

Honouring Stories: Mi'kmaq Women's Experiences With Pap Screening in Eastern Canada

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Mi'kmaq women are reported to have lower rates of Papanicolaou (Pap) screening and higher rates of cervical cancer than non-Aboriginal women. This qualitative participatory study used postcolonial feminist perspectives and Indigenous principles to explore Mi'kmaq women's experiences with Pap screening within the contexts that shaped their experiences. Community facilitators assisted with the research process. Talking circles and individual in-depth interviews were conducted with 16 Mi'kmaq women. Also, health-care providers were interviewed in 2 Mi'kmaq communities. The findings indicate that historical and social contexts are shaping Mi'kmaq women's screening experiences and that these experiences are diverse, as are their understandings about screening. Some women were accessing regular screening despite challenging personal circumstances. The results highlight the need for nurses and other health-care providers to understand the uniqueness of each woman's experiences with Pap screening. Improvements in screening rates depend on multifaceted nursing approaches developed in partnership with Mi'kmaq women.

Keywords: Aboriginal women, cervical cancer prevention, Pap screening, participatory action research, postcolonial feminist perspectives, health-care access

Histoires de dignité : comment le test de Pap est vécu par des Micmaques de l'Est du Canada

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Selon les données, les Micmaques subissent le test de Papanicolaou (Pap) en plus petite proportion que les femmes non autochtones et présentent un taux plus élevé de cancer du col de l'utérus. La présente étude qualitative et participative adopte une approche féministe postcoloniale et s'appuie sur les principes autochtones pour examiner la façon dont les Micmaques vivent le dépistage du cancer du col de l'utérus (test de Pap), et les différents contextes où leur expérience de ce dépistage prend forme. Des animateurs communautaires ont pris part au processus de recherche. Des cercles de discussion et des entrevues individuelles approfondies ont eu lieu auprès de 16 Micmaques. Des fournisseurs de soins de santé ont également fait l'objet d'entrevues dans deux communautés micmaques. Les constatations indiquent que les contextes social et historique contribuent à façonner l'expérience vécue par les Micmaques au moment du test de Pap et que cette expérience varie, de même que la compréhension qu'ont les femmes du dépistage. Certaines femmes participent à un dépistage régulier, malgré une situation personnelle difficile. Les résultats obtenus font ressortir la nécessité pour les infirmières et les autres fournisseurs de soins de santé de comprendre le caractère unique de l'expérience de dépistage vécue par chaque femme. L'amélioration des taux de dépistage est tributaire de la mise en place d'approches à multiples facettes des soins infirmiers élaborées en partenariat avec les Micmaques.

Mots-clés : femmes autochtones, dépistage du cancer du col de l'utérus, test de Pap, étude participative, approche féministe postcoloniale, soins de santé

The health of Aboriginal¹ women is foundational to the well-being of their families, communities, and Nations (Native Women's Association of Canada, 2007). Despite recent improvements in health status at the population level, and despite the collective efforts of Aboriginal women to foster strength and health within their families and communities, health and social inequities persist in this population in comparison with the general Canadian population (Halseth, 2013).

In this article we explore cervical cancer as one particular health issue that needs attention. Although Papanicolaou (Pap) screening has been effective in decreasing the morbidity and mortality rates of cervical cancer (Canadian Cancer Society, 2012), Aboriginal women continue to have lower rates of screening and higher rates of cervical cancer than other Canadian women (Brassard et al., 2012; Zehbe, Maar, Nahwegahbow, Berst, & Pintar, 2012).

Much of the health-care literature, particularly the epidemiological literature, reports that Aboriginal women have higher rates of cervical cancer than non-Aboriginal women. Often, these rates are reported along with risk factors for cervical cancer, such as certain high-risk behaviours, lower rates of screening, and high rates of sexually transmitted infections (Gerberding, 2004; Johnson, Boyd, & MacIsaac, 2004; Reeves, 2008; Sheets, 2002; UNAIDS & World Health Organization, 2006). When the high rates of cervical cancer among Aboriginal women are attributed to these risk factors, Aboriginal women are frequently labelled as "high risk in terms of their reproductive health" (Browne & Smye, 2002, p. 32). However, research indicates that multiple factors impact the health status of Aboriginal women and shape their access to health services and their health-care experiences. It is therefore imperative to contextualize health status in light of sociopolitical, historical, and economic factors affecting health (Adelson, 2005; Browne, 2007; Browne et al., 2011). It is equally important to recognize that women's health is shaped by various strengths and abilities, including knowledge of local languages and community and cultural practices and ceremonies (Kirmayer, Dandeneau, Marshall, Phillips, & Williamson, 2011).

