when the results are not communicated. Mylynn described physical discomforts and articulated the extreme fear she experiences about what the outcome of the procedure will be. She described herself as "being scared of the outcome, very scared, like my mind would go crazy." For this woman, the trauma is made worse by "having a male physician look down there" and she copes by talking herself into being comfortable "so I'm not tense for him 'cause it'll hurt me." Mylynn is communicating how, for her, having a male physician compounded feelings of being traumatized during Pap smear screening.

Aaden, an older woman, communicated that she felt terrified and traumatized, especially because she was not knowledgeable or informed about Pap smear screening.

I was terrified because that's the way it was like for my very first Pap. I was like; oh my God I was scared. Like I was practically traumatized from it, but I didn't know what a Pap was at that time. You know, I didn't know what it was. Nobody explained it to me. It was just like you just lay there.

Several women communicated that although they had never experienced sexual abuse they felt violated due to the type of equipment being used and the coldness of the equipment.

Muriel: Well it's like those clamps or whatever they use to open you up to get in

there, those are cold and metal, something that's not as cold and metally hard I don't know 'cause I find those are what makes the whole experience horrible, that one tool that they use.

Giselle, who had previously felt that Pap smear screening was violating acknowledged having a more comfortable experience when plastic equipment was used instead of metal. She expressed fears that the metal speculum may not be adequately cleaned during sterilization.

They have plastic ones. Yeah I know I was more comfortable with that because what freaked me out was the metal ones is being sterilized, so if they were to ask me which one you want I would take the plastic one 'cause it's in a disposable thing. The ones and that they're being cleaned, that would [put] fear me.

The findings from this study indicated that Aboriginal women have had negative experiences with Pap smear screening which some described as being violating and traumatizing. A few women also told stories about women in their community who had experienced sexual abuse and violence. Not accessing Pap smear screening was a way for some women to protect themselves from reliving past negative experiences with sexual abuse and violations. Even though some women in the study did disclose experiences of sexual abuse and violence, some continued to access Pap screening. Even women who had not experienced sexual abuse talked about Pap smear screening being a violating fearful experience and acknowledged that they were uninformed about the procedure. A few disclosed that even though they were informed about the procedure, they still remained terrified and afraid of the results.

Pap smear screening for some Aboriginal women can be viewed as an extension of colonization and the pain and suffering from sexual abuse and acts of violation that occurred in residential schools. These acts of violence and sexual abuse not only affected

residential school survivors, but their descendents as well. A potential additive effect of historical trauma and being sexually abused is having a Western healthcare provider, particularly a male, performing Pap smear screening. According to Gadow (2000), in mainstream healthcare women have no control over their bodies as they belong to the powerful experts that are providing care to them. Foucault described the body as the principal target of power whereby male dominance describes and controls women and women's health and health issues (Foucault, 1999). Western healthcare providers, particularly males, could be perceived by Aboriginal women as violators continuing on the violations and abuse of residential schools and colonization.

Add to this the positioning of the body during Pap smear screening—one of vulnerability with the woman naked from the waist down, lying on her back, with her knees bent, her legs spread apart, and her feet placed in stirrups. This may be considered a violating or an oppressive position, especially for women who have experienced past sexual assault and sexual violence (Van Til, MacQuarrie, & Herbert, 2003). Steven et al. (2004) reported that Ojibwa and Oji-Cree women found Pap smear screening to not only be degrading and extremely unpleasant, but also were more likely to experience shyness when being examined, and revealed feelings "of having their privacy violated" (p. 309). Steven et al. (2004) did not indicate whether any of these Aboriginal women experienced previous sexual assaults or abuse or what impact sexual abuse or assaults had on women's accessing of Pap smear screening.

A few women disclosed that they did not have adequate information about Pap smear screening, nor were they provided with adequate explanations of the procedure.

Some of the existing literature also highlighted the lack of knowledge and information that Aboriginal women had about Pap smear screening and some women not understanding what was happening to them during the Pap screening experience (Amankwah et al., 2009; O'Brien et al., 2009; Steven et al., 2004). In the present study, women linked a lack of knowledge and understanding of Pap smear screening with feelings of being traumatized or violated.

Notably, women demonstrated courage to move on from extremely violating experiences with sexual abuse and assaults to engage in Pap smear screening, a procedure that itself can be a violating experience. Women were motivated to access Pap smear screening to be able to care for themselves, their children, and their community; to be able to have children; and to prevent cervical disease through early detection. These motivations are linked to the previous sub-theme "Pap Smear Screening:"Important or Not."

#### **Summary.**

Aboriginal women's perceptions and understanding about Pap smear screening were varied and diverse and impacted by how they viewed the body and self, whether they perceived Pap smear screening to be important or not, and if they felt violated when they accessed Pap smear screening. Some women spoke about a cultural view of the body that they perceived to be different from Western perspectives and explained that the body was to be treated with respect and was holistic, not divided into individual components or parts as often viewed in Western society. Receiving Pap screening

services from male healthcare providers, particularly Western healthcare providers, having a history of sexual abuse and experiencing the effects of historical trauma can generate traumatic experiences for Aboriginal women during Pap smear screening.

Women detailed a wide variation in their experiences; some described having negative experiences such as feelings of being violated, terrified, embarrassed, uncomfortable, or self-conscious with a male physician. Several women described the male physician as though he was a violator who was continuing on the colonization, violations, and abuse endured at residential schools. Moreover, women explained how the equipment and healthcare providers' practice noticeably impacted their experience with Pap smear screening and citied explicit reasons for accessing or not accessing Pap smear screening services.

#### The Impact of History on Our Health and Healthcare Experiences

This theme is comprised of three sub-themes wherein women discuss the historical, social, political, and economic factors that influenced their health and healthcare and particularly their accessing of Pap smear screening services. The three sub-themes are: a) "The Scar has Been Placed"; b) Socioeconomic Factors; and c) "There are a lot of Issues on Aboriginal Women's Plates."

## "The scar has been placed."

This sub-theme represents the women's perceptions about the impact of historical trauma on their accessing of healthcare services, including Pap smear screening. Almost

every Aboriginal woman in the study described comprehensively the impact of historical trauma, particularly with references to residential school and/or colonization, and how this impacted Aboriginal people's lives and their access to healthcare and Pap smear screening services.

Although historical trauma has impacted and disrupted Aboriginal women's lives and health, they continue to thrive in less than adequate circumstances and struggle against negative forces that resulted from pain, suffering, and losses from residential schools. Two of the women were in residential schools themselves. The topic of residential schools was brought up by many women when they were asked about issues that impact their access to healthcare services and Pap smear screening or why some Aboriginal women may not be participating in Pap smear screening. Many women shared stories illuminating inequities in health and access to healthcare and the disempowering impact of residential schools.

Mylynn: And a lot are issues with trusting healthcare providers and the healthcare system, I think have been passed on from our history, from our ancestors that attended residential schools. Even when I am going to get healthcare, like going for a Pap I do not feel that I have the same opportunities as non-Aboriginal people do because of how we were treated in residential schools. Some of us feel like we will not be treated as well as White people when we go, then why would we want to go? They still have power over us, just like they did when we were in residential schools.

Many other women also communicated stories of historical trauma and how it affected their ability to trust and access healthcare professionals and the healthcare system.

Another woman described in a matter of fact tone, implications that history had on the fears people have about leaving their community and their lack of trust in healthcare

services outside their own community. Mya stated, "Like it's repeated history. I think they [community members] have a sense of fear."

Even when some of the Aboriginal women did leave their community to access healthcare services, they told stories of experiencing discrimination and were not treated well in encounters with some healthcare professionals. These experiences with discrimination compound the emotional distress, pain and suffering that resulted from residential school experiences and colonization. According to Dion Stout (2012), historical trauma and residential schools particularly "created unnatural, contrived environments that damaged Indigenous cultures, languages, traditions, and heritage" (p. 12) while leaving a cumulative scarring effect of physical, mental, emotional, and spiritual unwellness on Aboriginal people. One woman explains her experiences with hospital care and feeling that "being First Nations" she had to wait for care while other non-First Nation's patients did not.

Charity: I'll tell you if you were First Nation you sat there for a good long time. You were not in place, in number place, and we swear to that, and even to this day, like people will see a certain nurse, she's way up there now, that used to, they just walk the other way, they can't even look at her.

This quote demonstrates that some Aboriginal people experience discrimination and negative encounters with healthcare professionals when accessing healthcare services. Discrimination is one of the most enduring consequences of the colonial legacy with continued stereotyping of Aboriginal people in healthcare and social services (Browne, 2007; Browne & Fiske, 2001; McGibbon & Etowa, 2009).

Other women provided examples where they or community members experienced discrimination, stereotyping, or racism in encounters with healthcare providers, and this

was influential in shaping their accessing of future Pap smear screening services. For example, Nakita talked about being a First Nation person and being stereotyped when accessing healthcare, "Yeah, it's just like where you're from or what your background is or what your culture is, right away you're stereotyped just from what other people say." Another woman reported that racism is not only prevalent in healthcare, but exists everywhere: "No matter where you go there's still racism everywhere. Everywhere, I feel it all the time. I feel it no matter where I go" (Kayla).

Another woman described how her fellow community members experienced and dealt with discrimination.

Charity: Yeah they felt it was discrimination there. We've had a number of nurses where we felt we had been discriminated against, and they don't lodge complaints or anything, we just kinda like talked to [another healthcare professional] about it every now and then.

The same woman goes on to communicate that she believes although discrimination still exists, incidences are decreasing because doctors and nurses familiar to community members are educating other healthcare professionals about Aboriginal people's health and life circumstances.

The discrimination experienced by Aboriginal people has resulted in the mistrust of non-Aboriginal healthcare professionals, which in turn has led to discrimination towards non-Aboriginal healthcare professionals by Aboriginal people. Several of the women interviewed disclosed comments supporting the notion that discrimination against non-Aboriginal healthcare professionals also happens. For instance, referring to community members one woman said, "A lot they do say, oh she's White, and Natives need to know that too; not all White people are prejudiced" (Desiree). Another woman

identified that she was brought up mistrusting White people saying, "But I grew up like that. I grew up not liking non-Natives. I grew up being, like, racist" (Mylynn).

The disruption in traditional parenting and teaching of children about health that often resulted from historical trauma was evident in the stories of many participants. Women talked passionately about how parenting skills and the lack of expressing affection were the results of trauma experienced in residential school. One woman talked emotionally, with her hands placed on her head, about the impact residential school had on her relationship with her mother. She talked about not growing up with her mother, and not having a close relationship with her mother, attributing this and the lack of affection shown to her to the trauma her mother experienced in residential school. She also alluded to the lack of learning from her mother about being a woman which impacted her accessing Pap smear screening.

The historical trauma of residential schools can also be linked to issues with abuse and other forms of violence in many Aboriginal communities which, in turn, impacts access to healthcare services. Over half the women in the study talked about the abuse they see in their communities or abuse they experienced themselves as stemming from the residual impacts of residential school. Some women told stories about the long-lasting impacts that sexual abuse and violence experiences in residential school had on their relatives and community members. They acknowledged that residential schools started a cycle of abuse and violence that is being perpetuated within Aboriginal communities and by others from outside communities. Cumulative trauma and scarring from residential school experiences has resulted in lateral violence that "has Indigenous

people at war against themselves where the weaponry is pastahowin, transgression of taboos" (Dion Stout, 2012, p. 12). For example, sexual abuse and violence in Aboriginal communities are relational transgression taboos that have resulted from the long lasting impacts of residential schools.

When one woman was asked about the issues in the community as a result of residential school trauma and how it would affect some women accessing Pap smear screening, she responded candidly about sexual abuse in residential schools and in the community. As the following excerpt illustrates, sexual abuse experiences in residential schools has had a long-lasting scarring impact on Aboriginal people and their accessing of health services.

Mylynn: So I think that's why women are like that today. That they don't want no one down there [pointing to genital area] because the scar has been placed. . . . But women have to protect themselves a lot more than men. I do believe that the abuse was passed on. And that would stop them from going for Pap smears because of the privacy taken away, the innocence taken away.

Likewise, a few women blamed being uncomfortable physically and psychologically when accessing Pap smear screening due to the pain, suffering, and abuse that filtered down from residential schools and communicated that abuse still exists today in their community. May communicated, "A lot of people have been abused sexually and that's why probably some of them wouldn't come [for Paps]."

Although many of the stories women shared were about the traumatic impact of residential school on the lives and health of Aboriginal people, not all women shared these views. Charity reflected on the positive impact residential school had on her life saying that as a result of being in residential school she always finishes everything that

she starts, which is why she attends regular Pap screening and healthcare. She explained by saying, "I start something and I finish it, that's my whole big thing. I start something and I have to finish, and I think that's something I got from the residential school."

When asked about whether or not having her mother in residential school made a difference in her life or her health, another woman responded by stating, "No, my mom was good to us, and she made sure we were good, and my parents, both of them they were really good, and we turned out good . . . and we take care of our health" (Moriah). Yet another woman did not associate historical trauma with accessing Pap smear screening and asserted, "I don't understand why history has to be in it, if you're going to do a Pap smear you've got to do a Pap smear, history has nothing to do with it I don't think" (Kayla).

Although there were differences among women, the majority of Aboriginal women described the pain, suffering, and scarring effects of historical trauma, particularly residential school experiences, on Aboriginal people's access to health and healthcare services. The women told vivid and detailed accounts of being directly impacted by having been in a residential school themselves or of being indirectly impacted by having a family member or someone they knew who had been in a residential school. This, in turn, impacted some of the participants' ability to trust healthcare providers. Many women communicated that this study was one of the first times they had been provided with an opportunity to tell their stories about their experiences with accessing healthcare and Pap smear screening services, and many of the women exhibited an urgency and excitement to participate. The women's stories also

reflect how they have been resilient and resistant to the historical, socioeconomic and political contexts and forces that have impacted their lives and health.

The pain, losses, and the traumatic scarring impact of historical trauma, especially residential school experiences for many Aboriginal women, continue to have an impact on their accessing of healthcare services, particularly Pap smear screening. Some women disclosed not wanting to leave the safety of their communities to access healthcare, a lack of trust in the healthcare system due to discrimination experienced, disruption in parental teachings about health, and the abuse and violence that stemmed from residential schools. These findings are consistent with the literature about Aboriginal people's experiences with residential school and the impact on their health. Women in this study generally did not associate the lack of accessing healthcare services with lifestyle or personal choice, but instead pointed to a need for the examination of the broader historical, economic, and sociopolitical contexts that impact upon health and healthcare access (Browne & Smye, 2002; Brown et al., 2012; Reimer-Kirkham & Anderson, 2002). This is also supported by previous research that has shown that one of the primary reasons why Aboriginal women suffer a higher rate of cervical cancer and access Pap screening less often than their non-Aboriginal counterparts is linked with pain, suffering, grief, and losses attributed to residential school experiences (Black, 2009; Dion Stout, 2012; O'Brien et al., 2009). The health disparities of Aboriginal people are entrenched in roots of historical trauma and their relationships with mainstream non-Aboriginal people (Adeleson, 2005; Blix, Hamran, & Normann, 2012; Browne, 2005; Brown et al., 2012; Dion Stout, 2012; Fridkin, 2012; Haskell & Randall, 2009; Roberts,

2005; Warry, 2007). Furthermore, Canadian colonial policies and practices have compounded poor health and social suffering for Aboriginal people (Adelson, 2005; Fridkin, 2012). According to Adelson (2005), the institution of colonial policies and practices such as

the creation of the reserve system; forced relocation of communities to new and unfamiliar lands; the forced removal and subsequent placement of children into institutions or far away from their families and communities; inadequate services to those living on reserves and inherently racist attitude towards Aboriginal peoples" (p. S46)

all impact upon the poor health and inequities in access to healthcare for Aboriginal people.

The women in the study described historical trauma and abuse, and violence as being passed on inter-generationally and linked it to how people relate to each other and how it shapes their sense of trust when accessing Pap smear screening. Women also talked not only about the psychological impact of cycles of abuse and violence that resulted from historical trauma, but also some of the women told stories about physical discomfort accessing Pap smear screening due to abuse, pain, and psychological scarring that resulted from residential school experiences. Importantly, even a few women who did not experience past sexual or physical abuse attributed the Pap smear screening procedure with the pain and suffering that their Aboriginal ancestors experienced in residential schools. It was therefore evident that some women linked the traumatic historical past with shaping their current accessing of and experiences with Pap smear screening. These findings echo those reported by Black (2009) indicating that challenges Aboriginal women confronted when accessing Pap smear screening were related to the

effects of the historical trauma associated with colonialism, lack of cultural safety, and sexual or physical abuse that sometimes was noted to be related to residential school experiences. Discrimination, racism, and stereotypes of Aboriginal people were identified as barriers to accessing Pap smear screening and healthcare services.

In some of the stories shared by women, details about the mistrust Aboriginal people experienced when leaving their community to access healthcare services as a result of residential school trauma were highlighted. Historical trauma experienced as a result of residential schools engendered a lack of trust for non-Aboriginal people (Dion Stout, 2012; Waldram et al., 2006). Several women in this study communicated being afraid and apprehensive to leave their communities to access healthcare services and when they did, some reported that some healthcare providers had negative assumptions about Aboriginal people and presumed them as being different in healthcare encounters (Browne, 2007). Yet, unlike much of the current literature, a few women talked about discrimination towards and mistrust of "White" people. Not trusting non-Aboriginal healthcare providers may deter some Aboriginal women from accessing Pap smear screening.

Some of the women in this study also recounted stories about discrimination they or Aboriginal people they knew experienced with healthcare providers when accessing healthcare services. A number of studies have been done regarding the heightening awareness of some Aboriginal patients about their healthcare providers' perceptions and misconceptions about Aboriginal people, how this impacted their healthcare experiences,

and the care they were provided (Baker & Daigle, 2000; Browne, 2005; Browne & Fiske, 2001).

Echoed in the stories of many Aboriginal women in this study was the fact that Aboriginal children that attended residential schools suffered physical, psychological, sexual, and spiritual abuse; racism; and they were forbidden to speak their language or practice their customs and rituals. This is supported in the literature. Family ties were shattered and loss of language, culture, and health practices ensued (Barnes et al., 2006). Many of the women told stories about the pain and loss of their children and the disruption in traditional parenting and teaching of children that resulted from residential schools. Traditionally, women taught their daughters about the sacred body, being a woman, and how to act in the world (Aboriginal Nurses Association of Canada, 2002). Further, in Aboriginal communities the parents were responsible for assisting the children in forming their identity and consciousness, while godparents were vitally significant to assist the parents in traditional teachings, advice, and assisting with the raising of the children (Battiste & Henderson, 2000). These findings are congruent with those reported in the literature (Anderson, 2000; Battiste & Henderson, 2000; Department of Justice, 2005; Dion Stout, 2005; Knockwood, 2001; Ralph et al., 2006).

A few women in this study also stressed that when accessing healthcare services they felt that they were treated differently because they were Aboriginal and some disclosed that they often avoided seeking healthcare because of discrimination or being treated differently. This is supported by Tang and Browne (2008) in a qualitative study about Aboriginal people having perception that they were being treated differently by

healthcare professionals when accessing healthcare due to their Aboriginal identity and their low socioeconomic status. In addition, findings suggested that some Aboriginal patients did indeed avoid seeking healthcare based on the expectation of being treated differently by healthcare professionals. This highlights the importance of understanding healthcare encounters for Aboriginal women when accessing Pap smear screening from members of a dominant group. Also, it is important to understand the layers of historical pain and suffering that Aboriginal women have endured and continue to endure, and how for some women this may be compounded by accessing care from a non-Aboriginal healthcare provider. This is further discussed in the subtheme "Relationships: The fabric of our being."

It is important to note that in the study findings there were both similarities and differences in how Aboriginal women viewed residential schools and historical trauma as impacting their access to Pap smear screening. Despite being from the same communities, some women were negatively affected by residential school experiences and historical trauma while others were not as affected. The message here is that even though Aboriginal people have had a traumatic history, there are variations in their experiences and the ways they view the impact of residential schools and history on their accessing of Pap smear screening and other health services. The assumption should not be made that because of their history Aboriginal people will not access Pap smear screening or that the pain and suffering resulting from residential school experiences exists or is the same for all Aboriginal women.

#### Socioeconomic factors.

This sub-theme represents Aboriginal women's perceptions about the impact of socioeconomic factors on their accessing of healthcare services and Pap smear screening. Many women shared stories about being poor, not having money for transportation or childcare, having a lack of education, being young single parents, and being economically dependent on the government. Some women spoke of not accessing healthcare services unless they were ill or something was drastically wrong with them because of having little money. Some other women also alluded to their gender and being Aboriginal as factors that contributed to their socioeconomic status and subsequent access to healthcare.

Living in poverty was reported by many women in the study as being a part of Aboriginal people's communities and lives and impacting their health, even when they worked. For example, Faith recollected that "my father always had like very minimal health insurance coverage through wherever he worked." Being poor and not having money for babysitters and transportation was identified by many women as being a fundamental reason for not accessing health services.

As illustrated by Charity many women identified that solving the transportation and childcare issues is key for improving access to Pap smear screening:

Charity: I think Pap smears, if they were offered here, the transportation would be eliminated. If it was going to happen, I think that some kind of babysitting service really needs to be provided, 'cause I look at it myself, no matter where I went, either I was dragging tons of kids around, and that gets to be harder.

A few of the women perceived that living in poverty and having a lack of education was an impetus for some women not to value their health. It was evident in the

women's stories that having little education also accounted for the poverty experienced by some women in the community which they felt was a reason for them not accessing Pap smear screening. Mya, when asked about reasons for not accessing Pap smear screening, took a while to respond to the question and appeared deep in thought as she folded her hands on her lap and sat back in her chair and stated, "Like we never had education, we didn't know it [Pap smear screening] was important."

Added to the lack of education, some women indicated health and caring for themselves was not a primary concern for women in Aboriginal communities, except during pregnancy.

Desiree: Health in general is not important in our communities. Nobody thinks their health is that important. I feel like as a culture, we don't realize health as being important. It's just when they're pregnant is really when you hear people talking about health, with the vitamins and stuff.

Desiree continues on to explain that while some Aboriginal people do not view health as their first priority, it was a priority for her.

I usually write a little note, when was my last Pap, so I know when to go for my next one. And a lot of people don't write this stuff down. It's like oh, I went when I had this child.

Women relayed that there were young mothers in the communities as illustrated by Mylynn saying "we just had a 14-year-old have a baby." Although a number of women talked about many youth being pregnant at an early age, a few women in the study spoke about the relationship between pregnancy and economic support and security from the community. Desiree, who works outside her community, talked about youth being pregnant and being cared for financially by their community. She talked in a fast pace and tapped her hand on the table as she spoke and revealed the following:

Money yes. You would even get money for a crib. You do get extra money for milk when you're pregnant, you get milk tokens we call them. You get extra money on your check, because you're pregnant for even clothing, and if you have diabetes, like diabetic pregnancy, you get extra care too and we have hospital services that take you to and from the hospital too. Children are a gift from God, they're gold so that's the way my culture sees children. . . . And within the community they have their driveways ploughed. You make an appointment call, there's about four or five people in the community, they drive you to your appointments and you have to get your slips signed. So they do have access to healthcare.

Women told stories about how living in poverty and a lack of education have forced them to be economically dependent on government programs such as social assistance. These women told powerful accounts of being forced to rely on the government for small monthly allowances which they could depend upon, but which were never enough to provide a comfortable lifestyle. Charity describes how living in poverty and lack of education have impacted the youth in one Aboriginal community and eroded traditional self-sufficiency.

Charity: It doesn't matter whose kids they are, I want them to succeed. 'Cause I think that it's so important for them to strive to move ahead and to be as independent as possible. And that's what I really think that they should be working towards. Independence. And it's really hard to get them to see that because they have this concept, oh I'll go into the band office and get my ration cheque. My ration cheque every 2 weeks is \$185 and I keep trying to tell 'em, wouldn't you like to make \$300 a week as opposed to \$185? It's really difficult to get that into some kids' heads.

Desiree emphasizes that people in her community were traditionally self-sufficient, but now are dependent on government assistance for survival. She spoke with a passionate tone in her voice that traditionally Aboriginal people did not rely economically on others for food or health and that her family always had their own food. But now people in her

community are relying on welfare as a result of being put on reserves and losing traditional hunting and fishing skills and opportunities.

Women's stories revealed that socioeconomics was a primary reason associated with not accessing health services and Pap smear screening. Women identified that being poor, not having money for transportation or childcare, a lack of education, being young single parents, and being economically dependent on the government were factors that influenced their accessing of Pap smear screening services. Women could not think about what might happen tomorrow but focused on daily survival and trying to make ends meet. Consequently, some women did not access healthcare services unless they were ill or something was drastically wrong with them. Kurtz et al. (2008) maintained that economic and social disadvantage created by poverty, low education levels, and high unemployment rates is associated with poor health and health outcomes, especially for Aboriginal women. Black, Yamada, and Mann (2002) identified poverty, being

It is important to avoid framing poverty for Aboriginal women as merely economic deprivation. Rather, it is important to consider the impacts of colonization, gender, social suffering and inequities that are associated with poverty and impact healthcare and healthcare access (Dion Stout, 2012). According to Dion Stout (2012), the root causes of poor health and healthcare inequities for Aboriginal people lie in colonization and the losses suffered as a result of colonization, including poverty. Aboriginal status and being female were also identified predictors of poor health by participants in this study. Aboriginal women continue to suffer the poorest

socioeconomic and health status of all Canadians (Native Women's Association of Canada, 2007b) and many women have been forced to leave their communities and children to work in low paying jobs, or depend upon small welfare subsidies (Warry, 2007). Being poor and an Aboriginal female has been "directly linked to decreased access to health care and decreased health outcomes" (McGibbon & Etowa, 2009, p. 47) and prevents participation in health promotion programs. Also, a lack of education contributes to the poverty experienced by some Aboriginal women and until Aboriginal women attain post secondary education, they will continue to earn far less than their non-Aboriginal counterparts (Lambert, 2010). The government, by way of colonization and assimilation policies and through the institution of reservations, forced dependency on Aboriginal peoples as their land and livelihoods were disrupted. Being forced to live on reserves dramatically impacted Aboriginal people's socioeconomic status, and thus economic marginalization resulted (Battiste, 2000; National Aboriginal Health Organization, 2003; Warry, 2007). Since Aboriginal people are intimately connected to the land and the land is a fundamental component of their culture and beliefs about health and wellness, the loss of traditional lands and territories has had a significant impact on Aboriginal peoples (Richmond & Ross, 2009; Warry, 2007).