In many cases the mainstream health-care system is poorly aligned with the health-care needs of Aboriginal people because it tends to conceptualize health and illness as stemming from "lifestyle" or cultural differences and to overlook the contextual factors that shape health and illness (Browne & Dion Stout, 2012). Health-care policies and strategies

¹ The word Aboriginal refers to 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 (Aboriginal Affairs and Northern Development Canada, 2013).

aimed at helping Aboriginal people but based on Western models of health-care delivery and on individualistic, disease-based discourses can perpetuate racism, social exclusion, marginalization, and inequitable access to care (Barton, 2008; Martin, 2012). Nurses are in key positions to address inequities that affect access to Pap screening for Aboriginal women by incorporating the concept of cultural safety into screening practices, developing respectful relationships prior to screening, tailoring screening approaches to the specific needs of individual women, and adopting relational and collaborative approaches.

The purpose of this article is to report on findings from a community-based participatory study conducted in partnership with two Mi'kmaq communities in eastern Canada focused on cervical cancer screening. This qualitative study explored women's experiences with Pap screening in the two rural Mi'kmaq communities using a broader lens to conceptualize their health-care experiences. This allowed for women's participation in Pap screening to be considered with a fuller understanding of the historical, economic, and sociopolitical contexts that construct these experiences. Storied interviews were conducted with Aboriginal women and health-care providers. The research questions were as follows: 1. *What are Aboriginal women's experiences with Pap screening?* 2. *What are Aboriginal women's awareness of and knowledge about Pap screening?* 3. *What are the perceptions of Aboriginal women and health-care providers regarding the reasons why some Aboriginal women are not participating in Pap screening?* 4. *What are the sociopolitical, economic, and historical factors that shape Aboriginal women's participation in Pap screening?*

Theoretical and Methodological Perspectives

The study was informed by postcolonial feminist theoretical perspectives (Anderson, 2004; Reimer-Kirkham & Anderson, 2002) and Indigenous principles in a two-eyed seeing approach. The term "two-eyed seeing" (Sesatu'k Etuaptmnl) refers to the need to learn from one eye the strengths of Aboriginal traditional knowledge and from the other eye the strengths of Western scientific knowledge (Iwama, Marshall, Marshall, & Bartlett, 2009). Postcolonial feminist theory provides an analytic lens for exploring how women's lives and health have been positioned and shaped by politics and history (Browne, Smye, & Varcoe, 2005, 2007). "Postcolonial" does not mean that colonialism is over or completed: "the post in postcolonial refers to a notion of both working against and beyond colonialism" (McConaghy, 2000, p. 268). The use of postcolonial feminist perspectives allowed for Mi'kmaq women to be viewed not as a gendered group but as individuals with distinct historical, socio-economic, and political experiences (Lewis & Mills, 2003). There was an

understanding of how power, privilege, socio-economics, and race have contributed to inequities in access.

Indigenous principles fundamental to conducting respectful research with Aboriginal people provided the foundation for the theoretical development of the study (Martin, 2012; Weber-Pillwax, 2004). Indigenous principles of relationality, respect, reciprocity, relevance, and responsibility were also incorporated into the framework (Loppie, 2007; MacDonald, 2012). Respectful relationships with community members were developed through frequent visits to the health centre and attendance at community events prior to initiating the study. This was vitally important for the acquisition of knowledge about the communities, community members, community norms, and community expectations with regard to the research.

The Study

Qualitative Participatory Action Research Design

The research process was guided by a qualitative research design using participatory action research (PAR) and Indigenous principles. The qualitative nature of the study provided a means for analyzing and interpreting how the colonial past and the current sociopolitical and economic climate impact Aboriginal women's access to Pap screening. PAR principles of equity, social justice, democratic collective decision-making, and reciprocity (Loppie, 2007; MacDonald, 2012; Ortiz, 2003; Vollman, Anderson, & McFarlane, 2004; Vukic, Gregory, & Martin-Misener, 2012) were applied throughout the research. These principles were upheld by enabling the participation of community members, acknowledging that the viewpoints of all participants were valued, using collaborative decision-making regarding the research process and dissemination of findings, developing relationships, and fostering open communication. PAR is grounded in the practical problems and health issues of people in a given community. Thus, the research topic was determined with some community members by developing collaborative relationships while visiting the communities and the community health centre.