A notable point reported by several women in the study was that being pregnant ensured economic stability and being cared for by the community. Being pregnant was not linked with economic security in any of the current literature reviewed. Having children is valued in many Aboriginal cultures and women acknowledged that they were provided resources and access to healthcare including Pap smear screening services when

they were pregnant. Women did not expand on why they were only assured access to healthcare services such as Pap smear screening when they are pregnant or why resources for women to access Pap smear screening services when needed were not provided.

Many women in the study identified that solving the transportation and childcare issues is key for improving their access to Pap smear screening, a point which is also acknowledged in the literature (Mi'kmaq Health Research Group, 2007). To foster understanding about Aboriginal women's access to healthcare services and Pap smear screening, the broader socioeconomic factors and inequities such as poverty, lack of transportation and childcare, education, economic dependency on government, and the impact of colonization must be considered. Essentially, one cannot expect Aboriginal women to access healthcare when their basic needs are not being met and poverty related to colonization disconnection from lands, traditions, and families continues to exist (Dion Stout, 2012).

#### "There are a lot of issues on Aboriginal women's plates."

This sub-theme elucidates the issues and multiple and diverse roles and responsibilities of Aboriginal women that impact their access to healthcare services such as Pap screening. Some women dialogued about not taking care of themselves or not accessing Pap smear screening due to working outside of the home, attending school, housekeeping, community responsibilities, and childcare responsibilities. Many women described the numerous responsibilities and roles they have within families and mothering, and also their community. As one woman said, "Having a lot on their plates,

they [women] do not place themselves at the top of the list for care, particularly when they are single parents or have jobs" (Grace). Most of the women interviewed had children and one woman described in detail her multiple roles and responsibilities of attending university while working, being an "auntie," and helping her sisters with their children. Yet another woman expressed similar perceptions regarding women's roles and responsibilities and how it impacted their caring for themselves.

Giselle: I think there are a lot of issues on Aboriginal women's plates, you know things that happen within the family unit, and their community, the many jobs they have that you know it makes it hard for them to put themselves at the top of the list to say, I am going to take care of me.

Charity offers her perspective regarding the traditional roles and responsibilities of family members taking care of her when she had a hysterectomy. She implied that traditionally taking care of family members was part of their Aboriginal culture. Now as a result of increasing numbers of single parent families in her community, they are caring for their children and no one is taking care of the mothers.

Several women talked about currently attending university, up-grading courses or community college, and 12 women worked outside the home. Furthermore, almost half of the women in the study were single mothers and many of them worked, went to school, or did both. Another single mother described trying to upgrade her education by getting a high school diploma so that she could go to community college to make a better life for her and her children.

Several of the women in the study explained that due to having many roles and responsibilities they accessed healthcare services only when they were ill, had a health

issue, or experienced a physical emergency such as a broken arm or leg, and not for health prevention or health promotion services such as Pap smear screening.

Charity continues to work and is active in her community and also helps to take care of her grandchildren. She indicated that it is vital that women learn to take care of themselves for their own health and so that they are able to care for their families.

A lot of them are single parents like I said and they're so engulfed in taking care of their family, they don't give themselves the time to go to the doctors to get this Pap, and to do something for themselves. And then that's one of the things we have to learn as individual women, that it is for our own benefit, it is for us, to be able to survive, to be healthy for our family.

Even women with partners found it difficult to take time to access Pap smear screening. Muriel disclosed that even though she had a partner, she still found it difficult to work, be a parent, and take care of her health. However, some women, although busy, made time for Pap smear screening. Faith, a busy, working, married mother, indicated she took time to access healthcare and Pap smear screening. To do this she has to schedule the entire day off and often available appointments do not fit with her time schedule.

I've been really busy. Hard to find time, like I said if I'm going to the family doctor I pretty much have to slate the whole day for a Pap. You know no offence against him. He's a great doctor, but you know sometimes tryin' to figure out what day to get in there, it doesn't always fit with my schedule.

Clearly, the women who participated in this study identified having multiple and diverse roles and responsibilities that directly impacted upon their accessing of healthcare services and Pap smear screening. Women told stories of being busy with upgrading their education, attending school, working outside the home, providing care for children, and carrying out community responsibilities. This was reported by single mothers and women with partners or who were married. These findings are congruent with what is

reported in the literature. Black (2009), in a study examining cervical cancer screening strategies for Aboriginal women, found Aboriginal women had other concerns like caring for their children, community Elders, and youth that took priority over accessing Pap smear screening services.

Women's family and care-giving responsibilities and roles directly affect their health, and other healthcare priorities take precedence over women's health in many Aboriginal communities (Barnett, White, & Horne, 2002; National Aboriginal Health Organization, 2006b). Traditionally, roles and responsibilities in Aboriginal communities may have been assigned to men or women and gender roles were based primarily on equity (Native Women's Association of Canada, 2007a). Women's thoughts and perspectives regarding community issues, such as the social and economic organization of the community, were valued and women were considered powerful due to their ability to procreate (Kinnon & Swanson, 2002; Moore, 2002). Women were supported and continue to be supported when pregnant as evident by some women as discussed in the previous theme "Socioeconomic factors: Impacting Us." Women provided care for their families and families in turn provided care to their women when they were ill. For many women in this study it was evident that mothering and family are the most prevalent of all traditional roles and values (Blue & Darou, 2005). However, it was clearly demonstrated in the previous sub-theme that although women are cared for by their community when they are pregnant, the women communicated that when they were not pregnant they had to provide care for themselves and their children. Thus, women are forced to take low paying jobs outside the home and often outside the communities while continuing to be

responsible for caring for their families and communities, and this takes priority over their accessing Pap screening services.

## Summary.

Examining the women's highly personal stories about their experiences with Pap smear screening, it became apparent that their experiences were layered and interwoven with historical, economic, social, and political contexts. Many women talked about how residential school experiences, socioeconomic factors, and their own multiple roles and responsibilities impacted their access to Pap smear screening. Notably in the stories of the women, it was evident that although many women were confronted with a number of challenges and roles and responsibilities they are resilient and exerting their agency by displaying capacity to take on the challenges of everyday life (Dion Stout et al., 2001; Tousignant & Sioui, 2009).

## Healthcare Providers' Encounters: "Making a Difference in Our Path to Paps"

This theme has three sub-themes a) Relationships: "The Fabric of Our Being"; b)

Healthcare Providers' Practices and Encounters: "Making it or Breaking it" and c)

Healthcare Providers' Education: "Community as Teacher." This theme describes

Aboriginal women's perceptions of how healthcare providers are making a difference in their access to Pap smear screening services.

# Relationships: "The fabric of our being."

This sub-theme "Relationships: The Fabric of Our Being" discusses the women's perceptions about the impact of relationships with healthcare providers on their accessing of Pap smear screening. The majority of study participants detailed the importance of building meaningful, trusting and respectful relationships with healthcare providers and the positive influence this has on their access to Pap smear screening. One woman communicated that fostering relationships was "building a start to increasing Pap testing" (Grace). Charity expressed that "the way we are treated and looked at by healthcare providers plays a big part in how we see ourselves." Faith stressed that relationships mean everything in Aboriginal communities and they impact all aspects of life and health.

Our relationships affect every part of our life. We have relationships with other people, animals and the land. It is part of the fabric of our being and in every breath we take. We could not survive as a people without relationships.

Aaden talked about the importance of building a relationship that is not just based on the healthcare provider's previous work with First Nations People or learned from a book, but rather by going to the community and building a relationship. She also stressed the importance of not viewing all Aboriginal people and their experiences as being the same.

If you worked in a community before, worked with the First Nation people, not read them by a book and then go into their community and think you know, that's hard, what you're [the researcher] is doin' now like move into a community . . . Maybe start to build a relation with them [Aboriginal women].

Some women also indicated that the intimacy of Pap smear screening required a trusting relationship with their healthcare professional, especially for those women who

had experienced sexual abuse or were residential school survivors. Grace talked about having a relationship with the same physician she had been going to for Pap smear screening for 23 years. She considers him not only her physician, but a close friend and part of her family. To be called a family member is considered honorable in many Aboriginal communities as the family is the heart of the community and family members are responsible for educating, supporting, nurturing, and caring for one another.

Other women talked about how important it was for healthcare providers to assess each Aboriginal woman's knowledge of Pap smear screening as well as personal history factors that could affect her experience with Pap smear screening before conducting Pap smear screening. Knowing a woman's personal history is related to establishing a trusting relationship which in turn is related to the healthcare provider being there over time to build that relationship.

A few other women also talked about healthcare providers that they perceived to be dedicated to the community because they had formed trusting and respectful relationships with them and their Elders over time, and had visited their homes. A few others spoke about the importance of the healthcare provider building trusting relationships by learning about the culture and participating in cultural ceremonies and funerals in the community.

Faith: X [physician] has a relationship with a couple of the families in the community, like X [physician] gone to sweats with them, and you know smudge ceremonies and things like that. So X [physician] is not only educated about our culture, but participates. I saw where X even attended some funerals. So that support for the relationship as well, and for the trusting.

Faith's quotation demonstrates how important it is for healthcare providers to be educated in Aboriginal communities by Aboriginal community members.

However, it was evident that not all women agreed that non-Aboriginal healthcare professionals should take part in Aboriginal ceremonies and cultural traditions to build trusting relationships. Aaden felt that non-Aboriginal healthcare professionals participating in cultural events may not be welcomed by some community members and that it could actually interfere with developing positive relationships. Again, this reinforces the diversity of perspectives within Aboriginal communities and among Aboriginal community members as a result of the differences in historical and social experiences and encounters with non-Aboriginal people and healthcare providers.

Even when accessing healthcare providers outside the community, a few of the women discussed the importance of having a relationship whereby the healthcare providers take the time to respond to questions and explain things at a level and manner that they understand.

Mylynn: I feel comfortable with it because I've been going to X [physician] since I was a little girl. I have a very good relationship with X; I find X explains things very well for me. And if I have even the simplest question it may sound corny but X [physician] still answers it, and X knows how to explain it for me so I'll understand.

In contrast, Mya brought up an example of a healthcare professional that she accessed outside her community who did not take the time to explain the Pap smear screening procedure and as such, did not foster a trusting relationship with her.

All these years I'd been going to a doctor in town, and they don't explain anything, they just put it in [speculum], and they're rough and then they send you off. They don't take time with you . . . . And therefore you do not build trust with them and you; you never have a good relationship with them.

Mylynn also explained about another healthcare provider who made some members of her community feel uncomfortable because the healthcare provider was "non-Native." Mylynn explained that some women in her community felt uncomfortable because it was difficult to develop a relationship with this healthcare provider and they would not access Pap smear screening until they developed a relationship and felt comfortable. Mylynn is describing women who are exercising agency by refusing to access Paps smear screening and not subjecting themselves to a procedure done by a healthcare provider with whom they did not have a trusting relationship.

In contrast, a few women commented that they did not feel uncomfortable or threatened by a non-Aboriginal healthcare provider and developed trusting relationships with them.

May: I never thought about it [having a non-Aboriginal healthcare provider]. No, I never had any problems with trusting non-Natives because my first born, her father's a non-Native.

For some of the participants the gender of the healthcare provider also had an impact on their ability to form a relationship during Pap smear screening. Mya smiled as she described how she had accessed Pap smear screening from a female healthcare provider that worked in the community health centre. Mya communicated that a female healthcare provider understands what it is like to be a woman and knows what it is like to experience Pap smear screening. She developed a relationship with this healthcare provider and appreciated the healthcare provider's approach. The respectful relationship developed with the female healthcare provider made this woman feel more comfortable

and this relationship fostered positive experiences, thereby enabling her to continue accessing Pap smear screening regularly.

For a few other participants, the healthcare provider's gender was not considered important for relationship building when accessing Pap screening. A few women spoke of having male healthcare providers who were sensitive when doing Pap smear screening and with whom they had developed a trusting relationship. This was evidenced by Muriel who accessed the same male physician for 15 years for Pap smear screening.

Faith described that her lack of trust in healthcare providers had nothing to do with gender, but resulted from her being taught by her mother not to trust any physicians because her mother was sexually abused when she was young. Thus, the forming of a trusting relationship with healthcare professionals was not passed on to her by her mother.

My mother was sexually abused when she was young, and so ever since we were little like she always, you know tried to put the precaution in us, and even when we were little like even with all [female or male] doctors.

In summary, many women in the study stressed the importance of building trusting relationships to increase women's access to Pap smear screening and offered ways that relationships with healthcare providers could be fostered. Several participants suggested that visiting the community and attending cultural ceremonies and funerals were ways of building relationships. Other women expressed the viewpoint that not all healthcare providers were trusted by community members and therefore it complicated relationship building. Relationship building and maintaining relationships are considered the cornerstones for life, health, and survival in Aboriginal communities (Henderson,

2000; Wilson, 2001). As one woman in the study eloquently stated: "relationships are part of the fabric of our being."

The absence of respect for Aboriginal people can generate further mistrust and further strain relationships (Shahid, Finn, & Thompson, 2009). The mistrust of non-Aboriginal people, particularly White healthcare providers by Aboriginal people, must be viewed analytically with a broader lens that considers the destructive impact of colonization, lack of adherence to land treaties, exploitation of resources, institution of residential schools, removal of children from homes to welfare systems, and the implementation of assimilation policies and practices (Royal Commission on Aboriginal Peoples, 1996; Waldram et al., 2006; Warry, 2007). The establishing of trusting relationships with Aboriginal people must be considered in light of unequal power relations, particularly when the healthcare provider is non-Aboriginal and from a privileged position in society (McGibbon & Etowa, 2009).

Loppie (2007) claimed that establishing effective relationships is essential to successful collaboration in First Nation communities and healthcare access. Black (2009) stressed that relationship building was essential to increase access to Pap smear screening rates among Aboriginal women. Aboriginal women want relationships with healthcare providers that foster the creation of safe and ethical spaces, where their voices and concerns about health and healthcare access can be heard (Kurtz et al., 2008).

The concept of ethical space involves creating space for the purpose of communication between people with differing worldviews (Ermine, 2005), and builds relationships and fosters collaboration between Aboriginal people and healthcare

providers. By creating ethical space that includes both mainstream society and Indigenous knowledge systems and ideas, there is potential to implement actions that promotes Aboriginal health and reduce health inequities (Vukic et al., 2012). According to the women in this study, mutual respect and trust are fundamental to working effectively with Aboriginal communities. Healthcare providers working with Aboriginal people should not only develop relationships based on a foundation of mutual respect, but should also understand the concept of "mutual respect" within an Aboriginal context (Smylie, 2001). Mutual respect is considered the cornerstone in many Aboriginal philosophies and is given to all life forms and to all individuals equally and is absent when an individual offends another (Mi'kmaq Association for Cultural Studies, 2012).

Findings from this study indicate that for some women, but not all, the gender of the healthcare provider makes a difference in women's access to Pap smear screening. Although, some women preferred to access female healthcare providers for Pap screening, others preferred a male healthcare provider because over time they had developed a relationship with him. Women also expressed that the gender of the healthcare provider did not matter to them when it came to forming relationships. This suggests that by building trusting relationships, actively listening, and investing time with Aboriginal women, Pap smear screening goals can be achieved. This may increase the potential for Aboriginal women to access Pap smear screening services and create ethical spaces for Aboriginal women to be collaborative participants in their healthcare.

## Healthcare providers' practices and encounters: "Making it or breaking it."

This sub-theme refers to Aboriginal women's perceptions about healthcare providers' practices and encounters influencing their access to healthcare services and Pap smear screening. Women recalled particular examples whereby healthcare providers' practice either helped or hindered their accessing of healthcare services. Many of the stories women told were about some of the healthcare encounters that they, their families, or community members had experienced. Some women described not having positive experiences with healthcare providers and gave examples of discrimination experienced and a lack of culturally safe and competent care received. Some women communicated that mainstream healthcare services were not aligned to assist them to fulfill their needs when accessing Pap smear screening.

Disturbingly, almost every participant had a story that included accounts of discrimination, stereotyping, Othering, and racism which is still occurring in encounters with some healthcare providers. These experiences accounted for women not trusting the healthcare system and/or some healthcare providers and left women feeling unsafe when accessing healthcare services.

Faith: A lot of the stories I heard pertained to just the healthcare providers having stereotypical views of Native people, and making presumptions about people's lifestyles or healthcare practices just based on stereotypes and biases rather than what the patient's actually telling them . . . it does not make you feel very safe when going for care.

May, an Elder who considers herself as "a residential school lifer," talked about how healthcare providers stereotype Aboriginal people when they access healthcare.

They generalize us too much, they think we're drunks, you're hung over or something like that. Or pill pushers or you know pill poppers, I mean.

When asked what could be done to change discrimination or racism experienced by Aboriginal people from healthcare providers and educators May replied:

Each hospital should have an interpreter. But they should have an interpreter like even though they speak Mi'kmaq, to be comfortable with somebody. . . . Or if anyone comes in for a test, it would be nice if there was a worker [Aboriginal] here that would accompany people to the doctors like for tests.

Another woman, although she denied directly experiencing discrimination or racism in healthcare encounters herself, provided a powerful account about healthcare providers having stereotypical views of Aboriginal people and their lifestyles. She provided an emotional example of stereotyping of her aunt by a physician when her aunt accessed healthcare for stomach discomfort which he attributed incorrectly to alcohol sickness. Faith went on to say that the way her aunt was treated impacted other Aboriginal women's accessing of healthcare and Pap smear screening services in her community.

Faith: One example is my aunt, she was sick, she had a stomach ache and she went to the doctor and they told her to go home, she was just rum sick, and she was still really sick and she went back the next day and they examined her again and, I forget what was wrong with her, I think she had appendicitis or something that time, but they had sent her home, told her stop drinkin' and she would feel better, and she wasn't even drinkin.' So stuff like that impacts us for going for healthcare and Paps.

Avril spoke about having her baby in the hospital and described the Othering that she experienced from the nurses and one other patient who labeled her "the Native girl." Likewise, Giselle, who went to school outside her community, also described experiences with stereotyping. She talked about not knowing the word "savage" and suddenly finding out that she was one. Again, these stereotypical experiences negatively impacted the care they received at the time and their subsequent accessing of future healthcare services.

Charity shared some negative encounters with physicians outside her community. She told about her mother, who spoke mostly Mi'kmaq, and had died of cervical cancer despite accessing healthcare regularly. She described the physicians that her mother accessed as not relating well to First Nation people.

I couldn't even tell you if my mother knew what a Pap smear was. My mother could hardly speak English, and she had a doctor that was so old fashioned and then she had another doctor, and I don't think he knew how to relate to anybody that was First Nation. . . . Because my mom could hardly speak English, he never really tried, even when I went in, like I had no idea until my mother died that she had cervical cancer.

In this excerpt, Charity describes a physician who did not practice respectful or culturally safe care. The physician did not ensure that her mother was educated about the importance of having Pap smear screening or offer to provide information to her in a manner she could understand. Not sharing knowledge with women about Pap smear screening puts both the woman and her family in a vulnerable position. This quote also revealed the lack of explanations, respect, and marginalization this woman encountered, further demonstrating practice that did not embody a culturally competent or safe approach.

Other women spoke about accessing healthcare services that lacked or did not value or understand Indigenous knowledge and traditions, and described healthcare that was culturally unsafe. Charity explained that when Aboriginal people access healthcare services they experience the following:

They generalize us [Mi'kmaq people] too much when we go for healthcare and we are made to feel that we are not important and don't count. They need to look at where they are and focus on where we are because of our history and past bad experiences with Western healthcare systems.

Charity raised the notion of healthcare providers self-reflecting on their social positions and analyzing their positions of power and privilege as Western healthcare providers working in mainstream healthcare systems. She also implied that healthcare providers need to be aware of the historical context of Aboriginal people and give consideration to the care that has been provided to Aboriginal people in the past and continues to impact their current access. To provide quality care for Aboriginal people, mainstream healthcare providers must use self-reflection skills to establish therapeutic relationships and provide a holistic approach to care that represents the cultural values and customs of the individual which differ from their own (NAHO, 2006). Notably, healthcare providers must be aware that they are bearers of culture and that Aboriginal people's historical, social, and political contexts shape their health and healthcare access.

Another woman explained that First Nation people's knowledge and traditions are devalued in mainstream healthcare systems, and consequently, their care is negatively impacted.

Mylynn: 'cause everybody goes into that hospital and is treated the same. Our knowledge or traditions are not valued and our care is not as good as it should be. As a matter of fact I think our hospital is better than others, I've been to the one in x [place], I've been to the one in y [place], and I think the rapport with the First Nations in our hospital is a heck of a lot better than other hospitals.

Mylynn is talking about culturally unsafe healthcare practices that are occurring in some healthcare systems as a result of the devaluing of Aboriginal knowledge, traditions, and ways. Culturally unsafe nursing care and practices encompass situations whereby an action "diminishes, demeans or disempowers the cultural identity and well being of any individual (Nursing Council of New Zealand, 2011, p. 7). There was a lack of healthcare

providers' knowledge of Aboriginal traditions and customs in the stories of the Aboriginal women; not one woman communicated that a healthcare provider asked about any of their traditional customs or practices such as smudging or having a visit from an Elder.

Unfortunately, when accessing mainstream healthcare some women experienced a lack of cultural safety as a result of language issues. Moriah talked about accessing mainstream healthcare and not understanding what she was being told by healthcare providers.

I didn't know how to speak English. I always speak Mi'kmaq. Yeah, I'll say like, explain it. 'Cause sometimes I find that they're [healthcare providers] talking over my head about something and I do not understand everything that they're telling me.

Lack of cultural safety was also evident in the few Aboriginal pamphlets or teaching tools available or offered in mainstream healthcare service settings. Not a single participant identified that they had been provided with information about health or healthcare in their own language. When asked whether they ever saw or were given Aboriginal educational materials when accessing healthcare services one woman responded by saying, "No. There's nothing in Mi'kmaq" (Mya), and another Monique stated, "No, I never. No."

Even when women were provided with mainstream educational materials, some of the terminology in these materials was too advanced and literacy issues existed.

Desiree: They're [Aboriginal women] not educated enough and even when I think about them not knowing how to educate themselves [Aboriginal women], sometimes pamphlets like you see them they're too advanced for that person to read. They don't know it, and there's a lot of people I know that can't read.

Although, there were a variety of examples and consistent threads in the stories of discrimination, stereotyping, Othering, or racism when encountering healthcare providers in practice, a few women expressed the belief that the ways in which non-Aboriginal people were treating Aboriginal people were improving with better education and cultural sensitivity programs. Mylynn stated that, "I don't think its [stereotyping] as loud. People are very quiet about it."

Mya articulates that improving healthcare encounters with Aboriginal people requires being culturally sensitive, like one nurse that she accesses for Pap smear screening in her community.

She's [nurse] very culturally sensitive. She's into the community, and she knows, she always asks us questions like what do you think about this, if I said that then would I offend that person or, she's always asking questions and like before she does anything.

Mya is using dominant discourse about cultural sensitivity when discussing improving healthcare encounters for Aboriginal people, but Mya wants much more than just cultural sensitivity in healthcare. She wants healthcare that encompasses historical, socioeconomic, cultural, and political influences on health as well as access to equitable healthcare for Aboriginal people. She also describes that healthcare providers in encounters with Aboriginal people need to consider wider sociopolitical and historical forces that can perpetuate racism and Othering of Aboriginal people, while being cognizant of their position of authority in encounters. This provides consideration and context of the broader social structures and inequities in healthcare systems and in healthcare encounters that may assist in understanding why Aboriginal women may or may not be accessing Pap smear screening.

Although women seldom used the term "cultural safety" in their stories, they provided examples and described wanting culturally relevant healthcare services. Mya, in another instance, told a story of expecting healthcare systems and healthcare providers to be culturally safe when she accesses healthcare. She describes characteristics of a healthcare provider who she believes practices culturally safe healthcare.

I think that all parts of healthcare should be culturally safe . . . She's [healthcare provider] into the community, and she knows us like Aboriginal people, and she always asks us questions like what do you think about this, as she would not want to offend that person, or she's always asking questions before she does anything.

Although Muriel does not use the words 'culturally safe' when talking about changes needed in healthcare systems to increase Pap smear screening access for Aboriginal women, she does talk about some tenets of cultural safety. Muriel has brought up tenets of cultural safety such as the analyzing and valuing of history, culture, power imbalances, and institutional discrimination which impact access to Pap smear screening and other healthcare services for Aboriginal women.

A few other women communicated positive experiences with healthcare providers who explained information adequately so that women could understand procedures and provided women with test results even when the results were negative. Moriah, who primarily spoke Mi'kmaq, talked about her encounters with healthcare providers outside her community. She revealed that she did not access Pap smear screening until she was 47 or 48 years old. She communicated that some nurses took the time and interest to explain things to her in a manner that she could understand.

Mya, when asked about her encounters with healthcare professionals, recounted a positive encounter with a healthcare provider during Pap smear screening in the community.

Everything was positive, it was very informative and she [healthcare provider] was very gentle. The nurse was so professional; she listened to what I had to say and really cared about how I was doing during the Pap. It's something that I didn't get from going to other healthcare providers in previous experiences.

Aaden shared an educational encounter that she had with a nurse practitioner who gave her printed educational materials about Pap smear screening that were culturally appropriate and proved to be very helpful. She spoke also about other nurse encounters that were not positive because nurses did not inquire about what she wanted to know before performing Pap smear screening. In another example, Charity described how a hospital is becoming more culturally safe and inclusive by the hospital staff becoming educated about First Nation people and including First Nation representatives on hospital committees.

There exists substantial literature to support healthcare providers practices and encounters with Aboriginal women influencing their accessing of healthcare services and health outcomes (Adelson, 2005; Black, 2009; Bourque Bearskin, 2011; Browne, 2007; Browne et al., 2011; Fiske & Browne, 2006; O'Brien et al., 2009; Tarlier, Browne, & Johnson, 2007). Some women in this study had received culturally safe care from healthcare providers, while others had experienced culturally inappropriate care. For example, some women described how healthcare providers had informed them about Pap smear screening procedures and results in a way that they could comprehend and were helpful. This is what Browne and Fiske (2001) described as "affirming encounters" (p.

126). Affirming encounters are encounters in which there is sharing of knowledge and power with First Nation women about healthcare decisions, respect for women with unique cultural heritages, and reduction of the social distance between healthcare providers and the women (Browne & Fiske, 2001).