Women told stories from their contextualized social, economic, political, and historical realities and were considered co-investigators and active participants in different phases of the research. They provided input into the research questions, participant recruitment, data collection and analysis, modification of the interview guide, and dissemination of findings.

Ethical approval was obtained from the University Health Sciences Human Research Ethics Committee at Dalhousie University, Mi'kmaq Ethics Watch at Cape Breton University, and Mi'kmaq community leaders. The OCAP (ownership, control, access, and procession) principles

(1998) and the Canadian Institutes of Health Research (2007) guidelines for health research involving Aboriginal people were also followed. The OCAP principles were respected by informing the women about the entire study prior to their participation, discussing anonymity and confidentiality with them, ensuring that each informed consent form was signed and a copy given to the participant, and engaging participants in discussions about the findings and their dissemination.

Role of community facilitator. Community members, who were recommended (based on interest and willingness to participate) by health-care providers in each community, were invited and agreed to be the community facilitators. Their role was to organize the talking circles (described below), assist with recruitment, act as liaison between the community and the primary researcher, provide feedback regarding the interview guide and the research process, and review and comment on themes throughout the analysis. Community facilitators expressed an interest in being active throughout the research process and repeatedly affirmed the relevance of the research topic for their community. They communicated the information that there were some women in the community who did not go for Pap screening and that in each community they knew a woman who had a diagnosis of cervical cancer or who had died of cervical cancer.

Recruitment of Mi'kmaq women. Sixteen women were recruited using purposive and snowball sampling. Aboriginal women of diverse ages, socio-economic backgrounds, education, and Pap screening experiences were purposively recruited by community facilitators, who invited 20 to 30 Mi'kmaq women to participate in a talking circle with a health professional, a health centre director, and the primary researcher. The purpose of the talking circle was to facilitate collaboration and promote co-designing of the study.

The primary researcher used talking circles because traditionally a talking circle is structured to permit all voices to be heard (Tompkins, 2002). The talking circles for this study, one in each community, were premised on the PAR principles of respect, shared decision-making, reciprocity, and relationality, allowing for the mutual exchange of information in a comfortable environment with food. Women posed questions, made comments, told stories, and provided suggestions regarding the interview questions and the research process. The first talking circle comprised eight women and a nurse, while the second comprised 10 women, a nurse, and a health centre director. Those who participated in the talking circle informed other women in the community about the study, which resulted in the recruitment of a few other women.

To be included in the study, women had to (1) be a self-identified or status Aboriginal Mi'kmaq; (2) live in one of the two Mi'kmaq commu-

nities; (3) be between 21 and 75 years of age; (4) have had a least one Pap screening; (5) be able to provide informed consent; and (6) be able to read, understand, and speak English. A letter of introduction describing the study was distributed.

After consent for participation had been obtained, storytelling interviews using an in-depth guide, developed for the study with input from the community facilitators and women, were arranged at a time and location agreeable to each participant.

In-depth interviews. The women had the choice of taking part in one or two in-depth interviews so that each would have an opportunity to tell her stories about beliefs, attitudes, and experiences with respect to Pap screening. The interviews lasted from 60 to 90 minutes. A total of 16 women participated in the first interview (13 attended the talking circles) and all but one agreed to take part in the follow-up interview. The second interview took place following transcription of the first interview and preliminary analysis of the findings. During the second interview, the women were asked to provide feedback on data interpretation, preliminary findings, and emerging themes. Five health-care providers volunteered to take part in an in-depth interview and four agreed to a follow-up interview. In total, there were 40 interviews.