Although women rarely used the term "cultural safety," they described wanting healthcare systems and healthcare providers to provide safe, respectful, and relevant care. The participants clearly indicated that there is a lack of incorporating or valuing of Indigenous knowledge, traditions, or teachings in mainstream healthcare services. There is also a lack of accessibility to Aboriginal educational materials and attention to literacy issues which participants linked to culturally unsafe healthcare programs and services. Women described being treated differently in the healthcare system because they were Aboriginal. Inequities in healthcare access and power differentials can be redressed by using a cultural safety lens (Spence, 2001). A few women in this study also indicated that having an Aboriginal representative on healthcare committees is vitally important for questioning current policies and procedures that may contribute to culturally unsafe healthcare. Still a few others suggested having more Aboriginal healthcare providers in healthcare institutions as a way of educating other healthcare providers about providing culturally safe care to Aboriginal women. Assisting in educating other healthcare providers about Aboriginal people and contextualizing the way Aboriginal people view health, wellness, illness, and the accessing of healthcare services is essential to implementing cultural safety in practice (ANAC, 2009; Smith et al., 2010).

In congruence with the literature was the fact that some Aboriginal women have encountered healthcare providers that provide culturally unsafe care in their practice resulting in stereotyping, discrimination, and racism (Browne, 2005; Browne & Varcoe, 2006; McGibbon & Etowa, 2009; Reimer-Kirkham & Anderson, 2002; Tang & Browne, 2008). Women in the study communicated that they experienced racism and had been labeled "alcoholics" or "pill poppers" by some healthcare professionals. This is supported by McGibbon and Etowa's (2009) work which describes common stereotypical and colonial images of Aboriginal people that are rooted in Canadian culture and healthcare systems and are seen as discriminatory.

Not all women in this study acknowledged experiencing racism, discrimination, or stereotyping. Some believed that the healthcare providers they encountered provided culturally safe care. For the women in this study, a key requirement to providing positive and safe care was the development of relationships that were built on trust and mutual respect, as well as healthcare providers being educated about Aboriginal people and communities. Aboriginal women in this study also spoke of the need for healthcare providers to embody cultural sensitivity in their practice. However, it has been documented that relying solely on a culturally sensitive approach to healthcare for Aboriginal women is anticipated to have limited influence on access to mainstream healthcare services. Poverty issues, lack of access to education, social disadvantages, and discrimination are disregarded as factors influencing access to preventable health services for Aboriginal people (Browne & Smye, 2002).

# Healthcare providers' education: "Our community as teacher."

Some women had knowledge and suggestions to share with healthcare providers about Aboriginal women and Pap smear screening that would assist them in taking care of Aboriginal women's health. Their knowledge encompassed what, how, and where to teach Aboriginal women about Pap smear screening, as well as the appropriate resources that would be helpful in increasing knowledge and awareness about Pap smear screening. Women also described the importance of educating healthcare providers about Aboriginal women's unique needs and ideas to empower more women to access Pap smear screening services.

Aaden indicated that healthcare providers need to be educated about the community where they are working, not just by reading about the community and Aboriginal people. She communicated that the community would be the best teacher for healthcare providers.

Get educated and trusted in the community, and learn from the community as opposed to just a book. . . . Yeah, I think that maybe if they [healthcare providers] come study in here [community] for a bit, you know be around us [community members] for a little while, they [healthcare providers] would understand us more.

Similarly, Charity acknowledged the importance of healthcare providers learning from the community members about their own unique culture and history. Charity spoke about changing healthcare providers' curricula to encompass Aboriginal culture which she perceives would be beneficial to both Aboriginal people and healthcare providers. She believes that universities have difficulty in valuing the importance of implementing education about the culture of Aboriginal people into curricula. Charity continues on to

talk about healthcare providers being educated not only about the history of Aboriginal people, but also about the family unit which has changed with time.

I think they [healthcare providers] should know a little bit about the history, they should also know about family units, on how families survive. 'Cause this is contemporary now, it's different. It's not so much as all from Elders to babies in one household anymore. Individual families are taking care of their own. And even the Elders are living alone; they're living by themselves.

Charity is making an important point about ensuring that curricula are inclusive of the historical past, but also reflective of the current context of Aboriginal people.

The importance of healthcare providers also being able to speak some of the language was mentioned by a few women. Kayla stated that spirituality, culture, respect, and honoring what Aboriginal people believed would be important for healthcare providers to learn. Kayla also describes the importance of healthcare providers being able to communicate with community members when accessing healthcare (for example, knowing when a community member, especially an Elder, is unable to comprehend English and having the knowledge to make alternative arrangements to assist them to understand what is being communicated).

Aaden told a story about a physician who came to her community health center. This physician believed that he was educated about Aboriginal people and did not require further knowledge about working with Mi'kmaq people. However, the knowledge that he had learned about Aboriginal people was about different tribes and not knowledge that could be transferred and applied in her Mi'kmaq community.

I know the doctor, he's studied Aboriginal people, but he was doin' other cultures, like different tribes . . . he was talkin' to us about this American tribe and it was like completely different from us. But he's been goin' to the traditional walks, and goin' to visit an Elder up here . . . and goin' to the nurse. Speak with her to

understand more about us, as Mi'kmaq . . . 'cause he said stuff, and I was like that's not us [Mi'kmaq people].

In essence, the above quote reinforces the importance of recognizing the diversity that exists among Aboriginal people and stresses the importance of not essentializing all Aboriginal people, or using a one size fits all approach to healthcare in Aboriginal communities.

Notably, very few women mentioned that healthcare providers would require education and knowledge about the procedure of Pap smear screening, results, and treatments for abnormal results. It was taken for granted that healthcare providers would have that knowledge. As Giselle eloquently states in the following quote, learning about Pap smear screening is a skill that can be easily learned, but learning to work effectively with a First Nation community requires more specific and complex knowledge about culture, language, establishing connections, and strategies for teaching and learning.

Well, I know they would already learn about the Pap smears, but working with the community First Nations would be a big thing. And I'm pretty sure the providers here know of this cultural thing, and sometimes it's even a language problem, somebody comes in there is not completely understood of what they're saying . . . I know with some of my friends, they feel really intimidated when a non-native is talkin' to them, they panic they don't, you know it's just not intimidation, but not understandin', there's no connection.

Clara acknowledged that, "They [healthcare providers] need to be able to help us take care of ourselves." Several women described how healthcare professionals could present educational or information sessions and workshops in the community and offered detailed suggestions on how the sessions should be done and what to include. Mylynn suggested having "just information sessions, and just ask other women to come, and if they would consider sharing their stories 'cause I imagine every woman has a story." In

addition to sharing stories, the idea of having diagrams, models, pictures, and videos to augment teaching was also highlighted as important ways to educate Aboriginal women as some considered themselves to be visual learners.

Some women also shared their words of advice to healthcare providers and described using visual educational tools such as models and videos to assist in teaching Aboriginal women. Several women mentioned the implementation of workshops about Pap smear screening in their community would be helpful in educating women about the procedure, results, and the reasons for accessing regular Pap smear screening. Some women suggested that these workshops could be an enjoyable social event for women by having food, presents, or door prizes. Faith talked about having more educational workshops about Pap smear screening in her community followed by a series of days afterwards when Pap smear screening and a women's clinic could be offered. Faith identifies the importance of having educational sessions and offering Pap smear screening services in the community for better access for women. She goes on to explain that if healthcare providers offered women a little gift for attending workshops and educational sessions and had food, attendance would likely increase. Again, this indicates that making Pap smear screening a social event for women is one way to increase rates of Pap smear screening. Faith stated, "People like free stuff and free food. And tell them you're gonna feed them and give them a present, they'll usually come." This excerpt illustrates the significant role that small prizes and gifts, such as store coupons, can have to assist healthcare providers in recruiting Aboriginal women to educational sessions. Small incentives are considered tokens of appreciation, welcoming, and a sign of respect in Aboriginal cultures. When an Aboriginal woman gets a Pap smear completed, she views it as giving of herself. Thus, it is respectful to give her a small gift of appreciation as a way of demonstrating appreciation to her for coming in to get a Pap smear completed.

Educating young women about the importance of accessing regular Pap smear screening in the community was suggested by several women in the hopes that starting Pap smear screening early would instill a routine for regular access. Notably, the central focus is about getting information out to the women early to influence their knowledge about and access to Pap smear screening so that they are able to take care of themselves. Mylynn advised that healthcare providers target young teenage mothers in her community for Pap smear screening education as many are single parents, sexually active, and neglecting to take care of their health.

Like, we have a lot of young mothers in our community, a lot. We got a population of teenage mothers happening from the age of 15, 14 starting, she's 15 now her boy's 1 up to like 30s. That's probably 60% of the community of the population of 500. Young mothers in that age range that are single parents and that are sexually active and they need that information. They need to go for it [Pap screening] 'cause a lot of them have young girls.

She also suggested having a talking circle or offering private sessions for teenagers to obtain information on Pap smear screening. In contrast, another woman proposed that healthcare providers use printed materials such as pamphlets and posters for educating younger women, as they may not be comfortable to talk or ask questions about Pap smear screening.

Nakita: For younger kids it's probably information that they could actually read, because a lot of kids at a young age when they're first starting to have sex, they're

too uncomfortable to ask any kind of questions. So if they had the proper pamphlets like that they probably would read them.

Some women communicated that they would like specific information and education from healthcare providers as to what they look for in a Pap smear screen, treatments for abnormal results, when to have Pap screening completed, and the possible complications of not having Pap smear screening completed. Some additional suggestions were that women should be informed step-by-step about what is being done by the healthcare provider, be treated in a gentle manner, and offered to smudge. Faith raises an important point of asking each woman if she would like a family member or friend with her during the procedure, particularly given the trauma that some women have experienced as was discussed in the sub-theme "Pap Screening: Feeling Violated."

A few of the women described having positive experiences with taking care of their health when healthcare providers incorporated smudging in the preparation for procedures such as Pap smear screening. Smudging is a traditional spiritual purification or cleansing ceremony involving the burning of sacred plants and herbal resins for the purpose of ridding the body, place, or object of negativity or bad spirits (Canadian Health Network, 2000). Muriel acknowledged that for healthcare providers to assist women to take care of themselves they must be knowledgeable and educated about offering women the opportunity to smudge or perform other traditional practices or prayers prior to procedures like Pap smear screening.

Muriel: Somebody may have needed a smudge to help them get through it [Pap screening], or even after because you feel like you've been violated, maybe that'll help to ease some of the after feelings. Those [healthcare providers] doing Paps need to know about what we may want to do in our culture before a Pap and give

us an opportunity to do it. . . So it all focuses around my prayer and my strength and my culture and I do the things that I know will make me strong.

Notably, for some women not having traditional or cultural practices offered or accommodated impacted negatively on their Pap screening experience and ability to take care of their health. Aboriginal people's community structure, lifestyles, values, and traditional practices must be recognized and acknowledged to increase Pap smear screening rates (Burhansstipanov et al., 2000) and to assist Aboriginal women to take care of their health.

Women in this study indicated that healthcare providers working in Aboriginal communities require specific knowledge about the culture, history, and language which can be taught by community members. A few women also communicated the importance of healthcare providers being able to talk with community members and listen to their stories as a way of becoming knowledgeable about the community and community members. Thus, healthcare providers need to be educated about understanding nuances within communication patterns such as non-verbal communication and how to address an Elder, as well as when to offer an interpreter if a woman does not understand what she is being told about Pap smear screening. Also, learning how to initiate conversations about a sensitive topic like Pap smear screening is necessary. Zehbe et al. (2012) suggests adopting Ermine's ethical space to initiate conversations with First Nations communities. By using this approach, the authors were able to exchange knowledge and to dialogue about engaging First Nations women in the development of culturally safe human papillomavirus screening. Ethical space was a foundation for meaningful dialogue between community members and the authors.

Performing Pap smear screening with Aboriginal women requires healthcare providers to have excellent relational skills and knowledge about the historical past, as well as the current context of individual Aboriginal women's lives. Healthcare providers need to be knowledgeable about the historical legacies and the sociopolitical contexts of Aboriginal people's lives and experiences to assist in eliminating health inequities, increasing accessibility to healthcare services, and enhancing health outcomes. Healthcare providers often tend to disregard the sociopolitical context of healthcare encounters with Aboriginal people which leads to further marginalization of Aboriginal people deterring them from accessing mainstream healthcare systems and Pap smear screening services (Browne & Fiske, 2001). Healthcare providers must listen to and learn from Aboriginal people; they are the experts that can teach about their history, culture, and healthcare needs.

NAHO (2010) recommended that healthcare providers need to acquire education and understanding about cultural beliefs, attitudes, and practices in order to address barriers that Aboriginal people confront when accessing effective Pap smear screening. However, they do not clarify how or where the healthcare providers should attain education about the culture, attitudes, and practices of the community they are serving. Similarly, Murphy (2007) cited that healthcare provider communication and education are essential components of an organized Pap screening program, but also does not specify the type of education required or where healthcare providers should obtain it. In this study, the women clearly indicate that some of this knowledge is community specific and should come from the community.

Another important point raised in this study was that healthcare providers should not essentialize all Aboriginal people as being the same and should recognize and value the diversity and specific history and experiences of each individual. This is supported by Levin and Herbert (2004) who stated that "there are often differences in adherence to spiritual beliefs and practices, religious affiliation, kinship and interpersonal relationship and styles" (p. 172). Difference and diversity in and among Aboriginal people are influenced by life contexts and experiences, socioeconomic status, education, and encounters and experiences with non-Aboriginal people (Levin & Herbert, 2004).

Aboriginal women in this study are drawing on their culture by using games, prizes, and incentives as a means to increasing knowledge about and access to Pap smear screening. Women in the study highlighted the importance of having Pap smear screening days that were social and had food and prizes to increase attendance. Black (2009) also raised the idea of having a day or week dedicated to Pap smear screening in the community like Pap week or Papalooza with games and prizes as incentivizes. The concepts of games and prize incentives are traditionally linked with Aboriginal culture. Both children and adults in many Aboriginal cultures played games which typically were symbolic of a season and had religious meaning and/or were often used as teaching and learning tools. Games assisted in developing skills and building endurance, strength, and camaraderie while teaching about customs and culture (Arnason, Maeers, McDonald, & Weston, 2012). Thus, it is important that healthcare providers use this knowledge from the communities to teach Aboriginal women about the importance of Pap smear screening.

Findings in this study also indicated that university curricula for healthcare providers can be enhanced by incorporating Aboriginal cultural values and traditions and by valuing other forms of knowledge such as traditional, oral, and Indigenous.

Furthermore, healthcare providers' curricula need to encompass ethical space and relationships, "which honors Indigenous people's connection to self, others, the environment, and the universe" (Bourque Bearskin, 2011, p. 548). Aboriginal community members want to actively participate in the development of healthcare curricula for their people and have a voice in the development of procedures and protocols pertaining to Pap smear screening.

## Summary.

It was evident that healthcare providers make a difference in whether Aboriginal women access Pap smear screening or not. Women talked about the importance of healthcare providers establishing trusting relationships as a foundation to increasing Pap smear screening. Several women explained that healthcare providers' practices and education also impacted their access to Pap smear screening. Women want access to culturally safe and relevant healthcare services. By implementing the concept of cultural safety, healthcare providers become aware of how power relations impact their provision of care to Aboriginal people. Cultural safety fosters self-reflection about healthcare providers' own culture and location, while assisting to prevent and address discriminatory and stereotypical healthcare practices and policies. This theme demonstrates that using a cultural safety approach is a starting point to creating positive steps towards redressing

inequities in access for Aboriginal women while positively influencing women's ability to access needed resources for improving and maintaining their health (McCall & Pauley, 2012).

## "The Healthcare System is Complicating Our Going for Paps"

This theme describes how Aboriginal women perceive the healthcare system influencing and complicating their access to healthcare services such as Pap smear screening services. The two sub-themes include: a) Confidentiality and Privacy Issues: "I Don't Want Anybody Knowing" and b) Healthcare System Accessibility: "We Need More Services."

# Confidentiality and privacy issues: "I don't want anybody knowing."

In this sub-theme women's stories detailed issues around confidentiality and privacy that they or others had experienced, or fears about lack of confidentiality when accessing healthcare services, particularly with Pap smear screening. Notably almost half of the women from both communities disclosed not accessing their community health centre for Pap smear screening due to fears of experiencing breeches in confidentiality and privacy. Instead, they opted to leave their community to access Western healthcare services.

Desiree, while shaking her head, confidently described that she has never accessed and will never access Pap smear screening in her community health centre due to perceived and existing confidentiality issues. She drives a distance from her

community to have her Pap smear screening completed, even though the health center is closer and more convenient.

No. I've never actually been there [community health centre] for a Pap test. . . . The same reason it's; I know my results will come back there. I know my file will be there, everything about me, anybody can look at my file and I don't want anybody knowing, even the other people working in that building that are from my community that are not in the medical field can access my file, and I know that. That's why I won't go there.

She went on to elaborate that she was uncomfortable with other community members having access to her health file because the community is "so close knit" everyone knows each other.

Clara also expressed concerns that files are not handled in a confidential manner and believes that workers have open access to files. Several women acknowledged that confidentiality and privacy were difficult to maintain due to the community being so small and everyone knowing everyone else. This was also acknowledged by an Elder in the community. She explained that some community members will not access the physician at the health centre due to fears that confidentiality will not be maintained. However, she reported that years ago when she worked at a health centre confidentiality was maintained because all files were secured in a locked cabinet and only the physician viewed the files or had access to the them. She continued on to discuss that community members are also concerned about whether they can trust healthcare providers at the community health centre not to breech confidentiality as they are social with some community members.

Nakita, who does not access the community health centre for Pap smear screening or other healthcare, compares the privacy and confidentiality in the community health

centre to a physician's office in town when accessing Pap smear screening. She described the community health centre as a gathering place where community members often meet to use the computer or phone.

Yeah that would be my worst fear like somebody walking in, and then there's people in the hallway and people in the waiting room and stuff like that. There's people all over the place all the time in all these buildings around here. So that's a big confidentiality thing there, because in town you don't see that kind of stuff. Like the office, the door's closed and you have to wait in the waiting room and people sit there and wait until their name is called. But not on the reserve. They're all in the back; oh I'm going on this computer. I'm gonna go use this phone and that's how it is around here.

Although there are issues with confidentiality and privacy in the community health centre, according to Mya breaches are not deliberate or malicious and occur only because community members are social people. Mya continues on to provide an example where an employee at the health centre was breeching confidentiality unknowingly.

This is a perfect example. [Name] I know works at the clinic and in the waiting room this woman discussed that she had an injury. We had went to visit her godmother and she told her godmother about the girl that was in the waiting room, 'cause she had told everyone in the waiting room what was wrong with her. When we left there, I said you shouldn't have did that. She doesn't really understand, she said to me, well she told everybody in the waiting room. And I was like, but you're still there as a person working in the building. . You can't just announce everything that goes on in the waiting room that is still confidentiality.

From the clinic worker's perceptive, she did not believe that she was breeching confidentiality since the women revealed to everyone in the waiting room why she was accessing the health centre. Even though healthcare providers are bound by a code of ethics, this situation demonstrates that confidentiality may be more difficult to maintain in a community health centre where the healthcare providers may live and work or are related to some of the individuals accessing the health centre for care.

Charity explains that community members are also concerned about whether they can trust healthcare providers at the community health centre not to breech confidentiality as they are social with some community members.

Charity: It's like some people, there are certain professionals here, they go to them, but they don't give them the trust, because they're afraid that they'll go have a cup of tea on the other side of the reserve, and hear their conversation that they had behind closed doors over there, and that's why a lot of them don't trust each other, there's no trust.

Avril communicates another example of issues with confidentiality when being transported to healthcare services outside the community. Community medical drivers may be related to you and want to know why you are going to a certain appointment. They require completion of medical forms that state the reason for requiring medical transportation in order to be paid.

And then the conversation, because family are so connected, sometimes if it's a relative that's your carrier, they're gonna just be asking you. And part of it is because they know the person, the person's just, they're not being nosy, they're just being like a family member, they're just asking you so did things go well? And if you're young, it can be quite intimidating by that, right? If it's your uncle or your cousin, 'cause it's disrespectful in some way, not to be truthful.

According to Giselle, a reason for the lack of confidentiality and privacy in the community health centre is due to the central geographic location of the building which people access socially. The previous healthcare centre was not located in the center of the community and community members felt more comfortable accessing services because other community members could not see who was coming and going and fewer people socialized in the centre. Importantly, changing the location of the health centre in the community made it a more social place for community members to use the phone, access the computer, and gather to tell stories. While positive in many ways, the

downside of this change was that visiting the health centre for services became less private.

Giselle relates that the confidentiality concerns involved with accessing healthcare services such as Alcoholics Anonymous in her community are similar to the concerns expressed by community members with accessing Pap smear screening.

Yeah well I feel first time when this health centre opened up here, I thought it was too central, and that's because I have my clients that are uncomfortable comin' here, but also it's because of this same thing [confidentiality issues], the open area when we decided to have, I have AA [Alcoholics Anonymous] meetings, when I told them about the move up here they didn't wanna come here. So, I think AA [Alcoholics Anonymous] and Pap smear are kinda like on the same level, it's afraid people will know that's what it is. And the same with the Pap smear, afraid that you'll come out with somethin' bad and everyone will know.

Not all women had concerns about confidentiality or privacy issues in their community health centers. When asked about this, Mariah responded by saying; "Nothing at all [with confidentiality or privacy], no problems at all here at our health centre; I find it not an issue, they [healthcare providers] are well educated and no problems."

Monique, who works in the community health centre and had a Pap smear there herself, agreed that there were no issues around privacy or confidentiality. She indicated that she maintains confidentiality and privacy because it is mandated by the physician at the health center who instills in all the workers the importance of maintaining confidentiality. Monique makes the point that when healthcare providers stress the importance of confidentiality, other workers at the health centre will also value and maintain confidentiality.

The difficulties with maintaining confidentiality in Aboriginal communities were consistently reported in this study. For most of the women in this study confidentiality

and privacy issues were a major concern and impacted their comfort with accessing Pap smear screening. Some women chose not to access Pap smear screening even though the services were provided by their community health centre and went instead to a nearby town for the service. They made this choice even though it meant they needed to arrange transportation and babysitting because they perceived that confidentiality would be better maintained outside the community. Similarly, Black (2009) found that confidentiality and privacy concerns were identified as barriers for British Columbia Aboriginal women when participating in Pap smear screening. The author revealed that women residing on reserve did not want to access Pap smear screening in their community health centre when outside healthcare providers came to the reserve for the reason that other community members would know their business. While some of the women in my study expressed similar concerns, others chose to access the healthcare provider in their community health centre with whom they had established a trusting relationship and did so with no concerns about confidentiality or privacy. That, said clearly there are a number of confidentiality concerns that Aboriginal women have regarding Pap smear screening. Confidentiality concerns included being seen by others at the health centre, security issues with records, sharing of information by community members employed at the health centre, and sharing of information by healthcare providers who socialize with community members. Addressing these concerns is complex in small communities and requires input from Aboriginal communities and is further discussed in Chapter 6.

## Healthcare system accessibility: "We need more services."

Some women identified issues in mainstream healthcare systems that impact Aboriginal women's access to Pap smear screening. Accessibility issues were compounded by confidentiality concerns discussed in the previous sub-theme. Even when there are healthcare services available, they are often not accessible for all Aboriginal women. Several women reported there was a lack of Pap smear screening services, lack of timely appointments, lack of transportation, and lack of interpreters.

Lack of available Pap smear screening services was mentioned as an issue for a few women. In one community Pap smear screening is offered by appointment at any time and there is a well women's clinic twice a year. In the other community, two healthcare providers come into the community once every six months and Pap smear screening is available by appointment as well as in a well women's clinic offered once a year. There are plans for a community health nurse to be trained to complete Pap screening. Women in both communities can also access primary care providers outside their communities. Faith recommends that there is a need for more health and Pap smear screening services offered at the community health centre, noting that this would make accessing healthcare services easier.

We need more services. I like the idea of women's clinics and women's health days. I know a couple of times in our community in the past 3 or 4 years the community health representative has had women's health days or women health clinics and she did let us know that there would be a doctor or a nurse, I'm not sure but there would be somebody available to do Pap smear screening and breast exams.

Several women talked about difficulties with being able to get timely appointments with a physician both in their own community health centre and in offices outside the

community. As the following quote illustrates, not only is it difficult obtaining an appointment that is convenient for women at the clinic, there are also long waits until being seen.

Faith: I don't know 'cause the doctor I have it's hard to get in to see him and I end up puttin' it off a lot because I don't feel like spendin' a whole day in the doctor's office waitin' for my appointment. I need a less busy doctor. . . . The difficulty of you know tryin' to get in you know get an appointment where you can get in and get out.

Another working mother also communicated the difficulties with getting a timely appointment and how difficulties with transportation compounded the issue for community members.

Aaden: It's hard to get an appointment outside your community and then when you do get your appointment it's another thing to get a ride; especially if you don't have a car, and I know it happens to a lot of people.

When asked if she has problems with obtaining timely appointments for Pap smear screening, one working mother disclosed that it was dependent on the availability and reliability of the community medical driver.

Nakita: No, sometimes it is, it's all depending on what the medical driver's doing because sometimes an emergency pops up, and they have to go do something else, or if they forget or you forget to put your appointment in, or something like that always happens, but most of the time I always get to my appointments . . . but we need drivers in the community.

Likewise, Giselle added that the lack of transportation and issues with losing the medical taxi benefit to take them to healthcare appointments outside the community hindered accessing healthcare services. However, as Desiree's quote shows, transportation was not a barrier to accessing healthcare services outside the community for all women.

And really in the end of it there really is no reason [for not going to healthcare appointments]. We have our medical taxi. You make an appointment call, there's

about four or five people in the community, they drive you to your appointments and you have to get your slips signed. They get paid by the government, it's a government program. So they do have access.

Another woman elaborated that sometimes there are personal dynamics between medical drivers and those accessing healthcare services that affect accessibility.

Mylynn: We do but sometimes they're not always available and just like I said depending on who it is. Like some people, like my [relative] he's old school. He's a typical res [reserve] guy. He will not travel with X; he'll only travel with one medical driver. Yeah he'll only travel with one, there's three, and he'll only go with one because he doesn't like the other two because of his personal feelings towards them. And there's a lot of that in the community, so it depends.

These women's stories demonstrate that even when women are able to book an appointment for healthcare services there are other variables and inequities that require consideration such as socioeconomics, transportation, priority for medical appointments, and existing dynamics between medical drivers and community members. For a few women who spoke primarily Mi'kmaq, there were literacy issues and a lack of translators offered or available when accessing services outside the community. One woman suggested that "each hospital should have an interpreter."

For some women, healthcare structures such as lack of Pap smear screening services, timely appointments, transportation, and interpreters impacted their accessibility to Pap smear screening. Some women revealed that there was a lack of flexible and timely appointments to access Pap smear screening, especially if they worked, attended school, or had children. Women perceived mainstream healthcare systems to be inflexible, unwelcoming, and indifferent and that their wishes and preferences were not being considered. According to Becker et al. (2006) injustices in our healthcare systems

are created by inflexibility of healthcare appointments for Aboriginal women and this directly impacts their access to services.

Black (2009) recommended that Pap smear screening be brought to Aboriginal women, particularly in remote communities, as a solution for access issues and to overcome issues presented by poverty, such as a lack of transportation and childcare. However, not all women in my study agreed that having access in the community was the solution because of their concerns with confidentiality and privacy. Barnett et al. (2002) suggested that healthcare services scheduling should not only be flexible and convenient for Aboriginal women, but also responsive to the diverse needs of Aboriginal women so that the right services are being offered to meet women's specific needs and life contexts. Likewise, findings in this study support that not all Aboriginal women's needs and preferences are the same when accessing Pap smear screening. Importantly, to respond to these differences healthcare services should be available in the community and outside the community.

Many of the women in the study communicated that once they had access to trusted healthcare providers they preferred to access the same healthcare providers for years. While it is important to assess the need for more Pap smear screening services for Aboriginal women, the findings from my study indicate that it is equally vital to evaluate and improve upon existing services such as community medical drivers and to promote flexibility in existing services to enable accessibility for Aboriginal women.

# Summary.

Evidence exists that the healthcare system influences Aboriginal women's access to healthcare services and health outcomes (Baker & Daigle, 2000; Black, 2009; Browne & Fiske, 2001; Browne & Varcoe, 2006; Kurtz et al., 2008; NAHO, 2010). Aboriginal women in this study described how the healthcare system influences and complicates their access to Pap smear screening. Some of the women told stories about confidentiality and privacy issues in addition to resource issues such as lack of interpreters, lack of timely appointments, and lack of transportation. Women also provided examples whereby mainstream healthcare systems did not incorporate Indigenous knowledge, traditions, or teachings and were inflexible.

## **Chapter Summary**

Aboriginal women linked the historical past with shaping their current accessing of and experiences with Pap smear screening and other healthcare services. The majority of Aboriginal women acknowledged that they experienced suffering and scarring from the effects of historical trauma, especially residential school and colonialism. Although women were negatively impacted by the traumatic scarring of historical trauma, many still accessed Pap smear screening. Importantly, assumptions should not be made that because of their history Aboriginal people will not access Pap smear screening or that the pain and suffering resulting from residential school experiences exists or is the same for all Aboriginal women.

For many women being poor, not having money for transportation or childcare, lacking education, being young single parents, and being economically dependent on the government impacted access to Pap smear screening. As a result women focused on daily survival and trying to make ends meet rather than on their own health.

The multiple and diverse roles and responsibilities of Aboriginal women were also found to impact their access to Pap screening. Although busy, some women made time for Pap smear screening. For many women their understanding and perceptions about Pap smear screening, view of the body, and past experiences impacted their access. Findings indicated that for some women accessing Pap smear screening was an act of courage having experienced the pain and suffering associated with physical and psychological traumas.

Many emphasized the importance of taking care of their health in the face of considerable historical, economic, and social disadvantage and adversity. These findings offer a perspective that is missing from the epidemiological literature that implies that Aboriginal women do not make personal efforts to take care of their health.

For many women, having a trusting relationship with a healthcare provider was the foundation for increasing Pap smear screening. They stressed that healthcare providers should be knowledgeable about the historical past and the current context of Aboriginal women. The importance of using a culturally safe approach became apparent as a starting point for redressing inequities in access for Aboriginal women.

Confidentiality, privacy concerns, and resource issues hindered women's access.

In the next chapter the perspectives of healthcare providers will be discussed.

These findings address the realities of Aboriginal women's lives, fostering Aboriginal women's access to Pap smear screening, and the ongoing challenges impeding Aboriginal women's access to Pap smear screening services.

## Chapter 5:

# Findings and Interpretation: Healthcare Provider's Perspectives

This chapter discusses the study findings from the analysis of stories related to Pap smear screening from five healthcare providers working with Aboriginal women in two First Nation's communities in Nova Scotia. The healthcare providers included two physicians, two registered nurses, and a nurse practitioner, none of whom were Aboriginal or lived in either of the Aboriginal communities involved in this study. Healthcare providers had between three and more than 20 years experience working with Aboriginal people. Two healthcare providers were employed full-time and the other three worked part-time in the community. None of the healthcare providers worked in both Aboriginal communities. Two major themes that emerged from their stories are: a) Understanding the Realities of Aboriginal Women's Lives and b) Fostering Aboriginal Women's Access to Pap Smear Screening.

#### **Understanding the Realities of Aboriginal Women's Lives**

To understand the complex reasons why some Aboriginal women may not be accessing Pap smear screening services, healthcare providers communicated the importance of considering a wider view of the realities of Aboriginal women's lives.

Some the healthcare providers indicated they did not appreciate this prior to working in Aboriginal communities. Within this theme two sub-themes emerged wherein healthcare providers talked about the importance of acknowledging the impact of historical trauma, socioeconomic factors, and racism. The healthcare providers communicated that these

factors directly impact women's access to health and healthcare services, particularly Pap smear screening. The two sub-themes are: a) History and b) Socioeconomic and Political Factors.

#### History.

This sub-theme describes the healthcare providers' stories about the importance of understanding the impact of history on Aboriginal women's lives and its impact on their accessing Pap smear screening services. Each of the five healthcare providers talked about historical trauma and the impact of residential school and colonization on Aboriginal people. John, who has many years of experience providing care to Aboriginal people, described the importance of understanding Aboriginal people's lives prior to European contact to comprehend the long-lasting impact of historical trauma on their health.

John: When you read European literature about North American Aboriginals, from the 1500 to 1650–1700 that era, one of the things that they were struck by is how healthy these people were. It was like, wow, compared to Europeans of the era. They were so strong and straight and tall and healthy and robust. It was like a big deal, and you read it all over the place, people are in awe of these [Aboriginal people] healthy, people. So if you keep in mind where they came from it helps you to realize how they got to be where they are.

In this excerpt, John demonstrated an understanding of the detrimental impact that colonization and historical trauma has had on Aboriginal people's health today. He made a point to describe the lives and health of Aboriginal people prior to colonization which was historically much better than present. John communicated that Aboriginal people were in shape physically, as they walked distances to obtain traditional foods and did not

have high rates of obesity, diabetes, or other chronic diseases like they do today. He communicates the importance of healthcare providers considering the impact of colonization on the lives and health of Aboriginal people, rather than placing blame on Aboriginal people for their ill health, lifestyle choices, and for not accessing Pap smear screening services. He concluded that it was our European ancestors that were involved in generating conditions that led to the demise of Aboriginal people's health and that as a society we should take responsibility and be accountable for this and do more to assist Aboriginal people with their healthcare needs.

John continued on to describe the violation of treaties and the colonization of Canadian Aboriginal people as being similar to the Jewish Holocaust. Although the Jewish Holocaust was an example of ethnic cleansing and not assimilation, John drew on parallels of the historical trauma and loss of culture that both groups experienced. Being historically disempowered and experiencing the deceptions associated with the violation of signed treaties has negatively impacted many Aboriginal people's trust in Western systems, particularly healthcare systems and their sense of well-being.

John: And I think that the sense of being, I guess this would probably be a really important one, historically being disempowered. If you feel powerless and I think that sense of disempowerment which was true and no redress to the law. I mean we violated every treaty we ever signed for hundreds of years.

Sue acknowledged the importance of understanding residential schools' impacts on Aboriginal people's health and access to healthcare, but related that she had limited knowledge about residential schools.

Sue: I really don't know a lot about residential schools or what the reasoning is for it, but it is important to understand. I can only kinda think maybe again people were in the residential schools and there was a gap of being able to share

the knowledge and I don't know, and the people just had their struggles when they got back and when they came out of school they were adults.

Notably, a few of the healthcare providers talked about or linked historical trauma with trust, as did the Aboriginal women in the study in the sub-theme "The Scar Has Been Placed." Lola, who had some experience working in a First Nations community, disclosed that it is important to understand their history but also makes a link between trust and historical trauma. Yet she made the point that First Nations people are diverse and suggested that there are individual experiences and variations within communities.

Lola: The importance of understanding their history, their culture, and that they're individuals, so you can provide them with the best Pap smear screening and healthcare. First Nations people that you meet, it takes a little bit longer because their past experiences and trauma history, but they are all so different.

Other healthcare providers demonstrated the importance of recognizing the impact of historical trauma on Aboriginal people, but many of their narratives tended to regard all Aboriginal people as suffering in the same ways as a result of residential schools, and none talked about any positive impacts of residential schools. Colleen talked about the ongoing impact of residential school experiences on Aboriginal people, but particularly the children of survivors.

I think we still see a lot of residual from residential schools. I know that even with the Elders we see that they are direct descendents. The Elders may be healing a bit but their children are still suffering.

A few other healthcare providers directly associated the historical trauma of residential schools with the lack of self care and the lack of accessing Pap smear screening in both of the Aboriginal communities.

Jane: I think there's a lot of issues around self care. . . . People don't get enough exercise, they don't eat right, they make unhealthy choices all the time, and First

Nations are even one step further away from that because of this whole residential school issue . . . and so I think, why don't people come [for Pap smear screening]? Super complicated. Super complicated.

The lack of caring for the self as a result of historical trauma was also mentioned by Lola as she stated, "Just generally not caring for oneself. Not valuing oneself due to historical trauma."

Even though many of the healthcare providers communicated the importance of acknowledging the impact of historical trauma on Aboriginal women's lives and access to Pap smear screening services, as did almost every Aboriginal women in the study, healthcare providers tended to have varying degrees of knowledge and understanding. Healthcare providers who worked longer in Aboriginal communities and spent time visiting the communities seemed to have a more in-depth understanding of the diversity in experiences and impact associated with historical trauma. The importance of appreciating this diversity was also stressed by the women in the sub-theme, "The Scar Has Been Placed." Even though from the same communities, some women disclosed being negatively affected by residential school experiences and historical trauma, while others were not as affected.

#### Socioeconomic and political factors.

All of the healthcare providers described the importance of acknowledging the many sociopolitical factors that influence Aboriginal women's lives and how this continues to have an impact on their accessing of Pap smear screening and other health services. In this sub-theme, "Socioeconomic and Political Factors," healthcare providers

told stories about the loss of culture, language, traditional knowledge about foods and the body, and the fracturing of the family unit and parenting skills as a result of historical trauma of colonization and residential schools. Also, healthcare providers talked about Aboriginal women living in poverty, lacking childcare and transportation, lacking access to education, and having multiple roles and responsibilities. They communicated that even when Aboriginal women did access healthcare services some experienced racism and stereotyping which impacted their future access.

Colleen explained how the losses of culture, language, trust, and access to traditional knowledge about foods and the body that were passed down from one generation to the next impact upon health. She also talks about the loss of trust in the system and how it impacts access to healthcare services.

Colleen: Loss of culture. Loss of language. Loss of trust in the system, in particular. I think even like we were just talking this morning about we have someone coming to talk about switching back to traditional diet and how you can decrease your obesity and diabetes, but as we said this morning First Nations people are still too far out of their element to be able to take on all the traditional eating. It's not something that's going to happen. . . . All the losses impact upon their [Aboriginal people's] access to health.

Not all healthcare providers agreed that traditional language in the communities has been lost. Lola commented:

[Community X] is actually a community that has a very strong language [Mi'kmaq], even children. We have in Head Start, Aboriginal Head Start on reserve, which is the day care and the kindergarten schools they have integrated language there, so it's not as bad as it's on other reserves.

Almost all of the healthcare providers communicated that the loss of parenting skills, mental health issues, suicides, addictions, and abuse that they observed in the communities was an outcome of generations of historical trauma suffered from

residential schools and colonization. The fracturing of the family and loss of parenting skills were highlighted by many healthcare providers as being extremely influential in impacting Aboriginal women's access to Pap smear screening and other healthcare services. Historically, the family was central in health education and teaching young girls about their bodies and caring for their bodies by passing knowledge from one generation to the next by way of storytelling. As a result of residential schools and colonization, teaching and information about the body has also been lost (Barnes et al., 2006). Jane describes the loss of parenting support and the family disruption by saying:

And some of them have grown up in homes where they haven't had the parental support that they might have had in a traditional First Nations home. So there is quite a bit of family disruption.

Jane did not blame Aboriginal women for their lack of parenting skills, but instead continued on to talk about Aboriginal women not being parented themselves, perpetuating a cycle of parenting skill loss to the next generation and the loss of knowledge about health that was traditionally passed on to children.

Well what the Aboriginal women tell us is that the people who have been victims in residential school settings have had a harder time with the parenting because they themselves were absent from the parental home, when you know they were requiring parenting.

John added that in addition to the effect on parenting skills, the historical legacy of residential schools has also reduced the confidence of many Aboriginal women and that this, in turn, impacts their access to Pap smear screening services.

One of the things I do find, because of the history of lots of different things, the residential school system being a big one and the legacy that it's left behind, in terms of people having difficulty raising their families, is that there's lots of people that lack confidence and I find that females in particular, which impacts health.

Various participants communicated their views on the health impacts of the loss of traditional knowledge transferred from generation to generation. As illustrated in the following quote from Sue, not knowing about or being unable to access traditional foods was linked to Aboriginal people's decline in health by a few healthcare providers.

Sue: When people were in residential schools there's that whole gap about how people lost that information that needed to go from that generation to the next generation. Information got lost about all those life skills. We're trying to work to rebuild them, the community's trying to work to rebuild them, but there was a huge gap there, so even nutritional stuff. There's lots of chronic illness; lots of chronic disease, lots of diabetes and hypertension. So there's a whole nutrition piece too.

Some healthcare providers linked reduced self-care practices with the loss of traditional knowledge regarding medicines and healing practices passed down from one generation to the next orally. One example was illuminated by Sue, who wanted to do some teaching with Aboriginal women about menopause and incorporate some information about traditional practices into her educational session. She found that women were not knowledgeable about traditional practices related to menopause or sexual health, and it appeared to bother some women that they had lost traditional knowledge and ways of knowing about their bodies.

Although many healthcare providers acknowledged the losses experienced by Aboriginal women, healthcare providers rarely talked about the positive aspects of what they observed in the community or how women exhibited resiliency or exerted their agency in spite of experiencing historical trauma and multiple losses. Healthcare providers did not talk about Aboriginal women who were returning to school to be educated or about women who were accessing Pap smear screening services despite

experiencing sexual abuse and violence. Furthermore, healthcare providers seldom mentioned some of the healing that is occurring in the communities.

It is essential for healthcare providers to gain understanding of the multifaceted impact of historical trauma as it pertains to Aboriginal health to improve inequities in healthcare access and improve health status (Struthers & Lowe, 2003). According to Health Canada (2002), Aboriginal health is primarily perceived from a biomedical approach supported by epidemiological data emphasizing high incidence and prevalence of diseases. Thus, it is important for healthcare providers to be cognizant of the potential to view Aboriginal health in a narrow biomedical framework that pathologizes Aboriginal health based on diseases, treatments, and preventions (Arnold & Bruce, 2005; Hunter, Logan, Goulet, & Barton, 2006).

All of the healthcare providers in this study acknowledged the dramatic impact that historical trauma has had and continues to have upon Aboriginal people's lives and their accessing of healthcare services. Many of the healthcare providers talked about historical trauma with regards to the violation of land treaties; losses of language, traditional medicines, foods, and parenting skills; mental health issues; addictions and abuse; and lack of self-care, all of which are supported by literature (Anderson, 2000; Arnold & Bruce, 2005; Battiste, 2000; Dion Stout, 2005; Knockwood, 2001; Ralph et al., 2006). These findings are consistent with the stories that many of the Aboriginal women in this study offered about the impact of historical trauma on Aboriginal people's lives and their access to Pap smear screening in the sub-theme, "The Scar Has Been Placed." At the same time, women in this study offered many stories describing Mi'kmaq

women's personal strength of character, resilience, and how women are continuing to thrive in less than adequate circumstances by becoming educated and returning to their language and traditions. In contrast, this was not mentioned in the stories of the healthcare providers in this study. As Arnold and Bruce (2005) have noted, "it is difficult to find information on the inherent strengths and abilities of First Nations' populations for their own health and healing" (p. 260). Consequently, healthcare providers primarily view Aboriginal health within a biomedical framework focused on diseases and deficits.

Despite the dominance of the biomedical model in mainstream healthcare, understandings about phenomena from multiple perspectives and diverse ontological domains are becoming more explicit in some of the healthcare literature (Arnold & Bruce, 2005). Nursing scholarship is making strides to shift the discourse about Aboriginal health to encompass the legacy of colonialism and the impact of historical trauma on health and inequities of healthcare access (Anderson, 2004; Battiste, 2000; Browne, 2007; Browne et al., 2007; Dion Stout, 2012; Dion Stout et al., 2001). Although "nursing tends to fit within a Western scientific view of healthcare" (Hunter, Logan, Barton, & Goulet, 2004, p. 278), nursing paradigms must encompass historical trauma and the health disparities and inequities in access to healthcare experienced by Aboriginal people (Palacios & Portillo, 2009).

Notably, one healthcare provider in the study made an analogy to the historical trauma of the Jewish Holocaust as being similar to that of Aboriginal people's historical trauma. Although this analogy is supported in some of the literature, it has been reported that transmission of the traumatic effects of the Jewish Holocaust survivor populations

has ended by the third generation, but continues to impact consecutive Aboriginal generations (Palacios & Portillo, 2009; Whitbeck, Adams, Hoyt, & Chen, 2004). This underscores how important it is for healthcare providers to understand Aboriginal historical trauma as a force that will continue to impact generations of Aboriginal people. However, it is also important to be aware that not all Aboriginal people experienced or continue to experience historical trauma in the same way and although many Aboriginal people were confronted with historical trauma, there are Aboriginal people that have maintained their identities, languages, cultures, and traditions (McGuire, 2010). What is important is that all healthcare providers working with Aboriginal people have at least a basic understanding of the disruptive impact that historical trauma has on the health and well-being of the specific Aboriginal people with whom they are working (Brown et al., 2012; Dion Stout, 2012).

The narratives of many healthcare providers also described accounts of Aboriginal women living in poverty, lacking childcare and transportation, lacking access to education, and having multiple roles and responsibilities. As Jane stated, "We have access issues . . . they're all kind of the determinants of health; they're around transportation, education, geography, finances, poverty all that kind of stuff."

Sue acknowledged that for many Aboriginal women accessing Pap smear screening is not seen as a priority because they are just trying to survive daily and provide their children with the necessities of life.

Sue: Basically [Aboriginal women] they're trying to survive. There's child care issues. There's priority issues. It's [Pap smear screening] just not necessarily a priority. They got other stuff happening in their lives. And so, if they go every 7 years that's good. They don't see it as an immediate need. It's [Pap smear

screening] not a priority for them. . . . Other things are important; I mean are they looking after children. Yeah I think that's more of the issue. And what gets priority. And like I said I highly doubt the Pap screening's the priority.

Jane also supported the perception that accessing Pap smear screening is not a priority for Aboriginal women and relates it to their multiple roles and responsibilities.

Jane: I think the there are a lot of issues on Aboriginal women's plates, you know things that happen within their family unit, and their community that you know it makes it hard for them to put themselves at the top of the list, to say I am going to take care of me.

## Living in poverty.

Living in poverty was cited by many healthcare providers as being one of the major reasons for Aboriginal women to not access Pap smear screening services. When Colleen was asked what she perceived to be the major issues for Aboriginal women accessing healthcare and Pap smear screening services she responded by saying, "It would be economic, it would be historical, poverty driven definitely for a lot of them." While this participant noted that poverty was a major issue preventing Aboriginal women from accessing Pap smear screening, she had a broader perspective, linking poverty with history, and did not blame Aboriginal women for being poor or living in poverty. Likewise, John stated, "poverty's a big issue." John, who considered himself privileged being White and a financially secure healthcare provider, described how poverty marginalizes Aboriginal people and impacts various aspects of life like their health and access to education. He also linked poverty with the purchasing of cheaper, higher fat content foods which negatively impacts health.

Over half of the healthcare providers also pointed out that a major issue confronting poor or low income Aboriginal women was the lack of affordable and accessible childcare services for women seeking services outside the community.

Lola: If they're going off reserve they have to arrange for transportation and child care, but if it's here in the building, if they don't have child care, they bring the child with them and somebody's going to look after them.

John related being poor to marginalization by mainstream society and the medical community. According to John, the marginalization of Aboriginal women living in poverty further compounded why they may not be accessing Pap smear screening and other healthcare services.

With regards to the poverty issue and how we get treated from rural poor backgrounds by the wider community, it's not positive. Add that to being a visible minority, you're instantly recognizable as being Aboriginal, and it becomes compounded. It's disempowerment, poverty, marginalized by the wider community, being marginalized by the medical community, treated as second class citizens generally speaking. It's not peculiar to Aboriginal people, it happens to poor people.

Another participant agreed that poverty impacts access to healthcare for some Aboriginal people, but sometimes the problem is not insufficient money, but rather how money is being spent or distributed in communities. She communicated that Aboriginal women experienced poverty more so than Aboriginal men and some families are disadvantaged more than others.

Sue: It does have to do with poverty for sure, although there's lots of people who live in that community who make great money too, so it's not always about the money, but maybe how the money gets spent. Or who has it. And most of the stuff we know, most of the people I see are women, so they tend to have it [poverty] much more.

Sue and a few others talked about the high rates of teen pregnancies in Aboriginal communities. Sue provided details about the economic support and security offered by the community to care for many of the pregnant youth. An advantage of being pregnant is that it offers some relief from poverty.

Sue: There's lots of young teenage pregnancy. But the other thing too is there's money connected to having children in that community too, right? In housing and all kinds of benefits connected to the child bearing. I never see the panic about a pregnancy, which I see outside of that community.

## Transportation.

Like the women reported in the sub-theme "Socioeconomic Factors," many healthcare providers identified that Aboriginal women living in poverty experience issues with transportation and childcare which impact their access to health services. As Lola explained,

Yeah there's problems; there's transportation issues. We have a lot of issues here with medical transportation and transportation to other healthcare facilities and stuff.

Not only are there problems with lack of available transportation, Sue revealed another fundamental issue was that even when transportation exists in the community, the driver, referred to locally as "the carrier," may be related to you and want to know why you are going to a certain appointment.

Another reported barrier is that drivers, or carriers, are required to complete medical forms that state the reason for medical transportation. Sue explains that in order to be paid for driving to the appointment, the medical drivers require a form to be filled

out by the healthcare provider and although the information provided is vague, it is still information that the patient potentially might not want the driver to know.

Even the medical drivers ask on the form sometimes why the person has been there. And so I have to fill these forms out when they go off community and they'll say reason for visit. So I say medical visit. But how many people [healthcare providers] actually write a reason for visit. You don't know who this is going to . . . You can almost imagine what the conversation is on the way back home. Well how was your medical visit? It's just conversation but.

#### **Education.**

A few healthcare providers discussed how education is indeed valued in Aboriginal communities, but there is a lack of access to education due to poverty. This is cohesive with what the women communicated in the sub-theme "Socio-economic Factors." John, not blaming Aboriginal women for their lack of education or knowledge about Pap smear screening, talked about education as being primarily designed for "White women."

And education is a big thing for Aboriginal people, but I think that because they are poor and don't have access to educational resources, that people with professional educated backgrounds have. It's a class thing; that they need an extra leg up, and if they had it, because they're smart. They're just as smart as you and I. They're just like us; they're just exactly like us. They don't score well on IQ tests, but they're meant for people from a White background. White middle class really is what it's aimed at.

While this participant noted that Aboriginal people do not have the same access to education as "White middle class" people, healthcare providers still expect to educate Aboriginal people using "White" ways and tools which does not seem reasonable or appear to work. John continued on to disclose that part of his role as a healthcare

provider is to encourage Aboriginal people to further their education by attending university and community college.

While there was some recognition that awareness of the importance of Pap screening was improving, most healthcare providers indicated that Aboriginal women lacked knowledge and education about Pap smear screening. Healthcare providers pointed out that it was part of their responsibility to educate women and heighten awareness in the community about Pap smear screening to increase access. Jane cited "lack of knowledge" as one of the primary reasons for Aboriginal women not accessing Pap screening and suggested that "it might be helpful to have a little more information on what to expect with a Pap smear before they [Aboriginal women] came for one."

A few of the healthcare providers emphasized that being poor and lacking education has led some women to not value their health and accounts for Aboriginal women not accessing Pap smear screening.

Lola: So in context of education women [Aboriginal] weren't educated, women don't value their own health as much as they probably should. So the value of a Pap screen and even older women, I find that they're misunderstanding that well if they're not sexually active they believe they don't need have Pap screens and stuff.

In some instances, the verbal tone and the manner in which healthcare providers spoke tended to put the responsibility for not accessing screening on the women themselves without consideration of inequities in access to Pap smear screening services, or the broader contexts of women's lives such as socioeconomics, historical trauma, or racism.

Aboriginal women lack education . . . No, I don't think until they [Aboriginal women] realize the importance of it [Pap smear screening] and what it means. We had a 53-year-old yesterday that probably had not had a Pap test in 20 years.

All five of the healthcare providers shared a genuine interest in working with Aboriginal women and told stories about the impact that socioeconomic factors had on Aboriginal women's access to healthcare services, including Pap smear screening.

Consistent with the Aboriginal women's socioeconomic findings in the study, healthcare providers acknowledged that socioeconomic factors greatly influenced Aboriginal women's access to and experiences with healthcare services. Poverty impacted not only access to health, but also access to education, which in turn impacted access to health and health outcomes. Further, healthcare providers cited transportation issues, lack of childcare services, and women having multiple roles and responsibilities as impacting women's accessing of healthcare services, all of which were described by the women in this study and have been reported in the literature (Black, 2009; Bourassa et al., 2004; Letendre, 2008; Morgan & Wabie, 2012; Smylie, 2000; Waldram et al., 2006; Wilson, 2002).

### Racism and stereotyping.

Notably, many of the healthcare providers acknowledged that Aboriginal people experience racism and stereotyping when they access healthcare. This mirrors what the Aboriginal women talked about in the sub-themes, "The Scar Has Been Placed" and "Healthcare Providers' Practices and Encounters: "Making it or Breaking it." Sue

communicated that she had some preconceived ideas about Aboriginal people before coming to the community to provide Pap smear screening and other healthcare.

I think I had some preconceived ideas before I started working in that particular community and I didn't really necessarily know exactly what the needs were going to be.

Healthcare providers' perceptions of Aboriginal people can either facilitate Aboriginal women's access to healthcare services or further marginalize Aboriginal women from accessing healthcare systems (Browne, 2007; Morgan & Wabie, 2012). In this subtheme, healthcare providers discussed their perceptions of Aboriginal people. In many, but not all instances, their stories countered cultural assumptions and expanded beyond professional and middle-class values to views located within wider historical, socioeconomic and political contexts.