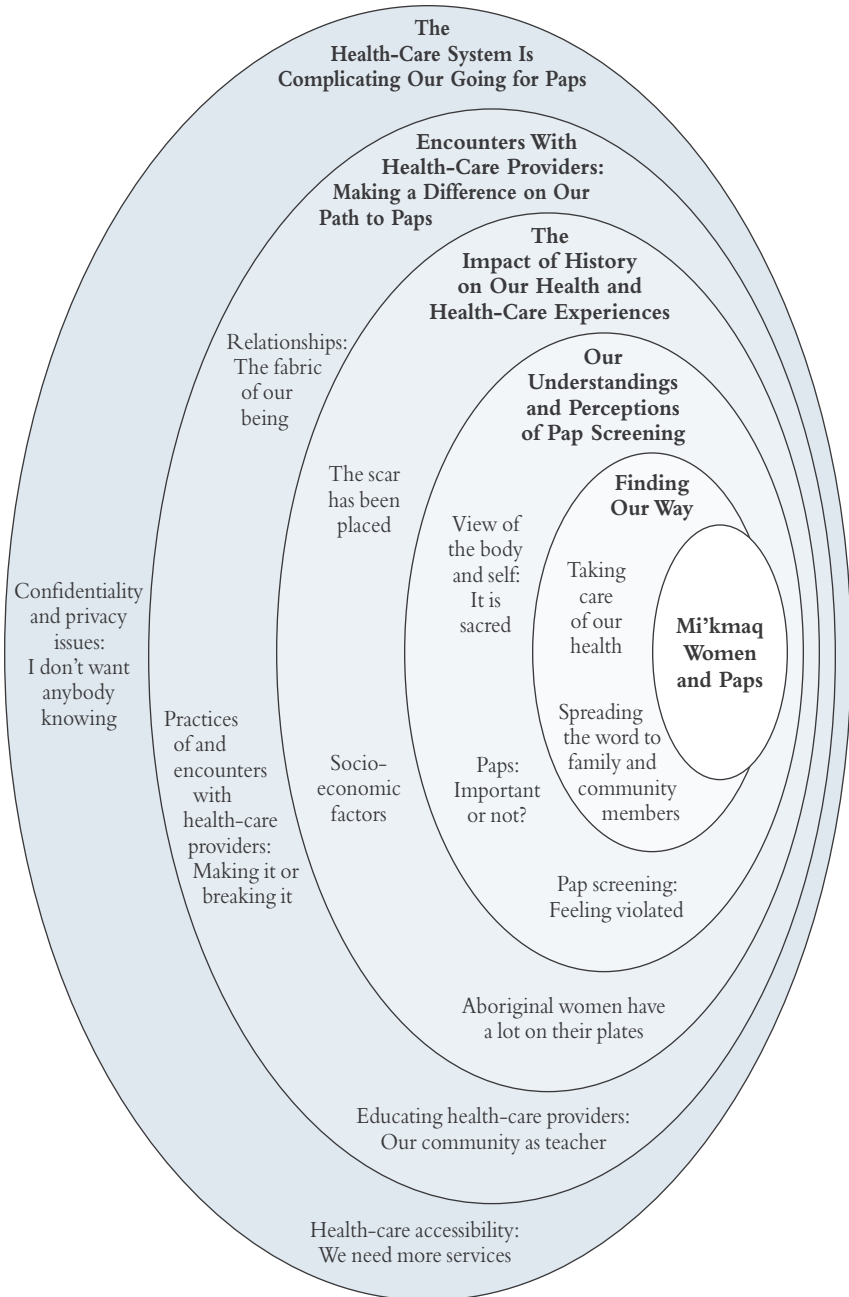
Data Analysis

After the audiotaped interviews were transcribed verbatim, data were imported into NVivo 8 qualitative software. Women had an opportunity to read and validate their transcribed interviews and provided input about preliminary themes and subthemes. Thematic analysis processes described by Sandelowski (1995) and O'Connor and Gibson (2003) were employed to identify themes elicited from the participants' stories. Although these themes were coded primarily by the researcher, women changed some of the titles of the themes and subthemes and offered explanations from an Indigenous perspective why the titles were or were not appropriate. Women clarified, altered, or confirmed that the data adequately reflected and were consistent with their stories and their experiences of Pap screening. Community facilitators also reviewed some of the coding processes to ensure validity of themes and subthemes. The trustworthiness of the research was enhanced through member checking, recording of field notes, forming of partnerships with and debriefing with community facilitators, peer review, and debriefing.

Findings and Discussion

The five themes and subthemes (see Figure 1) identified in the Mi'kmaq women's stories will be presented by integrating excerpts from inter-

Figure 1 *Themes and Subthemes: Mi'kmaq Women's Experiences With Pap Screening*



views. The findings and their interpretation are interwoven with the literature in a relational manner that honours and represents Aboriginal women's stories in an attempt to minimize the fracturing of knowledge passed on in oral form (Brown & Strega, 2005; Smylie, 2001).