John disclosed that he had been providing healthcare to Aboriginal people for many years and he still viewed racism to be a huge issue for Aboriginal people when accessing mainstream healthcare services. John also acknowledged that there were societal stereotypical views about Aboriginal people and that many Aboriginal issues were class based.

The White people have been telling them they're stupid Indians forever. A lot of the problems about Aboriginal people are class not race based, same as they are in the Black community. Racism is an issue, but racism often is a class issue.

Likewise, Jane recognized that some Aboriginal people experienced discrimination and racism when they accessed mainstream healthcare services and this prevented them from accessing follow-up care and services.

Jane: Well according to what I hear, First Nations people feel discriminated against. First Nations people had a little bit of a different history and I'm finding

in some areas that people would say, oh they have it easy, they've got a card, but some First Nations people may say that they've felt discriminated against or had experience with racism when they went to the health care system, and that's why that prevents them from follow-up care and what not.

Lola articulated that racism for some Aboriginal people is manifested by using popular colonial discourses labeling them as "Indian" and by viewing or essentializing all Aboriginal people as being the same.

It's a lot of like talking down to someone or their experience has been like, well they're Indians and they're all the same. And just that kind of attitude. . . . Like stereotyping them. Like that they feel stereotyped.

An example of this type of labeling and essentializing came from Sue, one of the healthcare providers in my study who said, "I just think the substance use in that particular culture and that particular community seems to start really young . . . It's part of their culture."

Healthcare professionals in this study talked about the racism, discrimination,
Othering, and essentializing that Aboriginal people experience when accessing healthcare
services, which is supported in literature (Anderson et al., 2009; Black, 2009; Browne,
2007; Browne & Fiske, 2001; Browne & Varcoe, 2006; Vukic et al., 2012). Their
narratives revealed their belief that healthcare providers' perceptions of Aboriginal
people are expressed in words and/or actions that facilitate or further marginalize
Aboriginal people from accessing mainstream healthcare services. Similarly, Aboriginal
women's findings in the study indicated that healthcare providers were influential in
enabling or impeding access to Pap smear screening in the theme, "Healthcare Providers'
Encounters: "Making a Difference in Our Path to Paps." Many of the healthcare
providers' stories contained indications of their attempts to counter cultural assumptions

about Aboriginal people by trying to understand the broader historical, socioeconomic, and political contexts that impact their lives. Healthcare providers acknowledged that negative and discriminatory assumptions and stereotypes about Aboriginal people exist and that they originate from societal middle-class values and biomedical perspectives and the legacy of colonialism. The extent of the discrimination and stereotyping experienced by Aboriginal people is well documented in the literature (Adeleson, 2005; Baker & Daigle, 2000; Browne et al., 2011; Browne & Varcoe, 2006; Trees, 2008).

However, there were examples when healthcare providers used language that was discriminatory without recognizing what they were doing. Browne and Varcoe (2006) explain that popularized negative assumptions and preconceived notions about Aboriginal people and Aboriginal health are deeply rooted in Canadian consciousness and reflective of societal and colonial ideals that tend to shape healthcare providers' views and perceptions about Aboriginal people. For example, Browne (2007) identified that nurses attributed the quietness or passivity exhibited by First Nation women to be a cultural characteristic, rather than due to power imbalances, paternalism, and the legacy of colonialism.

### Fostering Aboriginal Women's Access to Pap Smear Screening

Healthcare providers working with Aboriginal community members are endeavoring to foster access and improve Pap smear screening rates among Aboriginal women (NAHO, 2010). To achieve this, it is imperative that healthcare providers share awareness and recommendations about how they can improve screening processes and

experiences for Aboriginal women. The theme, "Fostering Aboriginal Women's Access to Pap Smear Screening" with four sub-themes, describes what healthcare providers in this study consider important and would thereby endorse and recommend as a means of increasing Aboriginal women's access. These recommendations are based upon healthcare providers' experiences and knowledge acquired while working in Aboriginal communities. The sub-themes include: a) Trusting Relationships; b) Cultural Safety in Practice; c). Confidentiality Issues; and d) Optimizing Processes to Improve Experiences.

# Trusting relationships.

In this sub-theme, healthcare providers describe the value and importance of building respectful relationships with Aboriginal people based on trust and the impact this has on healthcare access. For many historical and contemporary reasons, building trusting relationships with Aboriginal people takes time and patience. Lola described that in her practice with Aboriginal women she learned the importance of developing a trusting relationship before initiating healthcare, such as Pap smear screening. She communicated that respect, connection, relationship, and family are very important values held in high esteem in Aboriginal communities.

You do that [develop trusting relationships] in your practice, yeah, 'cause like I said that is a really huge, huge issue, not issue; connection is big here, family, relationships, respect, that kind of stuff. Building trusting relationships is key.

Colleen had witnessed firsthand the importance of building trusting relationships over time emphasizing that more women are accessing the community healthcare centre for Pap smear screening than in the past. Colleen described that having a full-time nurse

working in the community had provided an opportunity to develop trusting relationships which increased women's access to Pap smear screening. Colleen also talked about how this nurse built trusting relationships in the community by attending community events and getting to know the community members.

Colleen: I think by [the nurse], being a consistent person that they see. They had enough change in nurses in the few years prior to the nurse coming. And I think when they see you at events after work hours, they know that they can trust you and that you're not going anywhere. Until you gain their trust you won't get a lot of openness with them. By being honest. By sticking around, and I think also by participating in community events outside work.

Sue revealed that she also learned the importance of trust in the Aboriginal community where she provided care and that as a healthcare provider she perceived that she was trusted right away, which was unanticipated because of what she had heard from other healthcare providers. Sue continued on to explain how a healthcare provider performing Pap smear screening in an Aboriginal community should develop relationships. Similar to Colleen, she suggested that as a healthcare provider you should visit the community first, meet and talk with some of the women, and build relationships prior to offering Pap smear screening services.

Like Colleen's experience with developing trusting relationships in the community, Lola explained that developing a trusting relationship with some community members takes a long time to establish. Sue described building trusting relationships as a strategy to recruit other women in the community to access healthcare services. Sue also commented on the importance of healthcare providers considering themselves as guests when accessing Aboriginal communities.

Well, when we go out to their community we [healthcare providers] were going

there as guests with a clinic in mind to do Pap screening, but they know that. . . . We do a screening process, but we allow an hour for that screening process, only because we are trying to establish a relationship with the people.

Lola highlighted not only the importance of establishing relationships, but that healthcare providers needed to have a broad lens about women's previous screening experiences, access, education, and abuse.

Lola: So it's just takes time and you [healthcare provider] need to develop professional relationships. And it's the same as providing Pap screens to any Aboriginal woman. There's always stuff you [healthcare provider] have to think about. Why maybe they're [Aboriginal women] not coming, why maybe this is the first time and they're over 40. What's their access been? What's their education? What's their experiences? How do they feel about that whole experience? Like I said, if there was abuse or anything of that nature.

Lola demonstrated an understanding of some of the determinants of health that are shaping Aboriginal women's accessing of Pap smear screening. She stressed that healthcare providers needed to look at access and inequities to access within wider perspectives that counter blaming women for not having sought screening. However, it takes time to develop relationships and to address complex issues with Aboriginal women prior to performing Pap smear screening. Issues such as abuse, particularly sexual abuse, which may impact Pap smear screening experiences, are not being addressed or viewed as a priority by all healthcare providers due to time constraints. Lola communicated that once you make time to build a trusting relationship with Aboriginal people then they respect you as a healthcare provider and will feel comfortable coming to you not only for Pap smear screening, but for other reasons as well.

Every healthcare provider in the study communicated the importance of building a trusting relationship to foster Aboriginal women's access to healthcare services and Pap

smear screening. This is congruent with the literature (Black, 2009; Brown & Strega, 2005; NAHO, 2010; O'Brien et al., 2009; Shahid et al., 2009; Smith et al., 2010; Steven et al., 2004; Wilson, 2008) and with the Aboriginal women's findings in this study (subtheme, "Relationships: The Fabric of Our Being").

Relationship building with Aboriginal people is particularly important considering the marginalization, subjugation, and control Aboriginal people experienced and the mistrust in relationships that ensued, and continues today as a result of colonial practices and government assimilation policies (Smith et al., 2010). This in turn impacts relationships between Aboriginal and non-Aboriginal people and further promote social, economic, and political inequalities that impact the health and access to health for Aboriginal peoples (Smith et al., 2010). Healthcare professionals working with Aboriginal people need to be cognizant of the power imbalances that oppress Aboriginal people and communities, promote the valuing of differing world views, and employ a two-way process of teaching and learning that fosters new levels of understanding (ANAC, 2009). While healthcare providers in this study did recognize and acknowledge that they are privileged, there was no mention of the power imbalances that exist in healthcare systems and in healthcare encounters. This begs the question of the depth of their understanding of their own privilege. Unpacking White privilege is a very difficult task and is central in anti-racist practices and working with Aboriginal people (McGibbon & Etowa, 2009).

## Cultural safety in practice.

All of the healthcare providers perceived that their education or lack of education about cultural safety dramatically impacted Aboriginal women's access to Pap smear screening. Healthcare providers' stories comprised accounts of their learning from the community by experience or by attending community ceremonies and events. Many of the healthcare providers indicated they had learned about culturally safe and appropriate practices from Aboriginal community members, not in their formal education, and described "the community as their teacher." This is evidenced by Colleen as she explains:

The [members of the] community('s) [have] been very good to explain things around traditional medicine or traditional teachings. And I think you learn as you go from them [community members].

Sue identified some of the types of education that healthcare providers require to work with Aboriginal people.

Well, you [healthcare providers] need cultural safety education about the residential schools and around the difficulty with parenting as a result. And the violence, lots of anger, lots of addiction issues arising out of all that. And even just know around the policies, around how the money filters down in that community and around housing and their own determinants of health. Like what does that all look like and why does that happen? I think just understanding their infrastructure even around health.

John explained that he acquired his education about cultural safety informally from going to the Aboriginal community, saying "there is a lot to learn, it is not in any book."

Likewise, Sue and Lola identified health care providers having a responsibility to become educated about Aboriginal people if they are going to work in Aboriginal communities. Sue explained that she lacked formal education about Aboriginal people prior to working in the community. She articulated that she educated herself by visiting

the community and community health centre providers to gain an understanding of the supports there, as well as community norms and acceptable behavior for healthcare providers. A few other healthcare providers talked about attending community ceremonies and events as a way to get educated about Aboriginal people and Aboriginal history.

All of the healthcare providers either explained or alluded to the importance of having cultural safety, cultural competence, or cultural sensitivity in their formal education so that they would be competent to provide healthcare to Aboriginal people.

Although healthcare providers used different discourses such as cultural safety or cultural sensitivity, they explained the necessity for provision of culturally safe healthcare for Aboriginal people. Many spoke of not having cultural safety, competence, or sensitivity in their formal education and, as the following quote illustrates, their recommendation was that it be added.

Colleen: Unfortunately, I don't think we're taught much about cultural safety while we're in school. But I think even for it to be built in, in a relevant way for healthcare providers in university now, for students, to build in that piece of understanding, whether it's Aboriginal or Muslim, that they gain that knowledge, and that they're taught not to be afraid to ask questions. . . . Build into the curriculum a course on its own about cultural safety.

Some healthcare providers made the point that you cannot learn cultural safety in its entirety in formal education prior to going to the community and that some of this learning occurs in informal and formal ways in the community. Healthcare providers can learn about cultural safety informally by encouraging the people they work with "to be open to saying and telling you about what is culturally appropriate or not" (Colleen).

More formal mechanisms can occur through organized education offered by the community, as Jane described in the following quote.

Well, we [healthcare providers] had a 4-hour orientation given by an Aboriginal woman who is an OT [occupational therapist]. She is not Mi'kmaq, she's a Cree from either Manitoba or Saskatchewan, and she certainly told a story that was not unfamiliar to me. Growing up in a First Nations family, the story of family disruption and in her case I think there were addiction issues as well, possibly other issues. So I think that was a good orientation for people who aren't familiar with that.

Jane suggested that healthcare providers should "go in with open eyes and don't say too much, just observe and listen." John added that healthcare providers should learn about culture from Aboriginal teachers and Elders saying, "There's lots of articulate smart Aboriginal people, men and women who can lead the way."

According to Young et al. (2000) healthcare providers require knowledge and understanding about Aboriginal communities and cultural beliefs, practices, and values. Thus, healthcare providers require education to develop a cultural consciousness to work with Aboriginal people and implement cultural safety into their practice (ANAC, 2012; Browne & Varcoe, 2006). Many healthcare providers highlighted the importance of having cultural safety education as well as learning from the community and by attending community ceremonies and events. Almost all of the healthcare professionals reported a lack of formal education regarding Aboriginal people and their history, culture, economics, knowledge, medicines, healthcare, or healthcare access in the curricula of their professional programs. This finding is cohesive with the literature (ANAC, 2009; Browne & Fiske, 2001; Letendre, 2008; O'Brien et al., 2009; Palacios & Portillo, 2009;

Sherwood & Edwards, 2006) and with some of the findings from the women's stories in the sub-theme "Healthcare Provider Education: Our Community as Teacher."

The lack of education about Aboriginal people that healthcare providers receive tends to continue to colonize Aboriginal people and negates the acknowledgment of inequities that exist in society and in the accessing of healthcare services (Sherwood & Edwards, 2006). Healthcare providers should reflect and examine personal and professional assumptions and beliefs about Aboriginal people (Sherwood Edwards, 2006).

Many of the healthcare providers in this study acknowledged that community members such as Elders were their primary teachers about Aboriginal history, traditions, and knowledge; some healthcare providers identified that what they had learned from this experience could not be attained in formal education. Seeking education and knowledge from the community, particularly Elders, is supported in the literature. Weber-Pillwax (2004) reinforced that Elders are respected teachers and historians who guide individual and collective development.

### Confidentiality issues.

All of the healthcare providers in the study communicated the importance of maintaining confidentiality and reported that part of their role as a healthcare provider was to ensure that confidentiality was maintained. Notably, almost all of them identified challenges with maintaining patient confidentiality in community health centers. Not having proper procedures and policies for housing patient data and personal information

has led to breeches in confidentiality and some community members employed at the health centre have access to personal information about other community members.

Sue: I think confidentiality is a huge issue. They're [health centre workers] not used to having that formal structure or policies. There are files that are kept there, but I have no idea how they're kept there. They have community people who live in their community work in that facility, and who have keys to that building [health centre] . . . And when I get the comment saying they [Aboriginal patients] don't want it [the results of tests] to come back to the health centre that's the reason [lack of confidentiality]. They don't want anybody seeing their reports. They don't trust the information being housed. They don't trust that process. They need policies.

Jane acknowledged that there are confidentiality issues with data storage in Aboriginal community health centers that impact women's accessing of Pap screening and attributed the lack of confidentiality to living in a small community and to community members working at the health center.

There's a lot of issues around confidentiality in the First Nations people. Huge issues. I mean just the fact that they walked in the front door, somebody at the front desk who is their neighbour, possibly their sister or cousin, has seen that they've come in to see the Pap doctor. So that's a real problem for some people, they just don't want other community members knowing their business. . . . And also, I know you're talking just really about Paps, but there was also a huge issue around if somebody has addictions, and a lot of people have addictions and does that affect their sexual health?

Jane also talked about the confidentiality concerns associated with the current method of providing transportation to healthcare services outside the community. This was also discussed by the Aboriginal women in the study in the sub-theme "Confidentiality and Privacy Issues: I Don't Want Anybody Knowing." In the communities, taxi drivers who transport women to healthcare services outside the community require transportation documentation in the form of a slip. In many instances the taxi driver, knowing the women, will inquire in casual conversation as to why they are attending a healthcare

clinic or physician's appointment. Many women felt obligated to tell why they were going for healthcare when questioned because not responding may be viewed as being disrespectful.

Likewise, Sue told a story about the lack of confidentiality created by the taxi slips. Her solution to the breach of confidentiality is to write "medical visit" on the form as the reason for accessing the clinic. For other healthcare providers finding solutions to the confidentiality challenges has not been as easy.

Jane: We [healthcare providers] find it very, very fuzzy, the boundaries [health center], very, very fuzzy there. And again, if I was working there I can assure you I would stamp my feet around a few things around confidentiality, but it's very hard in that one-stop visiting to say it's not appropriate for you to be knowing about your neighbour and you really should not be telling me that.

Although healthcare providers identified that maintaining confidentiality is part of their role and code of ethics, Sue articulated that sometimes healthcare providers or staff in the health center breeched confidentiality unintentionally in casual conversations or social settings, for example, they might mention seeing an individual at the health center.

Because the community is small and close-knit information breeches such as this can create "a real barrier to some of the access of care for Aboriginal community members."

Sue attributed the issues around confidentiality to the relative newness of health clinics that employ Aboriginal people from the community. Although Sue agreed that there are confidentiality issues in the health centre and that community members working there do breech confidentiality she states, "it's just their [community health center employees] caring, wanting to know if that report came back to see how they [community members] are doing. It's not a malicious intent."

A few healthcare providers pointed out the perspectives regarding confidentiality within Aboriginal communities differ from mainstream perspectives. Jane related the lack of emphasis on confidentiality and privacy in Aboriginal communities as being due to a cultural difference.

So there are big cultural differences and there's big differences about living in a First Nations community around confidentiality and privacy, and I feel in healthcare we really put a huge emphasis on people's personal privacy and I don't think that same emphasis is there in First Nations communities.

Likewise, Lola also asserted that in an Aboriginal community a concept such as confidentiality may have different meanings than what it has in mainstream society.

Well it's a specialty nursing [Aboriginal health] because it's culture and it's a specific culture and it's not everybody could understand the importance of certain elements of that, I believe. So you have to understand that things may mean different things than in mainstream society, like confidentiality.

John suggested that there is emphasis on confidentiality in Aboriginal communities, but the meaning of confidentiality within an Aboriginal context differs from mainstream and healthcare provider meanings. John asserted that in certain situations that involve the community, healthcare providers are expected to discuss healthcare issues with Elders and/or family members, which contrasts mainstream healthcare policies and protocols.

John: Confidentiality is important over certain things, but you're expected to talk to family members about important stuff. So there's a whole different ethic. Now I don't mean if someone's got chlamydia you should go tell everybody on the reserve that Mary's got chlamydia, I don't mean that. Obviously that's private and personal, there's no need for anyone to know that. But if there are issues that involve, wider community involvement then you're [healthcare provider] expected often to speak to the Elders, and family members and things like that and discuss the case. My experience is that Aboriginal people wait for you to do that.

All of the healthcare providers and many of the Aboriginal women in the study consistently communicated the importance of maintaining confidentiality for Aboriginal women to access Pap smear screening. Healthcare providers expressed confidentiality concerns with storage of data and personal information, different perspectives about confidentiality than Aboriginal women, and healthcare providers or other staff not always keeping patient information confidential. Likewise, women communicated confidentiality concerns about being seen by others at the health centre who will then know why they were there, security issues with records, sharing of information by community members who are employed at the health centre, and sharing of information by healthcare providers who socialize with community members. However, some of the healthcare providers seemed to have the idea that confidentiality is understood differently in Aboriginal culture, almost attributing or explaining the lack of maintaining confidentiality as having a cultural basis. Although the women did not attribute confidentiality to culture, many reported valuing confidentiality in their communities, but maintained that living in small communities makes maintaining confidentiality and privacy a challenge.

### Optimizing processes to improve experiences.

This sub-theme describes what the healthcare providers in this study recommend to improve Aboriginal women's experiences with and access to Pap smear screening. All of the healthcare providers in the study shared practices to improve Pap smear screening experiences and access to services.

Community input. Some of healthcare providers included accounts of asking the community and women what they wanted or needed to improve Pap smear screening experiences and access. This was not a common practice of all healthcare providers providing services in the community. Healthcare providers suggested that community members, especially women, should have input into Pap smear screening education and recommendations to improve screening and access. In addition, they indicated women should have a choice about who will perform their Pap smear screening.

John strongly recommended that healthcare providers need to ask the communities about their perceived needs and what they would recommend to healthcare providers to improve experiences and increase women's access to Pap screening services. John advised that healthcare providers not go into Aboriginal communities with preconceived solutions from mainstream society and expect that these will be accepted by or effective for Aboriginal women. Consulting with communities is not only respectful, but enables healthcare providers to develop trusting relationships with community members, which in turn assists in gaining knowledge and fostering solutions to accessing Pap smear screening services.

They [healthcare providers] need to ask, [community members] not tell in the first place. What's appropriate here? How can we be of assistance? Not coming with a solution from the White world. You need to ask what's appropriate. People will tell you. What do you think of this? I can ask Elders. And understand that there are cultural differences, and if you don't know what's right, ask. What's appropriate in your culture? What should I do here? Should I talk to you about this [Pap smear screening]? Am I allowed? . . . They [healthcare providers] need to take it to the First Nations community.

John continued on to recommend that to improve Pap smear screening experiences the community must not only have general input, but specifically Aboriginal women must have input with regards to decision-making and choices. He offered an example regarding having choices about sexually transmitted infection testing and clarifying their wants and expectations during Pap smear screening to improve their experiences.

Although Colleen also talked about the importance of Aboriginal women having input and choice into Pap smear screening education, she swiftly recommended having workshops in the community as one way to increase access to Pap screening. Yet, she cautioned that the women must be offered choice in what they want to be taught in the workshop by healthcare providers. Colleen communicated that until recently, the community did not have much input into what they wanted in regards to Pap smear screening and other healthcare services.

Notably, almost half of the healthcare providers recommended that there be input regarding the gender of the healthcare provider offering Pap smear screening in their community, particularly if the woman has experienced sexual abuse.

Sue: Because some of them have a male provider. That's one issue. Maybe they [Aboriginal women] have a past history of abuse or maybe they're just uncomfortable having a male do their Pap in general just because it's a very personal thing. They don't want that relationship with a male provider. They want a female provider doing that procedure with sensitivity.

However, a few other healthcare providers suggested that for Aboriginal women who have been sexually abused, the issue is not the gender of the healthcare provider doing

the Pap smear screening that is important. Rather it is having continuity with the same healthcare provider performing the Pap screening over time.

Colleen: I think by the nature of how invasive it is into their private space, if they've been abused they may not disclose it up front. And I think that's the biggest issue for them is not knowing and not always having the same person . . . It does not need to be a female doing the Pap.

More convenient and accessible Pap screening. Some of the healthcare providers told stories that included references to Aboriginal women needing more convenient and accessible Pap smear screening services in the community. This was commonly perceived by healthcare providers as a strategy to improve overall Pap smear screening rates. According to healthcare providers, by offering more convenient and accessible services in the communities, issues such as childcare and transportation would be reduced, thus making access more possible for women. Convenient services such as offering evening Pap screening with childcare services or offering accessible services in the community like Pap screening clinics offered at different times were suggested by healthcare providers. When questioned about whether there was anything that would assist Aboriginal women to have equitable access to Pap smear screening, Sue responded by saying:

Well they need to have access. So they need to have services where people are. So they need to have these services in their community and they need to build an infrastructure that involves the women of the community to develop a program that is responsive to their needs. But it should be in their community and their own policies.

Sue recommended not only having services in the community that are convenient and accessible, but also having Aboriginal communities contribute to decisions about the type

of Pap screening services they want to access, and to participate in developing programs that meet their specific community needs. Sue suggested that community members contribute to the development of policies and practices related to Pap smear screening that are pertinent to their particular needs.

Jane agreed that there are not enough Pap smear screening services being offered in Aboriginal communities and associates this with why Aboriginal women may not be accessing Pap smear screening. Sue and a few other healthcare providers also recommended that the timing of appointments impacts women's access to Pap smear screening. Sue suggested that healthcare providers need to offer more convenient afterhour clinics and clinics more regularly so that women who are working or in school can attend screening.

Sue: Like sometimes we'll do after hour clinics for the younger people that are in school and that works. So we know what the issue is there. It's just a timing issue . . . We don't always run constant clinics that the community really needs and that's why we're trying to work with the nurse down there.

Jane and Sue expect that increasing screening services in the community will automatically increase the rates of access. While increasing services is important, the complexities that encompass the web of realities of Aboriginal women's lives discussed in the theme "Understanding the Realities of Aboriginal Women's Lives" suggest that improving access will require multiple strategies.

## Approaches to improve service delivery.

Many of the healthcare providers in the study told stories that recommended Aboriginal women be targeted for increasing Pap screening rates and suggested various innovative approaches.

"A Social Women's Health Day." Some healthcare providers in both communities described that making Pap smear screening social with food was a successful innovative approach that they had implemented. They reported it had fostered improved accessing of screening services and increased awareness and knowledge about Pap smear screening. Jane suggested:

Having an open house for First Nations women so they could come in one afternoon and have tea and see [healthcare providers] and increase awareness about Pap screening socially. . . . That's what they [Aboriginal people] do. It is a social thing. There is food. There's always food on the First Nations reserves right, that part of their culture is come and feel welcome.

Jane recommended having "A Social Women's Health Day" that included food and prizes for women to empower women to have screening completed. Women were provided ample opportunity to voice what they wanted to know about Pap smear screening and to talk about issues they had with access or experiences they have had with screening. Women were able to make an appointment for future screening or have screening done that day if possible. Women could come to "A Social Women's Health Day" at the health center and bring their children thereby eliminating the need for childcare. Jane added that having social Pap clinics benefits healthcare providers'

because it increases their knowledge of the traditions and challenges within the community.

Similarly, Colleen talked about a "Pap Screening Day" held in the community health center as another innovative approach to increasing Aboriginal women's access to screening. When questioned how she got women to attend these days, Colleen replied:

The first ones we offered food and other incentives like door prize incentives. Now we don't need to. We might offer snacks. Once a year we try to have one Well Woman's clinic that we have poster boards and other information displays out. We post, we put a flyer out in our newsletter with the date of the next one, and they generally call in, and we book our appointments that way. They [Aboriginal women] now come. Most of the women before our first Pap Day had not had Pap screening done in years. We actually have a waiting list now.

Once women attend a "Pap Screening Day" some women continued to attend Pap screening regularly.

Jane revealed that a phone call from healthcare providers from the community health center is another approach to getting women to attend screening services.

The health center calls them, that's how it works . . . There'll be those who get their Pap at the family doctor, what works for them, their family doctor says you need a Pap. There'll be others that haven't had a Pap for years or think, oh gosh I see somebody's coming, they'll self present. But what truly works is when the community medical center says well, they're coming to do Paps this month, when was your last one, let's get you in . . . So it's a different style.

According to some of the healthcare providers, calling women has increased rates of Pap screening within the communities, especially for women with children and those that work outside the home. Although healthcare providers admitted calling took time, they indicated it was well invested time because many women came in for screening.

Targeting youth. Lola suggested having innovative Pap smear screening educational sessions that target young girls in the community which she calls "Get a Pap Win an iPod." She communicated that having these types of sessions is a way to increase young women's knowledge and awareness about Pap smear screening, and they have notably increased Pap smear screening rates in the community where she works.

Normalizing Pap smear screening for youth in school may set a trend to attend regular screening.

I have a separate educational session that I do on Pap screens and that's mostly focused towards youth. But it's to kind of get them thinking in that line 'cause I think the earlier that we start with this the less likely they will forget, and then you can kind of talk about the screening protocol for Nova Scotia. How you want three in a row that are, then you can go every 2 years and stuff like that.

As well, many other healthcare providers in this study acknowledged that Aboriginal women, particularly young women, require education about the procedure, screening guidelines, reasons to access Pap smear screening, and results. They recommended targeting the youth in school about Pap smear screening in the hopes of increasing their decision to access screening and to get into a routine of regular screening. Two healthcare providers talked about a need to educate young Aboriginal women about the need to take care of themselves as part of Pap smear screening education. Lola explained:

They [young women] need more education about the importance of Pap screens. There's a lot of issues around not caring for yourself and not feeling important enough to care for yourself. Like I said we're working [educating young women] on changing that for the next generation.

Jane perceived that self-care is the responsibility of the individual and an indication of self valuing which, if instilled at a young age, may continue on throughout their life.

Lola recommended that in order for youth to be knowledgeable about Pap smear screening "we have a designated room that I've worked really hard at stocking it with all kinds of information and posters [about Pap smear screening]." Lola perceived that having more Aboriginal educational and teaching tools at the health centre where young women often drop in may be a way to encourage women to attend screening. Lola believed seeing a young Aboriginal woman's face on a pamphlet or brochure may inspire other Aboriginal women to attend screening.

According to Sue, targeting youth by using innovative approaches, such as the "Inspire Program," is proving to be effective in the community where she is employed for raising awareness about and recruiting young Aboriginal women for Pap smear screening.

Yeah, they're going [Pap smear screening] because of the Inspire Program that's in this particular community has really given the girls some knowledge around the fact that they need to be going and why they need to be going, so they encourage each other, like sometimes they'll come in two and three, right? Yeah they'll come together, and I just think then the young girls encourage their mothers . . . And maybe we could change that by doing a clinic for 60- and 70-year-olds too.

Sue identified that as women become educated about Pap smear screening they, in turn, inspire and encourage other women to go for screening. This converges with what the women in this study said about how they were spreading the word about Pap smear screening.

Going step-by-step and providing Pap results. Going step-by-step during Pap smear screening and informing women of results were other approaches identified by some healthcare providers to improve Aboriginal women's Pap smear screening

experiences and increase their attendance at regular screening. Healthcare providers revealed the importance of talking women through screening to decrease fears and anxiety, while building trust. Many of the healthcare providers that did go step-by-step with women throughout the Pap screening procedure relayed that women appeared more comfortable and that knowing what to expect next alleviated women from tensing up, thus decreasing discomfort. Sue talked about the importance of step-by-step coaching during the procedure itself, especially if women have been sexually abused in the past.

Just the act of Pap screening. Just the technical act of Pap screening. If they've [Aboriginal women] been sexually abused in any way. And I ask the question if there's a past history for that reason, because I know that they're going to be more sensitive. I explain the Pap step-by-step. I show them all the instruments and I explain how to try to relax. I'm going to give them the power to stop it any time they want to stop the procedure. And I do see a higher rate of sexual abuse . . . I'm totally coaching the whole time I'm doing the procedure.

A few of the healthcare providers discussed the importance of informing Aboriginal women of their Pap smear screening results. Lola revealed that it is part of her role to inform and educate her patients of all test results, whether positive or negative, as well as to ensure they understand about follow-up care. She provided them with a timeframe of when to expect results to reduce anxieties during the wait. However, other healthcare providers talked about the impracticalities of calling all women with negative results and that this is not an expected part of the usual standard of care. Jane went on to explain that calling women with results has its own challenges.

To say I have trouble tracking down First Nations people with results is a complete understatement. And I have a huge problem with getting people to follow up. I'll say. I'd really like to see you again in a month to follow up on something, would you come into the women's center? I always call them first. I give them the chance to be home, but we don't call for normal Pap results.

NPs and registered nurses to perform Paps. Over half of the healthcare providers in the study suggested that having a nurse practitioner or a registered nurse who works in the community and performs Pap smear screening would provide better access to and quality of screening services. Further, a nurse practitioner or registered nurse in the community would develop relationships in the community, know the health histories of the women, and have a vested interest in the health and well-being of the women. In addition, they would allocate time to educate women about screening and results in a manner in which women can understand.

Jane: I think in Canada and in First Nations communities, we're looking at who gives the most appropriate care, and I really see a role for either a family practice nurse or a nurse practitioner. I see that as a very significant, that would be a very helpful role. I think they would provide a lot of expertise that physicians wouldn't provide in terms of community assets and I see that as perfect for access [to healthcare].

Lola also communicated the importance of using nursing roles effectively and having a registered nurse educated and competent to complete the Pap screening in Aboriginal communities.

I just think that always ensuring in the community that it's available here in the community, easy to access, and you have reliable nurses. I really am a big promoter of the RN Pap screeners and I'm kind of the school of thought that doctors don't need to be doing those things. It's a different type of relationship in that the RN is very capable of doing that and pulling in the physician when need be for anything that's outside of that. 'Cause it's a primary prevention. So that's left in the hands of a nurse, should leave the acute care stuff and that to physicians, and because we have the time.

For other health care providers, the concern was getting Pap smear screening completed, not who did the screening.

Funding, resources, supplies, and services. Many of the healthcare providers told stories about the lack of available funding, resources, and supplies for education and Pap smear screening in Aboriginal community health centers, which posed ongoing challenges for women wanting to access Pap smear screening in their community.

Providing adequate funding was highlighted as being essential for ensuring access to Pap smear screening services for Aboriginal women. It was recommended by many healthcare providers that policy-makers and government develop innovative ways to reallocate or increase resources for Pap smear screening supplies, educate Aboriginal women about screening, educate healthcare providers to perform screening, and increase screening services offered in Aboriginal communities. Healthcare providers talked about there being no specific funds allotted for Pap smear screening services in Aboriginal communities and that healthcare providers often needed to obtain supplies from the hospital to perform screening in the community.

Sue: There isn't money in that community for Pap smear screening. We partner with the teaching staff because we don't have the resources that we should have in the communities. We take all our own equipment and they use their nurse [community health centre] on that day we're down there. Everything comes out of the X [outside] budget to go down every time we do a program. They don't pay for any of our services. They don't have the money to do that, so policies need to change.

For some healthcare providers not being able to count on having supplies and equipment for Pap smear screening in the community meant that they did their screening in locations outside of the community.

John: Yeah, it's not set up to do Pap smear. It's hard to keep supplies, unless you know you're going to have a clinic, and you make sure of it ahead of time. On

ordinary office days you really have to be diligent on supplies and stuff, because things wouldn't be there when you need it and stuff. So because they come to my office a lot I've just always done them there.

Jane talked about the lack of funding and follow-up services for women that have been sexually abused. Although acknowledged by healthcare providers that sexual abuse and violence exists in the communities, the issue is not being addressed during screening. Jane commented that healthcare providers often do not ask about sexual abuse during Pap screening due to time constraints and it is not a question on the standard recording form used in a healthcare visit. Also, she indicated there are not adequate supports in place for healthcare providers to address or deal with sexual abuse and this was another reason they did not ask questions regarding abuse prior to or during Pap smear screening.

Jane: We [healthcare providers] know there's abuse. We don't in the Pap. I've got to [be] really honest. Because although I would be very happy to address that [sexual abuse], I would be there for the month. So, it's not on the standardized form. But there is no question about sexual abuse and in my clinical experience over the last 28 years certainly when you ask that question one in four people answer yes. But in terms of sexual abuse, is it addressed well on the Pap visit? Not necessarily. . . . So, I'm not actually feeling at the moment that that's a terrible omission, because there isn't the necessary support to be able to deal with what if it's a yes.

Jane communicated that many women who come for Pap screening have been sexually abused and that health care providers do not routinely screen for it in their assessments. She recognized the impact of a history of sexual abuse on women's experience during Pap smear screening, and at the same time knew that time constraints and lack of adequate supports limited the capacity of healthcare providers to address the ongoing psychosocial needs of women who have been sexually abused. Therefore healthcare providers often do not ask women the question. This can be an ethical

dilemma for healthcare providers. They know the importance of inquiring about abuse to enable healing and intervene in the cycle of abuse; yet know they do not have the resources to allocate to follow up with these women. Not being able to provide follow up to help women deal with the pain and suffering associated with abuse, leaves healthcare providers hesitating to even ask the question.

## **Chapter Summary**

Healthcare providers communicated the importance of taking a wider view of the historical context and the realities of Aboriginal women's lives. Although many healthcare providers acknowledged the impact of socioeconomics and losses of culture, language, traditional knowledge, and the fracturing of the family unit as stemming from historical trauma, healthcare providers did not talk about the positive aspects of what they observed in the community or how women exhibited resiliency or exerted their agency in spite of experiencing historical trauma and multiple losses.

Healthcare providers identified a number of approaches to foster Aboriginal women's access to Pap screening as well as challenges that impact accessing of Pap screening for Aboriginal women. Confidentiality issues were a particular concern.

The final chapter will summarize the key findings; discuss the implications of these findings for practice, education, research, and policy and the study strengths and limitations.

## Chapter 6:

# Overview, Study Strengths, Limitations, Implications and Conclusion

This study explored Mi'kmaq women's and primary healthcare providers' experiences with Pap smear screening in two rural Mi'kmaq First Nations communities in Eastern Nova Scotia. This final chapter will provide a brief overview of the study; discuss the study strengths, limitations, and implications for practice, education, research, and policy. The chapter will conclude with some personal reflections, lessons learned, and final thoughts.

## Overview of the Study and Study Findings

## Study relevance.

In Canada, higher numbers of Aboriginal women are reported to be diagnosed with cervical cancer in comparison to non-Aboriginal women (Integrated HPV Working Group, 2012). As such, regular Pap smear screening is recommended for all sexually active women for early detection of abnormal cells and ultimately, the prevention of cervical cancer. To date, however, there is limited research that looks specifically at Aboriginal women's perspectives about Pap smear screening and their experiences with accessing this service. This study examines participation in Pap smear screening services from women's perspectives and those of healthcare providers in two Mi'kmaq communities in Nova Scotia. Through the use of PAR and Indigenous principles a partnership was developed whereby women and healthcare providers were empowered to

provide rich contextualized accounts of their experiences, as well as their recommendations for improving Pap smear screening for Aboriginal women.

This study builds upon existing research by critically analyzing the perceptions of Aboriginal women and healthcare providers as to why Aboriginal women may or may not be participating in Pap screening services. This research shifts the focus of situating personal characteristics and cultural difference as reasons for not accessing Pap screening services to the impact of wider historical, political, and social conditions that have resulted from colonialism, residential schools, and assimilation and continue to shape healthcare access for many Aboriginal women. This research conveys the similarities and diversities in Mi'kmag women's experiences and perspectives about Pap smear screening. It reinforces the importance of not essentializing or generalizing Aboriginal women's views or experiences. Mi'kmag women have been underrepresented in the previous Pap smear screening literature. To understand Mi'kmaq women's perspectives, experiences, and the contextual realities that shape those experiences, the stories of Mi'kmaq women need to be heard. This research adds to the knowledge about the complexity of factors influencing access to Pap smear screening and reveals the importance of including Mi'kmaq women in decision-making about Pap smear screening services. This research also provides insights into the impact of women's previous experiences with healthcare providers and healthcare systems that may impact their current access. It is hoped that dissemination of the results of this research will lead to more equitable, respectful, and culturally safe Pap screening services supported by appropriate policies, procedures, and resources.

## Study design and methodology.

In this qualitative study informed by a post-colonial feminist lens, I integrated participatory action research approaches and Indigenous principles in a two-eyed seeing approach to explore the diversities and multiple realities of Mi'kmaq women's and healthcare providers' experiences with Pap smear screening in Nova Scotia. Two-eyed seeing involves the blending of Euro-Western methodologies and Indigenous research principles to enhance the relevance of the outcomes of research for Aboriginal people (Marshall, 2007). Two-eyed seeing helps to shape research for addressing the healthcare priorities of Aboriginal people, and supports Aboriginal traditions while acknowledging that power imbalances exist in society and in healthcare systems (Hatcher, Bartlett, Marshall, & Marshall, 2009; Vukic et al., 2012). In this study, the inclusion of both participatory action and Indigenous principles guided a relational approach for conducting research and provided a deeper and broader understanding of Mi'kmaq women's experiences with Pap smear screening, than by employing only one set of principles. Decision making was shared with the community facilitators, women, and myself in the development and promotion of the study, recruitment of participants, and guidance with research specifics such as location for interviews and knowledge translation. Talking circles provided an opportunity to develop relationships, explain the study to the community members, have members ask questions and make suggestions about the study, while creating an opportunity for knowledge sharing.

Interviewing most (all except two) of the women and healthcare providers twice not only provided an opportunity for member checking, but also an opportunity for participants to expand and clarify their stories. It also enabled me to seek clarification and check whether my understanding and interpretation of what they were saying was as accurate and contextualized as possible. This enhances the credibility of the findings. By interviewing Mi'kmaq women and healthcare providers about Pap smear screening, multiple perspectives, contexts, and experiences were made visible which enriched and broadened the study findings. Trusting and respectful relationships were formed between me and the Mi'kmaq women which were fundamental to the mutual creation and respect of knowledge from both worldviews. Building trusting relationships and mutually creating knowledge aligns with Aboriginal traditions and Indigenous epistemology (Battiste, 2000; Vukic et al., 2012).

Participatory research approaches and principles promote the building of ethical spaces for conducting research with Aboriginal people (Ermine, 2005). Ethical space was created by having open communication throughout the research process. Decision making throughout the research process with community facilitators and the women was based on equitable power sharing and a partnership approach.

Postcolonial feminist theoretical perspectives also informed this study. According to Reimer-Kirkham and Anderson (2002) post colonial theory is a relevant and appropriate perspective if you want to consider and study areas of inquiry about Aboriginal people, as "contemporary constructions of race, ethnicity, and culture, continue to rely on colonialist images and patterns of inclusion and exclusion within

health care settings" (p. 10). Using post colonial feminist theoretical perspectives in this study enabled me to capture women's experiences with Pap smear screening and to further understand these experiences within the broader historical, socioeconomic, and political contexts that shaped experiences. Importantly, Mi'kmaq women's strength of character, courage, resiliency, and agency in the face of immense pain, suffering, and injustices were made visible and acknowledged.

## **Overview of Major Findings**

# Historical and social contexts shaping Pap smear screening.

Notably, both the Mi'kmaq women and the healthcare providers generally did not attribute the lack of accessing healthcare services to lifestyle or personal choice, but rather to the broader historical, economic, and sociopolitical contexts that impact access. Almost all of the study participants discussed the impact that history, particularly residential school and/or colonization experiences, had and continues to have on access to Pap smear screening. Although there were differences among the women, the majority described the pain, suffering, and scarring effects of historical trauma, along with socioeconomic challenges and their own multiple roles and responsibilities as key influencing factors that impact Pap smear screening. This finding is aligned with literature that supports the impact of these factors on Aboriginal women's access to Pap smear screening (ANAC, 2012; Black, 2009; Browne & Smye, 2002; Letendre, 2008; Morgan & Wabie, 2012; O'Brien et al., 2009; Steven et al., 2004). This study is the first

to describe the historical and social contexts shaping Mi'kmaq women's experiences with and access to Pap smear screening.

While Aboriginal women told rich, experiential stories about how the historical past has impacted and continues to impact their present healthcare and healthcare access, when healthcare providers spoke of the historical trauma of Aboriginal people it tended to sound factual and somewhat academic. There did not seem to be awareness that not all Aboriginal women are impacted by history or socioeconomics in the same manner. For example, healthcare providers did not consider that for some women there may be some positive outcomes from residential schools that impact access. This is also not noted in the current literature about Aboriginal women and Pap smear screening. Clearly the pain and suffering of historical trauma has affected many women, however, assumptions that essentialize women's reasons for not accessing Pap smear screening should not be made. It is equally important that healthcare providers acknowledge the personal strength of character and resilience that enables many women to survive and even thrive in less than adequate circumstances. Perhaps most importantly, this study underscores that to understand Mi'kmaq women's experiences with accessing Pap smear screening, the women themselves must be asked.

#### Mi'kmaq women's understandings of and experiences with Pap screening.

Throughout this study Mi'kmaq women discussed a multitude of diverse beliefs, understandings, experiences, and feelings about Pap smear screening. For example, some women spoke about being motivated to access Pap smear screening as a means of caring

for themselves, their children, and their community; to be able to have children; and to prevent cervical disease through early detection. Others described having negative experiences and feeling violated, terrified, embarrassed, uncomfortable, or self-conscious. Women communicated that experiencing discrimination in previous healthcare encounters hinders subsequent accessing of healthcare services, and for some it compounded the emotional suffering and distress that resulted from residential school experiences and colonization.

There were variations in women's views about the appropriateness of speaking about Pap smear screening and reproductive organs. Some viewed women's bodies through a Mi'kmaq cultural lens and held traditional beliefs about the body being "sacred" and expressed the importance of treating and talking about women's bodies in a respectful manner. Others felt that Pap smear screening and "private" or "sacred" areas of women's bodies were not topics that were appropriate to talk about in their communities. The healthcare providers did not recognize that Aboriginal women may view the body as being "sacred" or did not even consider traditional or cultural beliefs. Neither the healthcare providers nor the women mentioned the impact that Christian religious teachings may have on their beliefs and values regarding how they view the body and self. I am uncertain as to why religion was not part of the discussion.

As with the impact of historical and social factors described above, what is important to note is that there is diversity in Aboriginal women's experiences and perceptions about Pap smear screening. For some women, receiving Pap services from male healthcare providers or having a history of sexual abuse can generate painful

experiences during Pap smear screening. Some women avoid Pap smear screening as a way to protect themselves from reliving past negative experiences with sexual assaults or abuse. For some women, when Pap smear screening is performed by Caucasian men it is experienced as a further insult perpetrated by their colonizers. Remarkably, some women continued to access Pap screening regularly in spite of these painful past experiences. Although Pap smear screening was "unpleasant, but necessary," several women talked about it to be able to care for their children or to be able to have children. Others were motivated to be screened because of having had cervical cancer themselves or knowing someone who had cervical cancer. At the same time, others' fears of being diagnosed with cervical cancer were the reason for not accessing Pap smear screening.

A few women linked not having adequate information about Pap smear screening and not being provided with adequate explanations of the procedure as reasons for negative experiences or not accessing future Pap screening. This is consistent with some of the literature (Amankwah et al., 2009; Black, 2009; O'Brien et al., 2009; Steven et al., 2004). Having educational tools, posters, and pamphlets developed specifically for Mi'kmaq women that are culturally safe and representative of Aboriginal women with appropriate literacy levels are important to raise awareness about or access to Pap smear screening. Currently, women are forced to rely on Western educational tools that are not always reflective of their realities.

Healthcare providers perceived that Mi'kmaq women lacked knowledge about Pap smear screening, a view that is supported in some of the literature (Amankwah et al., 2009; Clarke et al., 1998; Hislop et al., 1996; NAHO, 2010; O'Brien et al., 2009; Smith

et al., 2003; Steven et al; 2004). However, healthcare providers felt that they were responsible for educating women and heightening awareness about Pap smear screening. Consistent with the literature, women in this study stressed that for education to be effective healthcare providers must consider Aboriginal women's literacy levels; use appropriate literature, educational tools, and methods of learning; and address what women want to know about Pap smear screening in a respective, reciprocal, and culturally safe manner (Black, 2009; Bourque Bearskin, 2011; Letendre, 2008).

### Mi'kmaq women are accessing Pap smear screening.

Although statistical data indicates that there are low rates of Pap smear screening and high rates of cervical cancer among Aboriginal women, findings in this study suggest that many women are in fact taking care of their health by accessing Pap smear screening. Although statistical data are important to raise awareness and highlight the importance of Pap screening programs for Aboriginal women, they do not reflect broader determinants that impact Mi'kmaq women's access to Pap smear screening such as literacy, power imbalances, healthcare encounters, policies, and discrimination. This, in turn, influences not only how others view Aboriginal women, but how the women view themselves. Statistics alone can be problematic, portraying a negative representation that perpetuates stereotyping of Aboriginal women. Women in this study are telling a different story than the one being explained by the use of statistics alone.

## Healthcare providers are influencing Mi'kmaq women's access.

Several women indicated that healthcare providers are making a difference in whether or not they access Pap smear screening, and particularly emphasized the importance of trusting and respectful relationships. Women attributed having a positive relationship with a healthcare provider as definitely influencing their access to regular Pap smear screening, whereas strained relationships lacking trust hindered access. Some even recommended that visiting the community and attending cultural events were ways healthcare providers could foster relationships with community members. However, not all agreed on this point and some relayed that it could actually hinder the building of relationships by making some women feel uncomfortable. Some added that healthcare providers should visit the community at the invitation of community members and be knowledgeable about and respectful of community norms. Clearly there is no one formula for building trusting relationships that should be applied in all circumstances.

All the healthcare providers in the study supported the fostering of trusting relationships as a means of increasing the women's access to Pap smear screening. This parallels the literature that has been conducted with Aboriginal women in other Canadian provinces (Black, 2009; Brown & Strega, 2005; NAHO, 2010; O'Brien et al., 2009; Shahid, Finn, & Thompson, 2009; Smith et al., 2010; Steven et al., 2004; Wilson, 2008). However, it is also important for healthcare providers to be cognizant of their privileged positions as White healthcare professionals and the power imbalances that exist in relationships with Aboriginal people. Without such reflection, healthcare providers may unintentionally stigmatize or marginalize Aboriginal women from accessing healthcare

services by attributing lack of access to personal choices or lifestyle behaviors, rather than to socioeconomic and educational inequities or inequities inherent in the healthcare system.

Some Mi'kmaq women described negative experiences with healthcare providers including experiences of discrimination and stereotyping, and a lack of cultural safety. These experiences have been well documented in the current literature (Browne, 2007; Browne et al., 2011; Dion Stout, 2012; Martin, 2012; McGibbon & Etowa, 2009; Reimer-Kirkham & Anderson, 2002; Tang & Browne, 2008). To change this pattern, women identified that healthcare providers require knowledge and understanding about Mi'kmaq culture, history, and social context. Several of the women cautioned that healthcare providers should not categorize all Aboriginal people as having the same cultural, historical, or sociopolitical experiences and that they should address the unique needs of each Aboriginal woman when she is accessing Pap smear screening.

#### Healthcare systems are influencing Mi'kmaq women's access.

Women reported that healthcare systems are shaping their access to Pap smear screening. For example, confidentiality and privacy issues, lack of interpreters, lack of timely appointments, and lack of transportation are presenting challenges for their access to screening. Furthermore, because healthcare systems tend not to incorporate Indigenous knowledge, traditions, or teachings into institutional policies or educational materials, women's unique needs often were not addressed.

Mi'kmaq women and healthcare providers reported that confidentiality and privacy issues in Aboriginal healthcare centers negatively impacts access to Pap screening. Until confidentiality and privacy issues are addressed, some women will not access community-based services at all and others will go outside the community to receive services. While it is important to increase Pap smear screening funding and services in Aboriginal communities as a means to increase access, it is unlikely that these efforts will result in improved screening unless confidentiality and privacy issues are addressed.

The multiple jurisdictions involved in Aboriginal health funding make healthcare services complex and funding challenging in First Nation communities (Fiske & Browne, 2006). Federal, provincial, and local jurisdictions are responsible for multiple portfolios related to Aboriginal people's health, including Pap smear screening. The extent to which this screening is prioritized in comparison to other health programming initiatives such as diabetes, HIV/AIDS, healthy child development, and immunizations is also a concern (First Nations & Inuit Health, 2012).

#### **Overview of Healthcare Providers Perspectives**

Healthcare providers in the study demonstrated a genuine interest in working with Aboriginal people and identified the importance of understanding the impact that history, sociopolitics and economics play in shaping Aboriginal women's lives and access to Pap smear screening. Fostering Aboriginal women's access requires the building of trusting relationships, cultural safety in practice, and the addressing of confidentiality issues.

These findings are congruent with what the Aboriginal women reported. Confidentiality in Aboriginal communities was associated with culture by healthcare providers. Lack of confidentiality was attributed to not having proper procedures and policies for housing personal information and data, as well as the employment of community members at the health centres.

The healthcare providers acknowledged that racism and stereotyping in mainstream healthcare and healthcare encounters exists and that discrimination originates from societal middle-class values and biomedical perspectives. Yet they did not talk about their own positions of privilege and power when talking about Pap smear screening encounters with Aboriginal women. Most healthcare providers in this study continued to indicate that Aboriginal women lacked knowledge and education about Pap smear screening with little recognition about the lack of available Aboriginal tools and information to educate women.

#### **Study Strengths and Limitations**

Using participatory action research approaches and Indigenous principles as well as talking circles and in-depth interviews enabled respectful and trusting relationships to be developed between the researcher and participants. This approach fostered open dialogue and the opportunity to share in rich stories communicated by women about Pap smear screening within the context of Mi'kmaq women's lives. Many of the women in the study communicated that they had not talked about their experiences with Pap smear

screening previously. Thus, it was evident that this research provided women with an opportunity to give voice to their stories and experiences.

The use of in-depth interviews captured the diversities between and among women and the diversities in women's experiences with Pap smear screening. The diversity of the participants and the two Mi'kmaq communities strengthens the transferability of the study finding. The interviewing of both Mi'kmaq women and healthcare providers offers multiple perspectives while highlighting the complexities of Pap smear screening for Aboriginal women.

Although the study represents a broad range of ages, having only two women over the age of 60 is a study limitation. The inclusion requirement that women speak, read, and understand English may have been a deterrent. Women under 21 years of age were excluded from the study and therefore these findings may not be transferable to their experiences or perspectives.

#### **Implications for Healthcare Practices**

Healthcare providers are commonly the first point of entry to the healthcare system and advocates "for best practices in developing strong Aboriginal communities" (Barton, 2008, p. 28). Their approaches and interactions with Aboriginal people can influence future accessing of healthcare services (O'Brien et al., 2009). From this study, it is evident that healthcare providers need to consider the social determinants of health and the broader contexts of Aboriginal women's lives when considering why they may or may not be accessing Pap smear screening. It is also vital to understand the impact of

historical trauma, interpersonal violence- and trauma- informed care for Aboriginal people and at the same time be aware that Aboriginal people have strengths to counter traumas and violence.