Finding Our Way

This theme and its two subthemes reveal 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. Women described being committed to taking care of their health by seeking knowledge, becoming educated, and sharing knowledge with family and community members.

Taking care of our health. Many women described 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 disadvantages and adversity. Some talked about taking care of their health by becoming educated, being employed, and instituting early childhood learning. Others told stories about returning to cultural and traditional ways, revitalizing their language, and passing along parenting skills. For some women, seeking knowledge about health care was a way of taking care of their health.

A few women took care of their health by making sure follow-up appointments were made for their test results and treatments and keeping track of the dates for these appointments: "I know when my appointments [for Pap screening] are due. Usually I'll remember and I keep track."

These findings offer a counterbalance to much of the epidemiological literature implying that Aboriginal women do not take care of their health nor make personal efforts to do so. Much of the research has focused on women's low rates of Pap screening, high rates of cervical cancer, barriers to accessing health services, strategies to improve Pap screening rates, and reproductive health issues currently confronting Aboriginal women (Black, 2009; Johnson et al., 2004; O'Brien, Mill, & Wilson, 2009; Steven et al., 2004). Epidemiological statistics alone do not convey the current state of Aboriginal health (Graham & Stamler, 2010) and suggest that lifestyle choices are the reason for women not accessing Pap screening. According to Nelson (2012), the burden of responsibility for health and social problems is continually placed on Aboriginal people, who are denied the resources needed to adequately tackle these problems. Epidemiological research needs to be developed with other types of research that consider the contexts of Aboriginal people's lives.

Spreading the word to family and community members. This subtheme concerns the importance that the women placed on sharing their knowl-

edge and wisdom about health and Pap screening with family and community members. While some women said that there has been a loss of some traditional ways and knowledge, they continued to use storytelling with family and community as a path to taking care of their health. The women also spoke of the knowledge and advice they could share with health-care providers and policy-makers to make Pap screening a more positive experience. A few viewed sharing words of wisdom about Pap screening to be their personal responsibility as women, mothers, aunts, grandmothers, and friends, as it was traditionally with other aspects of health: "We learned about it [Pap screening] through word of mouth from family."

Some women in the community had taken on more formal educational roles, such as appearing on posters or presenting at health conferences; this was seen as important for raising awareness and recruiting Aboriginal women for Pap screening. One woman spoke of an acquaintance who attended health conferences and appeared on posters to share her knowledge about the importance of Pap screening and prevention of cervical cancer: "She was going to a health conference and they asked her to participate [in it] because she's . . . on the posters and stuff . . . that's probably the first time I really heard of it as cancer prevention, and that would have been . . . 4 years ago."

The interview data show that Aboriginal women are often forced to seek information about health care from Western sources such as pamphlets and other print materials, which are not always representative or reflective of their realities. Several participants indicated that brochures and other educational materials that are reflective of Aboriginal women's lives positively influenced Aboriginal women to access Pap screening: "It would seem important for them to attend [screening], and they could relate to those women in the pamphlets." This demonstrates the importance of having information that is relevant and appropriate for Aboriginal women and that promotes "the empowerment of Aboriginal women to take control of their own health care needs" (Black, 2009, p. 174).

Our Understanding and Perceptions of Pap Screening

The women expressed a multitude of beliefs, experiences, and feelings about Pap screening that often involved cultural ways of thinking about the body and self.

View of the body and self: It is sacred. Several participants explained 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 described their perceptions of the body and self as holistic, rooted in culture and traditions.

Some women described the perineum as a “sacred area.” One woman viewed that part of the body as sacred because “that’s where your baby’s life comes through, of course it’s sacred.” In traditional Aboriginal culture, the ability to give birth and raise children positions women in an esteemed, sacred, and respected role (Carroll & Benoit, 2004). Some women referred to the area of the body where Pap screening is conducted as a “private area.” A few said that they did not associate this part of the body with Aboriginal culture: “I don’t really feel like there’s a cultural thing — it’s a private area.”

Although some of the women expressed the opinion that Aboriginal and Western views of the body and self are different, others did not. One woman said, “Not all First Nations people view the body and self in the same way.”