## Individualize Pap smear screening.

Healthcare providers should not essentialize Aboriginal people but rather view them as having diverse needs, language, education, traditions, beliefs, practices, and social contexts. A "one size fits all" approach to healthcare practice will not work, and individualizing healthcare services like Pap smear screening practices is vital. An approach that works in one community may not be appropriate in another. Healthcare providers must also question the limitation of mainstream standards and best practice guidelines and recognize that these may not always apply to Aboriginal people. For example, the current Pap smear screening practice guidelines require healthcare providers to inform women of positive results only. Some women in this study, especially those with high levels of anxiety about test results, expressed a clear preference for being notified of negative test results as well.

#### **Building relationships.**

Time invested for the development of relationships with members of Aboriginal communities and getting to know the community and community members as well as becoming familiar with community practices, beliefs, traditions, and history is essential (Black, 2009; Browne et al., 2011; Loppie, 2007; Martin, 2012; NAHO, 2010; O'Brien et

al., 2009; Shahid, Finn, & Thompson, 2009; Smith et al., 2010; Steven et al., 2004; Vukic et al., 2011). Black (2009) suggests that healthcare providers organize and present health conferences and workshops in the Aboriginal communities, take time to visit the communities, and hold Pap smear screening events that are focused on Aboriginal women's health using Aboriginal teaching tools with Aboriginal role models. This is congruent with findings from my study. Building women's capacity by increasing their knowledge about Pap smear screening may potentially increase their access to Pap smear screening services (National Aboriginal Health Organization [NAHO], 2010; Smith et al., 2010; Steven et al., 2004).

# Creating safe spaces.

Healthcare providers are in key positions to enhance education and knowledge about Pap smear screening with Aboriginal women and to facilitate opportunities for these women to share their stories, perceptions, and experiences with other women. This would raise awareness of the importance of accessing Pap smear screening and honor storytelling as an authentic method for sharing knowledge. For example, some women in my study communicated that they were willing to share with healthcare providers the importance of what, how, and where to teach Mi'kmaq women about Pap smear screening. In addition, some were willing to inform healthcare providers about the use of appropriate resources and educational tools that would be helpful in increasing knowledge and awareness about Pap smear screening, but were never asked to do so. Yet

others spoke about the importance of sharing formal and informal knowledge about health and Pap smear screening with family, friends, and community members.

It is fundamental that healthcare providers be educated about the need to create safe spaces for Aboriginal women to dialogue with healthcare providers and each other about Pap smear screening during workshops and in clinics.

## Educating women.

It is also important for healthcare providers to provide education that involves Aboriginal women in the process and is mindful of literacy levels. Aboriginal women must be asked about what education they would like to receive and how they would like to receive it. Women should be included in planning educational materials and sessions about Pap smear screening and HPV prevention, including the Gardasil vaccine.

From the study findings it is important to educate women about Pap smear screening in diverse ways such as providing written materials, workshops, community meetings, and sharing circles. Distributing promotional materials about Pap smear screening in community health centers and community events would also potentially increase knowledge and may improve screening rates.

#### Violence and trauma-informed care.

Healthcare providers need to learn about the Aboriginal people in the specific community in which they are practicing to provide violence- and trauma- informed and comprehensive Pap smear screening. Healthcare providers performing Pap smear

screening must be cognizant that their practices can either make screening experiences comfortable, uncomfortable, or traumatizing. Thus, healthcare providers must be willing to talk with women about their histories of violence and trauma, specific requests, needs, or cultural practices prior to conducting screening (Browne, Varcoe, Wong et al., 2012; Elliott, Bjelacjac, Fallot, Markoff & Reed, 2005; Poole, 2012). In addition, healthcare providers need to be aware that there are various forms of trauma experiences (e. g., historical, violence, sexual assault, mental distress) and ways that people react to trauma. It is also important to be aware that not all Aboriginal people acknowledge experiencing trauma.

The following summarizes helpful healthcare providers' practices related to trauma-informed care (Atkinson, 2002; Elliott, Bjelacjac, Fallot, Markoff & Reed, 2005; Haskell & Randall, 2009; Poole, 2012). Healthcare providers should:

- Assess their awareness of the impact of trauma on Aboriginal people.
- Understand generational, collective-social, cultural and developmental trauma within Aboriginal families and communities.
- Understand cultural competency and cultural safety and how these relate to trauma recovery.
- Examine the rights and responsibilities of Aboriginal people; who has rights and who is responsible for what.
- Promote self-governance and self-care for individuals, families and communities.
- Explore how to integrate Western and Indigenous cultural practices into service delivery, including art and active listening activities.

- Understand that recovery is possible for everyone regardless of how vulnerable they may appear.
- Understand that not all Aboriginal people experience violence in the same manner.

Importantly, strategies for violence and trauma-informed care are needed to inform the structures and processes of primary healthcare organizations where Pap smear screening services are offered, such as community health centers and family practice offices. Browne et al. (2012) identify four dimensions of equity-oriented primary healthcare services including trauma- and violence-informed care, inequity-responsive care, contextually-tailored care, and culturally-competent care. The authors define trauma- and violence-informed care as "recognizing that most people affected by systemic inequities and structural violence have experienced, and often continue to experience, varying forms of violence with traumatic impact" (p. 5). Healthcare should encompass "respectful, empowerment practices informed by understanding the pervasiveness and effects of trauma and violence, rather than 'trauma treatment' such as psychotherapy" (p. 5). Inequity-responsive care addresses the social determinants of health in aspects of care and contextually-tailored care encompasses services tailored to the populations being served and to local contexts. Culturally-competent care takes into account "people's experiences of racism, discrimination and marginalization and the ways those experiences shape health, life opportunities, access to health care, and quality of life" (Browne et al., 2012, p. 5) as well as the cultural meaning of health and illness.

The following are 10 strategies to guide organizations in enhancing capacity for equity-oriented services (Browne et al., 2012, p. 5):

- Make an explicit commitment to equity
- Develop supportive structures, policies, and processes
- Revision use of time to meet the needs of client populations
- Attend to power differentials
- Tailor care, programs and services to context
- Actively counter oppression
- Promote community plus patient participatory engagement
- Tailor care, programs and services to histories
- Enhance access to social determinants of health
- Optimize use of place and space

## **Culturally safe practices.**

Healthcare providers must incorporate cultural safety into their practices. The implementation of cultural safety can lead to improved healthcare access for Aboriginal individuals by exposing the historical, political, and social contexts that shape healthcare for Aboriginal people. Practicing cultural safety enables the consideration of racism, discrimination, and prejudice and means that cultural safety should be determined with the recipients of care. Practitioners competent in cultural safety challenge power relations while providing a way to question and analyze cultural assumptions about Aboriginal people (Browne, 2007; Varcoe, 2004). Practitioners who use a cultural safety

lens in their practice critically analyze their own healthcare practices and policies. Thus, healthcare providers should reflect on their assumptions and biases about Aboriginal people and be mindful of the impact that residential schools and other historical trauma may have on inequities in access to services such as Pap smear screening. Since mainstream healthcare systems can perpetuate inequities in access for Aboriginal people, there is an urgent need to provide trauma-informed and culturally safe healthcare services (ANAC, 2009; Bourassa et al., 2004; Browne, 2007; McGibbon & Etowa, 2009).

# Going step-by-step.

Healthcare providers should go step-by-step during the Pap smear screening procedure to inform women about what they are doing so as to make the experience as positive as possible. Women should be offered the choice of having a family member or friend with them during Pap smear screening as a support. Although some of the literature (ANAC, 2009; O'Brien et al., 2009; Smylie, 2001; Steven et al., 2004) recommends that there should be more Aboriginal healthcare professionals and more female healthcare providers in Aboriginal communities to perform Pap smear screening, the findings from my study identify that women want to be able to choose the provider they are most comfortable with and their preferred characteristics of the provider varied. While some women had a clear preference for a female provider, others indicated that gender was less important than the relationship they had with the provider. Trust and continuity were the most important aspects of this relationship.

## Offering consistent and convenient screening.

According to the study findings, Pap smear screening services should be offered consistently by the same healthcare provider in the communities with extended clinic hours and personal reminders for increasing access potential for Aboriginal women. Healthcare providers may suggest child-friendly services for women without childcare so that they can access Pap smear screening. For example, they may suggest that women bring a friend or family member along with them to take care of their children and have a play room filled with toys.

#### Forming a Pap smear screening committee.

Aboriginal women should have a voice and choice in the types of education they want, methods and tools used to teach them, and a choice of having Pap smear screening completed in or outside their community. One recommendation to ensure inclusivity of Aboriginal women is to form a Pap smear screening community partnership committee in each community. The committee would make decisions regarding the types of education about Pap smear screening required, recruitment strategies for Aboriginal women, and the types of education required by healthcare providers to provide Pap smear screening in Aboriginal communities. As mentioned by some of the women in the study, including high school students is another important strategy to assist in educating and recruiting youth about the importance of regular Pap smear screening. This would also empower youth to take ownership of their health and normalize Pap smear screening for Mi'kmaq

youth (Black, 2009). The following summarizes recommended Pap smear screening practice strategies for healthcare providers.

## Healthcare providers should.

- become familiar with and implement the concept of cultural safety into
   Pap smear screening practice
- develop respectful relationships with women and communities prior to initiating screening.
- use relational and collaborative approaches to Pap smear screening by creating safe spaces for open dialogue to clarify questions and share information about Pap smear screening and HPV prevention
- learn about the principles of trauma-informed care which can guide approaches to interacting with women in the context of intimate health interventions, such as Pap smear screening
- provide Pap smear screening education that is framed in ways that acknowledge women's realities, needs, and requests
- individualize Pap smear screening procedures to meet the needs and requests of women
- go step-by-step when performing Pap smear screening to inform women of the process
- identify women's strengths, successes, and goals with regards to Pap smear screening and life realities

- offer consistent and convenient screening times
- notify women of Pap screening results whether negative or positive
- develop a Pap smear screening committee inclusive of Aboriginal women,
   community members, healthcare providers, and other stakeholders to
   inform education, decision-making, and screening practices

## **Implications for Healthcare Education**

The provision of culturally safe healthcare for Aboriginal people requires healthcare providers to have cultural safety education (NAHO, 2006). This is consistent with the Aboriginal Nurses Association of Canada (2009), the Canadian Nurses Association (2010), the Association of Faculties of Medicine of Canada (2009), and the Indigenous Physicians Association of Canada (2009) professional organizations, all of whom have incorporated cultural safety into their educational competencies. Attending educational opportunities such as conferences and workshops about trauma-informed care is also imperative so that healthcare providers can guide assessments and be educated about ways of interacting with women who may have experienced traumas about Pap smear screening.

It is also essential that healthcare professionals' education include opportunities for clinical practice placements in Aboriginal health centers and communities. This would not only provide students with knowledge about Aboriginal people's health, but also be a means for reciprocal sharing of information. Another strategy for educating healthcare professionals about Aboriginal health and access to healthcare, such as Pap

smear screening, is to invite Elders or community members to be guest speakers in classes and workshops. I have done this in one of my classes and students obtained information regarding historical trauma, the impact of residential schools on the health of Aboriginal people, and the use of traditional medicines. The Elder I invited to class called herself "a residential schools survivor" and she provided vivid accounts of her experiences. Students valued this class and recommended that I continue this practice as they found the Elder's stories of lived experiences provided more meaning than reading about it in a journal article or textbook.

Developing a full understanding of cultural safety is not learned in one course or workshop. Further, not all cultural safety education needs to occur at the entry level of healthcare provider education. Instead, cultural safety education needs to be threaded throughout courses and continue in workshops and educational sessions in healthcare institutions and practice areas. For example, Petersen et al. (2002) described a unique training program for nurses employed by the Indian Health Service, community clinics, and other clinics with large underserved Aboriginal populations entitled "Native WEB (Women Enjoying the Benefit)" in Rochester, Minnesota. The primary purpose of the training program is to educate nurses to perform breast and Pap smear screening techniques and to administer screening programs encompassing patient outreach, education, and training. The program consists of 40 hours of training and educational workshops and includes breast and cervical cancer screening techniques, breast self exam education techniques, the development and use of tracking and reminder systems, community education, cultural and gender sensitivity education, and dissemination of

continuous quality improvement skills to implement and maintain well women's clinics for Aboriginal women.

Discrimination, stereotyping, Othering, and racism are still occurring in healthcare providers' encounters with Aboriginal people (Browne, 2005). The implementation of mandatory workshops for healthcare providers pertaining to racism, stereotyping, and cultural safety in practice may assist in combating racism and promoting cultural pluralism as well as more equitable access to healthcare services for Aboriginal people. Also, healthcare providers must be educated about how to initiate conversations and confidently discuss Pap smear screening with Aboriginal women while being mindful that their previous experiences can profoundly influence their comfort in talking about Pap smear screening and the procedure itself. Specific implications for nursing education must include incorporating topics such as racism, stereotyping, and cultural safety into curricula and teaching communication skills that will enable initiation of discussions of sensitive topics such as Pap smear screening and sexual health. The following is a summation of recommended Pap smear screening educational strategies for healthcare providers.

#### Healthcare providers should.

be educated about cultural safety in university education curricula, workshops,
 and by Aboriginal community members and be knowledgeable about professional
 cultural safety guidelines (e. g., Cultural Competence and Cultural Safety in
 Nursing Education – A Framework for First Nations, Inuit and Métis Nursing,

2009 and First Nations, Inuit, Métis Health Core Competencies: A Curriculum Framework for Continuing Medical Education, 2009).

- have opportunities for clinical practice placements in Aboriginal communities.
- be educated about racism and stereotyping of Aboriginal people in healthcare encounters and mainstream healthcare policies.
- be educated about how to initiate conversations with Aboriginal women about sensitive topics like sexual health and Pap smear screening.
- be educated about providing trauma-informed care.

## **Implications for Research**

Research is required to improve evidenced-based and culturally safe practices that will positively impact equity in access to healthcare services for Aboriginal people and the provision of culturally safe healthcare (Barton, 2008). Research with Aboriginal peoples must be inclusive and reflective of their worldviews and epistomological approaches (Battiste, 2000; Henderson, 2000; Smith, 2000; Wilson, 2001) and respectful of community protocols and values (CIHR, 2007; Getty, 2010). As a result, the community members are "part of the whole process, not simply passive recipients of a grand plan' developed outside of themselves" (Smith, 2000, p. 213).

It is critical to follow appropriate protocols and practices regarding research in Aboriginal communities (such as the CIHR and the Mi'kmaq Ethics Watch Guidelines) and to be mindful and respectful of appropriate ways to gain access to the community to conduct research with community members. Accessing Aboriginal communities to

conduct research is a process that takes time as relationships need to be developed and mutual trust maintained throughout and after completion of the research. I recommend the use of community facilitators when planning to conduct research with Aboriginal communities. Community facilitators can assist with the planning, implementation, evaluation, and dissemination of research as well as assist with recommending research processes such as gaining community access and learning community norms.

There should be meetings with Elders, community members, the Chief and Band Council, and visits to the health centers to discuss the potential of conducting research in the community. Researchers need to listen to recommendations and suggestions from community members and involve them actively in all aspects of the research process. Throughout this research study, I found that it was vital to listen to the comments of community members and to continue to ask their opinions about the research. The following is a summation of recommended Pap smear screening research strategies for researchers.

#### Researchers should.

- know and adhere to research guidelines for conducting research with Aboriginal people (e. g., community protocols, OCAP, and CIHR guidelines)
- develop and maintain collaborative research partnerships with community members by visiting the communities
- with the community, determine the research topic and goals for research
- involve community members in all aspects of the research process

- employ decolonizing research methodologies like participatory action and
   Indigenous research principles in a two-eyed seeing approach
- create ethical spaces for sensitive research topics like Pap smear screening
- use a postcolonial feminist theoretical perspective

#### **Future Research**

There is a need for intervention studies using PAR and Indigenous principles to determine the effectiveness of approaches to increase Pap smear screening access and to improve Pap smear screening experiences. Using participatory action and Indigenous principles an intervention study could explore a peer mentoring strategy that may be helpful in increasing Aboriginal women's access to Pap smear screening. Also, research involving women over the age of 60 years and younger than 21 is needed to explore their perspectives and experiences with Pap smear screening. An intervention research study could also be conducted to explore the effectiveness and acceptability of vaginal self sampling approaches as an alternative to Pap smear screening performed by healthcare providers (Zehbe et al., 2011).

Studies are needed to develop and evaluate Pap smear screening education and teaching tools in collaboration with women. The effectiveness of recruitment strategies also requires evaluation. More information is also needed to gain knowledge and greater understanding about how Aboriginal women's multiple roles and responsibilities and their traditional social roles impact their accessing of Pap smear screening.

# **Implications for Health Policy**

To promote equity in healthcare access for Aboriginal people, healthcare providers need to actively engage in the development and analysis of existing healthcare policies and advocate for policies that are inclusive of historical, economic, and political realities of Aboriginal people (Hall-Long, 2009). Policies are required to address the complex determinants of health that contribute to major disparities in access to healthcare services such as Pap smear screening.

According to Fridkin (2012), policies are required that improve services and access to services for Aboriginal people. Aboriginal people must also be involved in all aspects of health policy development, implementation and evaluation in order to have policies that are inclusive and effective, especially with regards to healthcare reform, access to healthcare, and allocation of funding. The development and evaluation of policies requires collaboration with Aboriginal communities and must be responsive to specific and ever changing needs and choices of the community members.

An area identified in this study that requires action is the development of confidentiality policies in community health centers. When I inquired about confidentiality policies in the health center, there was not much knowledge about whether confidentiality policies existed in the communities or not. Each health center takes on the responsibility to determine or develop how they will address confidentiality in their health centre. There was no published literature found pertaining to confidentiality polices in Aboriginal community health centers. Much of the existing literature pertains to maintaining confidentiality about HIV/AIDS, mental health issues, or instructs

researchers on how to maintain confidentiality when conducting research (Bucharski, Reutter, & Ogilvie, 2006; Canadian Institutes of Health Research, 2007; Steenbeek et al., 2010; Vicary & Bishop, 2005). There is a need to formalize confidentiality and privacy policies with Aboriginal communities and to educate healthcare providers and other workers in community health centers about patients' rights to privacy and confidentiality. Community healthcare centers in this study did not have formal policies regarding patient confidentiality and privacy, even though women disclosed issues with the housing of personal information and data, and community members being employed at the health centers having access to personal information. After discussions with the director of one community health centre, formalized confidentiality and privacy policies were developed and a confidentiality binder and pamphlets developed in consultation with an Aboriginal lawyer. With permission from the community, these could be shared as a template with other community health centers. By establishing confidentiality policies and procedures and sharing them publicly with Aboriginal community members, women may be more likely to access Pap smear screening in their communities.

There is also a need to develop and implement confidentiality policies for medical drivers that transport Aboriginal women to healthcare services, including Pap smear screening. Policies are also required that clarify jurisdictional responsibilities for funding and supplies for Pap smear screening in Aboriginal communities. The following is a summation of recommended strategies for Pap smear screening health policies.

Health policies are needed that:

• address inequities in health care services including Pap smear screening and

- inequities in access to other healthcare services
- address inequities in determinants of health that impact access to Pap smear screening services
- address confidentiality issues with the housing of personal information in community healthcare centers and with medical drivers
- clarify jurisdictional responsibilities regarding funding and supplies for Pap smear screening in communities
- consult with Aboriginal women and community members in policy development,
   implementation and evaluation related to Pap smear screening and HPV
   prevention, including the Gardasil vaccine.

# **Reflections and Personal Learning**

There were a few salient learning experiences for me that occurred as a result of this research. I learned the importance of patience and active listening involving the participants in the research process and the importance of building trusting relationships with Aboriginal people prior to even initiating research. I learned about the resiliency of Aboriginal people and to be cognizant of how mainstream discourses, including research discourses, can negatively label and misrepresent Aboriginal people. I have also learned that conducting Aboriginal research can be challenging and takes time but is very rewarding. I learned that not every researcher can do research with Aboriginal communities. Furthermore, I learned from Mi'kmaq women the value of keeping alive

one's cultural practices and language which has resulted in me starting to learn the Gaelic language that was spoken in my home.

I learned the value of using participatory action principles, Indigenous principles, and post-colonial feminist theoretical perspectives in a two-eyed seeing approach to conduct collaborative and respectful research when gaining knowledge about Aboriginal women's experiences with accessing Pap smear screening services. By using this research design, I was able to honor Mi'kmaq knowledge and traditions, foster relationships, and gain an in-depth understanding of the forces and wider contexts that shaped Mi'kmaq women's access to Pap smear screening such as history, socioeconomics, healthcare systems, and healthcare providers. This research provided me with opportunities to learn about Pap smear screening and the resiliency and agency that Mi'kmaq women are exerting with regards to their health and healthcare.

This is the beginning of a program of research with Mi'kmaq women and Pap smear screening. As a next step, with the women in these two communities I hope to develop an educational tool to educate other women about Pap smear screening and to continue working with the women to promote screening to decrease rates of cervical cancer in Aboriginal communities.

#### Conclusion

The purpose of this qualitative study was to explore Mi'kmaq women's and primary healthcare providers' experiences with Pap smear screening in two rural First Nations communities in Eastern Nova Scotia and to consider the broader historical,

economic, and sociopolitical contexts that shape those healthcare experiences. It is important to recognize that some Aboriginal women are accessing Pap smear screening regularly in spite of challenging circumstances. The epidemiological data do not tell the entire story about women's experiences with Pap smear screening or identify reasons why women may or may not be accessing screening. There are multiple factors such as history, socioeconomics, politics, healthcare providers, and healthcare systems that impact women's access. What is critical is that healthcare providers and others understand these diverse factors and how they influence women's access to Pap smear screening. Improving Pap smear screening for Mi'kmaq women requires multifaceted approaches that are developed in partnership with Aboriginal women.

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## Appendix A

### **Information Letter to Community Facilitators**

**Study Title:** Exploring Mi'kmaq Women's Experiences with Pap Smear Screening in Nova Scotia

Researcher: Cathy MacDonald, PhD Student, School of Nursing, Dalhousie University

Supervisors: Dr. Audrey Steenbeek and Dr. Ruth Martin-Misener

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Dear		

My name is Cathy MacDonald. I am a nurse and a PhD student in the School of Nursing, Dalhousie University. The purpose of my research study is to explore Mi'kmaq women's and primary healthcare provider's experiences with Pap smear screening in two rural First Nations communities in Eastern Nova Scotia (Paq'tnkek First Nation, Afton and Waycobah First Nation). This study is very important because of the low rates of Aboriginal women going for Pap smear screening and the high rates of cervical cancer. In this study Aboriginal women and healthcare workers will be invited to take part in the research and tell their stories about Pap smear screening experiences.

There will be about 15 to 20 Aboriginal women and 5 to 10 healthcare workers from the two communities. Mi'kmaq women will be asked to take part in two talking circles and two interviews. Healthcare providers will be asked to take part in two interviews. Mi'kmaq women in this study will: 1) be an Aboriginal woman; 2). living in one of the communities mentioned; 3). be between 21 to 75 years of age, 4). able to provide informed consent, and 5). able to understand and speak English. The healthcare providers do not necessarily need to live in the community where they work, and maybe a Community Health Nurse, Nurse Practitioner, Physician.

I am inviting you to be a community facilitator for your community in this study. As a community facilitator, you be will be asked to contact and invite 20 to 30 Aboriginal women to take part in this study. You can approach the potential participants in the community in person or by telephone to tell them about the study and ask if there are interested in the study or not. If a woman is interested in the study, you will invite her to the first talking circle in your community to get information about the study.

As a community facilitator, you will also give me names of possible healthcare workers who I can contact in person or by telephone to participate. I will then follow up with those healthcare providers who may be interested in telling their story. I will set up with them a time to discuss the study, answer questions, and get permission from them to participate in the study (consent).

You will also be helping with organizing talking circles, acting as a community link, and giving input about the interview questions and possible themes when data collection is finished.

I have attempted to design this study in a way that does not risk any of the participants in any way. If the participants do not feel comfortable discussing their experiences during the interviews, they are free to refuse to answer any question or withdraw from the study anytime without being penalized. If any of the participants feel they need to talk to a counsellor at any time during the study, a name will be provided to them.

Ethical approval for this study will be obtained from the Dalhousie University Health Sciences Human Research Ethics Committee, the Mi'kmaq Ethics Watch Committee and the community. The OCAP (ownership, control, access and procession) principles of the National Aboriginal Health Association and the Canadian Institute of Health Research (2007) guidelines for conducting research involving Aboriginal people will be adhered to throughout this study. Confidentiality will also be maintained throughout the study.

By being part of this study your role as a community facilitator, you are helping to add to the knowledge about Aboriginal women's experiences with Pap smear screening. This in turn will possibly improve the current Pap smear screening practices, policies and ways of doing Pap smear screening with Aboriginal women. Maybe this study will increase Pap smear screening and possibly decrease cervical cancer rates.

If you are interested in participating in this study as a community facilitator, we will then meet in person to talk about the study. If still interested, you will be asked to sign a Community Facilitator Participation Agreement (Appendix B).

If you would like further information, you can contact me by phone at any time at 902-867-3653 (w) or 902-867-1497 (h) or e-mail: <a href="mailto:cdmacdon@stfx.ca">cdmacdon@stfx.ca</a>.

You will be offered a gift of \$50.00 to acknowledge your participation as a community facilitator in this study.

Thank you for your interest in this research study. Information from this study will be helpful in assisting nurses and other healthcare providers to understand Aboriginal women's experiences with Pap smear screening.

Respectfully Yours,

Cathy MacDonald, PhD(c)

## Appendix B



## **Community Facilitator Agreement**

**Study Title**: Exploring Mi'kmaq Women's Experiences with Pap Smear Screening in Nova Scotia

Researcher: Cathy MacDon	ald, PhD Student, Dalhousie Univ	versity, School of Nursing.
I ag	gree to be a community facilitator	in this study. I have
received a letter of introducti	on from Cathy MacDonald, and l	nave been given time to ask
questions and make commen	ts. I understand that my main role	e as community facilitator
will be to work closely with	the participants and the researche	r by helping with
recruitment of participants. I	will also be helping with organiz	ing talking circles, acting
as a community link, and giv	ing input about the interview que	stions and possible
feedback about the themes w	then data collection is finished. I	understand that I will not be
collecting or reading informa	ation or stories from or about any	of the participants. I agree
that I will not talk about or ic	lentify study participants or those	who decided not to
participate in the study.		
I fully agree with being in the	is research in the role of commun	ity facilitator.
Community Facilitator:		
(Print name)	(Signature)	(Date)
,	, 0	(Date)
Address:		_
Phone Number:	E-Mail Address:	
Researcher:		
(Print name)	(Signature)	(Date)

## Appendix C

## Letter of Information to Mi'kmaq Women Participants

**Study Title**: Exploring Mi'kmaq Women's Experiences with Pap Smear Screening in Nova Scotia

Researcher: Cathy MacDonald, PhD Student, School of Nursing, Dalhousie University

Supervisors: Dr. Audrey Steenbeek and Dr. Ruth Martin-Misener

Dear Community Member:

My name is Cathy MacDonald. I am a Registered nurse and a PhD student in the School of Nursing, Dalhousie University. The reason of my research study is to explore Mi'kmaq women's experiences with Pap smear screening in two First Nations communities in Eastern Nova Scotia (Paq'tnkek First Nation, Afton and Waycobah First Nation). This study is very important because of the low rates of Aboriginal women going for Pap smear screening and the high rates of cervical cancer. In this study Aboriginal women and healthcare workers will be invited to take part in the research and tell their stories about Pap smear screening experiences.