A few women attributed the reluctance to discuss or seek Pap screening to the legacy of residential schooling and abuse. Traditionally in Aboriginal culture, teaching and knowledge acquisition about the body and sexuality were passed on from one generation to the next orally by way of narratives, storytelling, talking circles, and sharing circles (Barnes, Josefowitz, & Cole, 2006). However, due to residential schooling and the fracturing of families, many teachings passed down to children about the body have been lost. Women talked about the loss of children to residential schools and the resultant disruption in traditional parenting and teaching. Children were removed from their family, community, and home environments and placed in a foreign environment where they were abused and forbidden to speak of or follow any traditional teachings. Consequently, children were no longer educated about aspects of the body, health, sexual health, and historical teachings that previously had been passed down and had contributed to their well-being and the strengthening of family ties (Kinnon & Swanson, 2002).

Paps: Important or not? This subtheme describes women’s understandings and perceptions regarding the importance of Pap screening and its impact on their accessing of screening services. Many women communicated similar yet at times diverse and conflicting perceptions of the role of Pap screening. Several believed that Pap screening, although uncomfortable and at times embarrassing, is important and continued to regularly access services: “I don’t like it, but I know it’s important to make sure, health-wise, everything is OK in your female area.”

Some of the women accessed Pap screening to remain healthy in order to care for their children, to be able to have children, and, when pregnant, to prevent cervical disease through early detection: “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, [that] they can get it early.” Others, however, illustrated that not all women view Pap screening as

valuable, relevant, or necessary, due to a lack of knowledge and the impact of residential schooling, which is discussed under the next subtheme.

In a few other instances, fear of having cervical cancer was a reason given for *not* being screened. This finding is similar to what others (Black, 2009; Letendre, 2008; O'Brien et al., 2009) have found in studies with Aboriginal women. Fear of cervical cancer prompted some women in the study to access screening and prevented others from doing so.

Pap screening: Feeling violated. This subtheme represents Aboriginal women's accounts of their negative experiences with Pap screening. Some women told explicit personal stories of Pap screening making them feel violated: "Sexual abuse could be a reason for our women [Aboriginal] not to go. It could bring up bad memories from the past."

Some of those who described feeling violated linked it to prior experiences of abuse and a filtering down from residential school experiences; others did not articulate this experience: "Abuse and everything that filters out of residential school . . . there [were] a lot of things that happened that make Paps uncomfortable."

For some women, not accessing Pap screening was a way to protect themselves against reliving experiences of sexual abuse and violation. Pap screening for Aboriginal women can be viewed as an extension of colonization and the pain and suffering from sexual abuse and acts of violence that occurred in residential schools. This abuse and violence has affected not only residential school survivors themselves but also their descendants. A potential additive of historical trauma and sexual abuse is having a Western health-care provider, particularly a male, perform Pap screening.

The literature highlights Aboriginal women's lack of knowledge and information about Pap screening and lack of understanding about what happens to them during the screening experience (Amankwah, Ngwakongnwi, & Quan, 2009; O'Brien et al., 2009; Steven et al., 2004). In the present study, women linked a lack of knowledge about and understanding of Pap screening with being traumatized or violated. A few even revealed that although they were informed about the procedure, they remained terrified and fearful of the results. Many of the women demonstrated courage in moving on from extremely violating experiences of sexual abuse and assault to engage in regular Pap screening, a procedure that itself can be a violating experience.

The Impact of History on Our Health and Our Health-Care Experiences

This theme comprises three subthemes wherein women discuss the historical, social, political, and economic factors that influenced their health, their health care, and particularly their accessing of Pap screening.

The scar has been placed. This subtheme reflects the women's perceptions concerning the impact of historical trauma on their accessing of health services, including Pap screening. Almost every participant described in depth the impact of historical trauma, particularly with reference to residential schooling and/or colonization, on Aboriginal people's access to health services and Pap screening. Despite the historical trauma, they continued to thrive in less than adequate circumstances and struggled against negative forces that resulted from pain, suffering, and losses inflicted by residential schooling. Two of the women had been in residential schools themselves. Many others shared stories illuminating inequities in health and access to health care and the disempowering impact of residential schooling: "Issues with trusting health-care providers and the health-care system, I think, have been passed on from our history, from our ancestors that attended residential schools . . . They still have power over us, just like they did when we were in residential schools."

One woman spoke of being stereotyped as a First Nation person when accessing health care: "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." This perspective is supported by the findings of a qualitative study conducted by Tang and Browne (2008) into Aboriginal people's perception that they are treated differently by health professionals when accessing care due to their Aboriginal identity and low socio-economic status. Discrimination, stereotyping, or racism in encounters with health-care providers was influential in shaping their access to Pap screening. Historical trauma as a result of residential schooling has engendered distrust of non-Aboriginal people and affected Aboriginal women's accessing of health services (Dion Stout, 2012; Haskell & Randall, 2009; Waldram, Herring, & Young, 2006).

Socio-economic factors. Socio-economics was a primary factor in the failure to access health services and Pap screening. Participants identified being poor, lacking money for transportation or child care, lacking education, being a young, single parent, and being economically dependent on the government as factors that influenced their accessing of Pap screening. Some alluded to gender and Aboriginal identity as contributing to their socio-economic status and access to care. The women were focused on daily survival and making ends meet. Reasons for not accessing Pap screening are summed up in the comment of one woman: "We never had a lot of money or education. We didn't know it [Pap screening] was important."

Kurtz, Nyberg, Van den Tillaart, and Mills (2008) report that economic and social disadvantage caused by poverty, lack of education, and unemployment are associated with poor health and health outcomes, especially among Aboriginal women. Similarly, Black, Yamada, and Mann

(2002) identify poverty, Aboriginal status, and lack of education as reasons for failure to access Pap screening. Essentially, one cannot expect Aboriginal women to access health care when their basic needs are not being met and poverty related to disconnection from lands, traditions, and families due to colonization persists (Dion Stout, 2012).

Several women reported that being pregnant ensured economic stability and being cared for by the community. Being pregnant is not linked to economic security in the literature. The women did not expand on why they were assured access to health services such as Pap screening only when they were pregnant or on why resources to access Pap screening when needed were not provided.

Aboriginal women have a lot on their plates. This subtheme elucidated the issues and multiple and diverse roles and responsibilities of Aboriginal women within their families and their communities that impacted their access to health services and Pap screening. Some participants spoke of not accessing screening due to working outside the home, attending school, keeping house, or having community and child-care responsibilities: "Having a lot on their plates, they do not place themselves at the top of the list for care, particularly when they are single parents or have jobs." However, some made time for Pap screening. One married working mother said that she took time for health care and screening: "I've been really busy, hard to find time, but I go for Paps."

These findings are consistent with those reported in the literature. Women's family and caregiving responsibilities and roles directly affect their health, and in many Aboriginal communities other health-care issues take precedence over women's health (Barnett, White, & Horne, 2002; National Aboriginal Health Organization, 2006). For many participants, it was evident that mothering and family were the most prominent of all traditional roles and values. Some women had been forced to take low-paying jobs outside the home or even outside the community while continuing to be responsible for the care of the family and community, which at times took priority over Pap screening.

Encounters With Health-Care Providers: Making a Difference on Our Path to Paps

This theme described women's perceptions of how health-care providers are making a difference in their access to Pap screening.

Relationships: The fabric of our being. This subtheme concerns the women's perceptions about the impact of relationships with health-care providers on their accessing of Pap screening. The majority detailed the importance of building meaningful, trusting, and respectful relationships with health-care providers, which positively influenced their access to Pap screening. One woman said that fostering relationships was "building

a start to increasing Pap testing.” Another said, “The way we’re treated and looked at by health-care providers plays a big part in how we see ourselves.”

Several participants suggested that visiting the community and attending cultural ceremonies and funerals were ways for health-care providers to build relationships in the community. Others expressed the view that not all health-care providers are trusted by community members and that this complicates relationship-building. These viewpoints reflect 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, including health-care providers. For some of the participants the gender of the health-care provider also had an impact on their ability to form a relationship during Pap screening. A young woman explained: “A female health-care provider understands what it is like to be a woman and knows what it is like to experience Pap smear screening.” For a few others, the provider’s gender was not considered important for relationship-building during Pap screening. Building and maintaining relationships are considered cornerstones of life, health, and survival in Aboriginal communities (Henderson, 2000; Wilson, 2001). Aboriginal women want relationships with health-care providers that foster the creation of safe and ethical spaces where their voices and their concerns about health and health-care access can be heard (Kurtz et al., 2008). One woman expressed this eloquently: “Relationships are part of the fabric of our being.”

Practices of and encounters with health-care providers: Making it or breaking