There will be about 15 to 20 Aboriginal women and 5 to 10 healthcare workers from the two communities. Aboriginal women will be asked to take part in two talking circles and two interviews. Healthcare providers will be asked to take part in two interviews.

I am inviting you to take part in this study and take part in two talking circles and two interviews. The first talking circle will be to introduce myself and the study to you and to give you a time to ask questions, make comments, and give ideas about the study. The reason for the second talking circle is to talk about the research findings. We will also talk about how and where to share the research findings. These talking circles will last approximately 60-90 minutes or until all your questions are answered.

There will also be two interviews. Both interviews will be tape -recorded with your permission, and you will be asked a few questions and tell your stories about Pap smear screening. The second interview will take place after your first interview is typed. You will be invited to read your typed interview and you can make changes if you like to what you said in the first interview. If you decide not to read your interview, then I can call you to give an overview of what was typed. During this interview, you can tell me if the themes stand for what you said in your interview and we can talk more about some of the things you said in your first interview. Each interview will be scheduled for 60-90 minutes, at a place of your choosing in your community. You will also be asked to fill some general questions about yourself, such as your community. You will also be asked to fill some general questions about

yourself, such as your age, number of children, education, income, partner status, and some questions about Pap smear screening

By being part of this study, you are helping to add to the knowledge about Aboriginal women's Pap smear screening experiences. This in turn may improve the Pap smear screening practices, policies and ways of doing Pap smear screening with Aboriginal women. Maybe this study will increase Pap smear screening, and possibly decrease cervical cancer.

Permission to do this study will be obtained from your community, from the Dalhousie University Health Sciences Human Research Ethics Committee and the Mi'kmaq Ethics Watch Committee.

If you are interested in taking part in this study then you can either come to the Talking circle or call me to talk about the study. If you have agreed to take part in the study, you will be asked to sign a consent form (Appendix E).

If you would like further information, you can contact me by phone at any time at 902-867-3653 (w) or 902-867-1497 (h) or e-mail: <a href="mailto:cdmacdon@stfx.ca">cdmacdon@stfx.ca</a>.

You will be offered a gift of \$20.00 to acknowledge your participation in the research. Thank you for your interest in this research study. Information from this study will be helpful in assisting nurses and other healthcare providers to understand Aboriginal women's experiences with Pap smear screening.

Respectfully Yours,

Cathy MacDonald, PhD(c)

## Appendix D

### **Letter of Information to Healthcare Participants**

**Study Title**: Exploring Mi'kmaq Women's Experiences with Pap Smear Screening in Nova Scotia

Researcher: Cathy MacDonald, PhD Student, School of Nursing, Dalhousie University

Supervisors: Dr. Audrey Steenbeek and Dr. Ruth Martin-Misener

Dear Healthcare Provider:

My name is Cathy MacDonald. I am a Registered nurse and a PhD student in the School of Nursing, Dalhousie University. This study is very important because of the low rates of Aboriginal women going for Pap smear screening and the high rates of cervical cancer. In this study Aboriginal women and healthcare workers will be invited to take part in the research and tell their stories about Pap smear screening experiences.

The settings for this study will include two rural Aboriginal communities in Nova Scotia, namely Paq'tnkek First Nation, Afton, Nova Scotia and Waycobah First Nation, Cape Breton. The reason for choosing two Aboriginal communities was to increase the number of women and healthcare providers willing to participate. You may know some other healthcare providers that may also be interested in participating in this study.

There will be about 15 to 20 Aboriginal women and 5 to 10 healthcare workers from the two communities. Aboriginal women will be asked to take part in two talking circles and two interviews. Healthcare providers will be asked to take part in two interviews.

I am inviting you to take part in this study, as you have healthcare experiences with Aboriginal women. You will be invited to participate in two interviews and asked to complete an information sheet identifying where you work, number of years working here, your previous employment, and the length of your experience working with Aboriginal people. Interviews will last approximately 60-90 minutes. The interviews will be tape-recorded with your permission, and will give you a chance to talk about your experiences providing healthcare/Pap smear screening to Aboriginal women.

The second interview will take place after your first interview is typed. You will be invited to read your typed interview and you can make changes if you like to what you said in the first interview. If you decide not to read your interview, then I can call you to give an overview of what was typed. During this interview, you can tell me if the themes stand for what you said in your interview and we can talk about some of the information you provided in your first interview.

Ethical approval for this study will be obtained from the Dalhousie University Health Sciences Human Research Ethics Committee, the Mi'kmaq Ethics Watch Committee and the community. The OCAP (ownership, control, access and procession) principles of the National Aboriginal Health Association will be adhered to throughout this study. Confidentiality will also be maintained throughout the study.

By being part of this study, you are helping to add to the knowledge about Aboriginal women's Pap smear screening experiences. This in turn may help improve Pap smear screening practices, policies and ways of doing Pap smear screening with Aboriginal women. Maybe this study will increase Pap smear screening, and possibly decrease cervical cancer.

If agreed to participate in the study, and have all your questions and concerns answered, then you will be asked to sign a consent form (Appendix F).

If you would like further information, you can contact me by phone at any time at 902-867-3653 (w) or 902-867-1497 (h) or e-mail: <a href="mailto:cdmacdon@stfx.ca">cdmacdon@stfx.ca</a>.

You will be offered a gift of \$20.00 to acknowledge your participation in the research.

Thank you for interest in this study. Information from this study will be helpful in assisting nurses and other healthcare providers to understand Aboriginal women's experiences with Pap smear screening.

Respectfully Yours,

Cathy MacDonald, PhD(c)

## Appendix E



### Informed Consent for Interviews/Talking Circles for Mi'kmaq Women

(Circle) either Interview or talking circle above

Title of Study: Exploring Mi'kmaq Women's Experiences with Pap Smear Screening

In Nova Scotia

**Principal Investigator**: Cathy MacDonald RN, PhD(c)

PhD Nursing Student

Dalhousie University, School of Nursing

Halifax, Nova Scotia. Phone: (902) 867-1497 E-mail: cdmacdon@stfx.ca

Faculty Co-Supervisor: Dr. Audrey Steenbeek

**Assistant Professor** 

Dalhousie University School of Nursing

Halifax, Nova Scotia Phone: (902) 494-2535

E-mail: audrey.steenbeek@dal.ca

Faculty Co-Supervisor: Dr. Ruth Martin-Misener

Associate Professor & Associate Director Graduate Programs

Dalhousie University School of Nursing

Halifax, Nova Scotia Phone: (902) 494-2250

E-mail: ruth.martin-misener@dal.ca

#### **Introduction:**

I invite you to take part in a study by Cathy MacDonald, a Registered nurse and a graduate student in the School of Nursing at Dalhousie University. This study is called "Exploring Mi'kmaq Women's Experiences with Pap Smear Screening in Nova Scotia." Your taking part in this study is voluntary and you are free to pull out from the study at any time. The reason for this study will be talked about below. Taking part in the study may or may not benefit you but we might learn things that will benefit others. At any time, you can ask questions about the study to Cathy MacDonald.

#### **Reason for the Study:**

The purpose of this study is to learn more about Mi'kmaq women's experiences and primary healthcare provider's with Pap smear screening in Nova Scotia. Mi'kmaq women will be invited to tell their stories about Pap smear screening. You can tell stories about

your meetings with healthcare providers and the healthcare system, and the reasons why they think Aboriginal women may or may not have Pap smear screening done.

## **Gathering Stories and Number of Study Participants:**

The stories of Aboriginal women and Pap smear screening will be gathered by me asking you some questions. There will be about 15-20 Aboriginal women and 5-10 healthcare providers asked to take part in the study.

## Who Can Take Part in this Study:

You may take part in this study if you are an Aboriginal woman, living in an Aboriginal community, between 21 to 75 years of age, had at least one Pap smear screening, able to give consent (agreement) to take part in the study, and be able to read, write, and speak English. You may also take part in the study if you are a healthcare provider working with Aboriginal women. The healthcare providers may be registered nurses, nurse practitioners, or physicians.

### Who will be doing the Study:

Cathy MacDonald, a nurse and graduate nursing student will be doing the study with you.

### What will you be Asked to do:

You will be asked to take part in two talking circles and two interviews. The first talking circle will be to introduce myself and the study to you, and to give you a time to ask questions, make comments, and give ideas about the study. The reason for the second talking circle is to talk more about the study by getting your ideas and changes for the interview questions, talk about any issues, concerns, or changes you would like to make in the study. We will also talk about how and where to share the research findings. These talking circles will last approximately 60-90 minutes. Also, I will arrange a third talking circle to share study results in each community, if women wish to have one.

There will also be two interviews. The interviews will be tape-recorded with your permission, and you will be asked a few questions and tell your stories about Pap smear screening. The second interview will take place after your first interview is typed. You will be invited to read your typed interview and you can make changes if you like to what you said in the first interview. If you do not want to read your interview, then I can call you to give a short story about what was typed. During this interview, you can tell me if the themes stand for what you said in your interview.

Each interview will be scheduled for 60-90 minutes, at a place in your community. You will also be asked to fill some general questions about yourself, such as your age, number of children, education, income, partner or not, and date of last Pap smear screen and who did it. You do not have to prepare for this interview.

## **Confidentiality and Anonymity:**

It may not possible to keep all information that you may tell me in the focus group private as your community is small and people may know you by what you say and how you say it. However, I will I will do everything I can to make sure that your name and all information about you will not be shared in any final reports or anything put in journals. You will decide on a made up name or code name that will be used in all reports and documents. All tape recordings, information, typed stories, and notes about the study will be locked in a filing cabinet in my office, that only I have access.

All information about the study will be kept for five years after the study is finished and reported. Then, they will be destroyed.

Any data about the study will stored on the computer will be protected by a password. This data will not be used in any other studies in the future. The computer data will be deleted after the study is reported in journals.

The results of this study and quotes will be published reports and journals, presented at conferences and to you and your community in a talking circle. Your name will not be identified in any reporting of the study results unless you want your name made known. If you want a copy of the results, I will make sure you get one.

## **Limitation to Confidentiality:**

I have a duty to report anything you may tell or suggest to me about abuse or neglect of a child or children to authorities.

#### **Possible Risks:**

There are no known risks to taking part in this study. But some women may feel that Pap smear screening is very personal, and some taking part in the study may find telling their story upsetting or not pleasant. If you have any feelings of discomfort or have any concerns or fears I can give you names and how to get in touch with a counsellor or support services in your area. If you find a question too personal you do not have to answer it. The tape recorder can be turned off at any time, if you wish. You can ask questions to me before, during, or after the interview.

#### **Possible Benefits:**

There may be no direct benefits for taking part in this study. However, you might benefit by telling your story, thoughts, and experiences with Pap smear screening. You might also get to know more about Pap smear screening. By you taking part in this study you are adding to research about Aboriginal women and Pap smear screening.

## Withdrawing from the Study:

You can remove yourself from the study if you wish and have your data removed at any time up until the time of my thesis defence. If there are any questions that you do not feel

comfortable talking about then you do not have to answer those questions. If you chose to withdraw from the study, I will offer to destroy all your data or return it to you if you wish.

## **Compensation:**

There is no cost to you take part in this study. You will receive a gift of \$20.00 for your taking part in the study. I will also try to make sure that there will be no costs to you by planning interviews where and when you want. Even if you leave the study at any time or do only one of the two interviews, you will still get the she will still receive \$20.00.

## **Ethical Approval:**

Research ethics committee reviews for this study will be done by Dalhousie University Health Sciences Human Research Ethics Committee, the Mi'kmaq Ethics Watch Committee and your community. The OCAP (ownership, control, access and procession) principles of the National Aboriginal Health Association and the Canadian Institute of Health Research (2007) guidelines for conducting research involving Aboriginal people will be adhered to throughout this study.

#### Additional Information about the Study:

If you have more questions or concerns about you taking part in the study please get in touch with Cathy MacDonald at 902-867-3653(work), 24 hour assistance: 902-870-1162 (cell phone) or e-mail: <a href="mailto:cdmacdon@stfx.ca">cdmacdon@stfx.ca</a>. Also, Dr. Audrey Steenbeek or Dr. Ruth Martin-Misener toll free at 1-800-500-0912. I will let you know if there are any new things that may come up during the study that may affect you taking part in the study.

## **Additional Contacts for Problems or Concerns:**

Any concerns or problems with the study or any part of the study, you may get in touch with Patricia Lindley, Director of Dalhousie University's Office of Human Research Ethics and Administration at (902) 494-1462 or e-mail her at patricia.lindley@dal.ca

<b>Voluntary Consent and Si</b>	C	
I	, have read and fully unde	erstand about this study. I
concerns have been answerd want to take part in this stud	t to take part in this study. Howev	k about whether or not I
Participant:		
(Print name)	(Signature)	(Date)

1,	agree to have my intervi	ew tape recorded.
Participant:		
(Print name)	(Signature)	(Date)
1 1	agree for my words or what ns or presentations. I am fully awatements, unless I want them to.	I say in my stories to be used as are that my name will not appear
(Print name)	(Signature)	(Date)
Researcher:		
(Print name)	(Signature)	(Date)

## Appendix F



### **Informed Consent for Interview for Healthcare Providers**

Title of Study: Exploring Mi'knag Women's Experiences with Pap Smear Screening In

Nova Scotia

**Principle Investigator**: Cathy MacDonald RN, PhD(c)

PhD Nursing Student

Dalhousie University, School of Nursing

Halifax, Nova Scotia. Phone: (902) 867-1497 E-mail: cdmacdon@stfx.ca

Faculty Co-Supervisor: Dr. Audrey Steenbeek

**Assistant Professor** 

Dalhousie University School of Nursing

Halifax, Nova Scotia Phone: (902) 494-2535

E-mail: audrey.steenbeek@dal.ca

Faculty Co-Supervisor: Dr. Ruth Martin-Misener

Associate Professor & Associate Director Graduate Programs

Dalhousie University School of Nursing

Halifax, Nova Scotia Phone: (902) 494-2250

E-mail: ruth.martin-misener@dal.ca

#### **Introduction:**

You are invited to take part in a research study being conducted by Cathy MacDonald, a Registered nurse and a graduate student in the School of Nursing at Dalhousie University, as part of her PhD program. This study is called "Exploring Mi'kmaq Women's Experiences with Pap Smear Screening In Nova Scotia." Your taking part in this study is voluntary and you are free to pull out from the study at any time. The reason for this study will be talked about below. Taking part in the study may or may not benefit you but we might learn things that will benefit others. At any time, you can ask questions about the study to Cathy MacDonald.

#### **Purpose of the Study:**

The purpose of this study is to learn more about Aboriginal women's and primary healthcare provider's experiences with Pap smear screening in Nova Scotia. Aboriginal women will be invited to tell their stories about their experiences with Pap smear screening and their encounters with healthcare providers and the healthcare system. You are invited to tell your story as a healthcare provider working with Aboriginal women

about Pap smear screening and the possible reasons why they may or may not be accessing Pap smear screening services.

## **Gathering Stories and Number of Study Participants:**

The stories about Mi'kmaq women and Pap smear screening will be gathered by me asking you some questions. There will be about 15-20 Aboriginal women and 5-10 healthcare providers asked to take part in the study.

## Who Can Participate in this Study:

You may take part in the study if you are a healthcare provider working with Aboriginal women. The healthcare providers may be registered nurses, community health nurse, nurse practitioners, and physicians.

## Who will be conducting the Study:

Cathy MacDonald, a nurse and graduate nursing student will be conducting the study. As well, I will be supervised by Dr. Audrey Steenbeek, Dr. Ruth Martin-Misener, Dr. Annette Brown and Dr Charlotte Loppie-Reading.

## What will you are Asked to do:

Healthcare providers will be asked to complete two interviews and asked to complete an information sheet identifying where you work, number of years working here, your previous employment, and the length of your experience working with Aboriginal people. Interviews will last approximately 60-90 minutes. Interviews will be audio-taped with your permission, and will give you a chance to talk about your experiences providing healthcare/Pap smear screening to Aboriginal women. The second interview will take place after your first interview is transcribed (typed), but there is no obligation to participate. The second interview will be held to give you an opportunity to add or make changes to the information you provided in the first interview. You will be invited to read your typed interview for accuracy, and you can make comments or changes to what you said in the first interview. However, if you decide not to read your interview, then I can call you to give an overview of what was typed. During this interview, you can tell me if the beginning themes represent what you said in your first interview and talk in more detail about some things you said in your first interview.

## **Confidentiality and Anonymity:**

It is not possible to keep healthcare providers' information truly anonymous due to the small numbers of healthcare providers in each community. However, every attempt will be made to ensure the utmost anonymity and confidentiality possible. Your name and all information about you will not be identified or shared with anyone. Your name will not be used in any report or publications of the research findings, unless you want to be identified. You will give me a made up name (pseudonym) or code name that will be used in reports and documents. All audio-tapes, information, transcripts, and notes pertaining to the study will be securely locked in a filing cabinet accessible only to me and kept for five years after the study is completed and published. Then, they will be destroyed.

Any data stored on the computer will be protected by a password. This data will not be used in any other studies in the future. The computer data will be deleted after the study is reported in journals.

The results of this research and quotes will be published in professional journals and presented at conferences. However, your name will not be identified, unless you request to be identified. If you desire a copy of the results, a copy will be provided upon request.

#### **Possible Risks:**

The risks for taking part in this study appear to be minimal. However, due to the personal nature of the topic, some healthcare providers may find it upsetting or unpleasant if they have not discussed the topic previously. If you experience any feelings of discomfort or issues arise, I can provide names and contact information for counselling/support services in your area. If you find a question too personal or uncomfortable, you do not have to answer it and the tape recorder can be turned off at any time. You are reminded that you can ask questions to me before, during, or after the interview.

#### **Possible Benefits:**

There are no direct benefits for participating in this study. However, you might benefit indirectly by telling your story, thoughts, and experiences with proving healthcare and Pap smear screening services to Aboriginal women. You might also gain more knowledge and awareness about factors that may affect Aboriginal women's accessing of Pap smear screening services. Your participation in this study adds to the research about Aboriginal women and Pap smear screening.

#### Withdrawing from the Study:

You can withdraw from the study and have their data removed at any time up until the time of the thesis defence. If you choose to withdraw from the study, I will offer to destroy all the data or return it to you if requested.

#### **Compensation:**

There is no cost to you to take part in this study and you will receive a gift of \$20.00 to acknowledge your assistance in the study. I will also attempt to minimize any cost to you by scheduling interviews at a convenient time and location to you. If you decide to withdraw from the study or complete one interview you will still receive the \$20.00.

#### **Ethical Approval:**

Research ethics committee reviews for this study will be completed by the Dalhousie University Health Sciences Human Research Ethics Committee, the Mi'kmaq Ethics Watch Committee and the community. The OCAP (ownership, control, access and procession) principles of the National Aboriginal Health Association and the Canadian Institute of Health Research (2007) guidelines for conducting research involving Aboriginal people will be adhered to throughout this study.

## **Additional Information Regarding the Study:**

If you have additional questions or clarifications regarding your participation please contact Cathy MacDonald at 902-867-3653(work)' 24 hour assistance: 902-870-1162 (cell phone) or e-mail: <a href="mailto:cdmacdon@stfx.ca">cdmacdon@stfx.ca</a>. Also, Dr. Audrey Steenbeek or Dr. Ruth Martin-Misener toll free at 1-800-500-0912. If there is any new information which may come up during the study that may affect your decision to part take in the study I will share this with you.

#### **Additional Contacts for Problems or Concerns:**

Any concerns or difficulties with the study or any aspect of your participation in this study, you may contact Patricia Lindley, Director of Dalhousie University's Office of Human Research Ethics and Administration at (902) 494-1462 or e-mail her at patricia.lindley@dal.ca.

	stand about this study. I
study and all my questions have n time to think about whether to onsent to participate in this study e study at any time without penalt	been answered to my participate in this study. . However, I realize that I
(Signature)	(Date)
(Signature)	(Date)
give permission to have	my interview audio-taped.
(Signature)	(Date)
(Signature)	(Date)
give permission for my word	ls or statements from my storie
	consent to participate in this study e study at any time without penals (Signature)  (Signature)  (Signature)  (Signature)  (Signature)

to.		
Participant:		
(Print name)	(Signature)	(Date)
Researcher:		
(Print name)	(Signature)	(Date)

aware that my name will not appear on any of these quotes or statements, unless I want them

## Appendix G

## Semi-structured Interview Guide for Mi'kmaq Women Participants

- 1 Please tell me a little about yourself?
- 2 Could you please describe your thoughts about Pap smear screening.
- 3 Could you please describe how you feel about Pap smear screening.
- 4 Approximately when was your last Pap smear completed? Where and by whom? How frequently do you go for Pap smear screening (Prompts: every year? every two years? Infrequently?)
- 5 Can you describe your last Pap smear screening experience? Is there anything in particular that stands out in your mind about your last Pap smear screening experience? (Prompts: Positive or negative? Educational or frightening?).
- 5. Please describe to me what you know about Pap smear screening? Where do you get most your information about Pap smear screening? (Prompt: Friends or family; TV; printed material; web-sites; other).
- 6. Is there a particular person you prefer to complete your Pap smear screening? Who? Are they in your community?
- 7. Can you tell me why you think some women in your community, or Aboriginal women in general may not be participating in Pap smear screening?
- 8. Can you tell me why you may or may not want to have a Pap test done?
- 9. Are there any things that may cause problems for you when accessing Pap smear screening? What are they?
- 10. Can you tell me a little about the healthcare providers that do your Pap smear screening?
- 11. How do you feel when healthcare providers are doing Pap smear screening?
- 12. Is there anything that concerns or challenges you about having Pap screening? (Prompt: privacy, access, confidentiality, timeliness of results, education about Pap smear screening, choice of healthcare provider and location).
- 13. Are there things that concern you about how the women in this community getting Pap screening? (Prompts: access, location, privacy, equipment)

- 14. Please describe to me what you would consider to be the best possible Pap smear screening experience.
- 15. What do you suggest health care providers and policy makers do to improve Pap smear screening?
- 16. Can you tell me if there are any challenges you face when accessing Pap smear screening? Describe.
- 17. Is there anything else that you would like to share with me? Do you have any questions for me?

# Appendix H

# **Demographic Information Sheet for Mi'kmaq Women Participants**

Community: Age:		
Relationship status: Please circle one Married Separated Divorced Widowed Single Living with a significant other		
Number of Children Employment Status: Please circle Unemployed Employed full time Employed part-time Receiving Disability Receiving Social Assistance		
Last level of education you had the opportunity Grade School Junior High School High School Graduated from High School Community College Attended some University classes Graduated from University	to complete: Please circ	le one
Income per year: Please circle one Less than 5,000 5,000-10,000 11,000-15,000 16,000-20,000 21,000-25,000 26,000-40,000 41,000-65,000 Over 65,000		
Last Pap smear screening: Date:etc.)	Location:	(clinic

How often do you go for Pap smear Screening?	How	often	do v	ou go	for Par	p smear	Screeni	ng?	
--	-----	-------	------	-------	---------	---------	---------	-----	--

Completed by: Physician: Yes No Nurse: Yes No Nurse Practitioner: Yes

## Appendix I

#### **Semi-Structured Guide for Healthcare Providers**

- 1. Can you tell me about your role as a healthcare provider to Aboriginal people in general and specifically Aboriginal women?
- 2. Can you tell me about your experiences providing care to Aboriginal women in this community? (Prompt: clinical, teaching, performing Pap smear screening, follow up communicating Pap smear screening results).
- 3. Does the care you provide to Aboriginal women differ from the care you provided to other patients?
- 4. Are there any challenges you have experienced working with Aboriginal people? With Aboriginal women? Please describe them.
- 5. As a healthcare provider working with Aboriginal people are there certain things that you needed to know or learn? (prompt cultural practices, traditional medicines, colonialism and historical trauma)
- 6. Why do you think some Aboriginal women may or may not be participating in Pap smear screening? (Prompt: access, location, personal choice, other commitments, unable to choose healthcare provider, fear regarding the procedure).
- 7. What aspects of Pap smear screening do you think maybe problematic for Aboriginal women? And for healthcare providers? (Prompt: are there different problems/issues for various ages of women; Are there technical issues or issues

- related to safe transport of specimens; Is there not enough time to do teaching about Pap smear screening).
- 8. What are some recommendations would you make for other healthcare providers and policy makers to provide Aboriginal women with equitable access to Pap smear screening?
- 9. What knowledge and expertise do you believe is important to have when providing healthcare/Pap smear screening to Aboriginal women?
- 10. Is there anything else you would like to add or any question you would like to ask I wonder?

# Appendix J

## **Demographic Data for Healthcare Providers**

Where do you work? Community:		_ Live:
Age?		
Healthcare Provider:		
RN		
NP		
Physician		
Other		
Number of Years working in this A communities?		
What is the total length of time you Last level of education you had the		
Where were you employed before	coming to work in this comr	nunity?
In what role?		
Do you have any formal courses of What type of education was this?_		
Employment Status: Please circle		
Employed full time		
Employed part-time		
If you are employed part-time do y	you work in another healthca	re facility?
Where? In what		•

## Appendix K



## **Transcriptionist Agreement of Confidentiality**

	ident at Dalhousie University, Sc oring Mi'kmaq Women's Experie	
I		criptionist, agree to keep all
the research information shar	red with me confidential.	
	y of the research information in a transcripts) with anyone other that	• •
-	nformation in any form or formature while it is in my possession.	(e.g., all data, materials
I agree to return all research have completed transcription	information to the researcher, Ca	thy MacDonald, once I
2	with the researcher, to erase or de egarding this research project tha	•
Transcriptionist		
(Print name)	(Signature)	(Date)
Researcher		
(Print name)	(Signature)	(Date)
Cathy MacDonald	University	sed to: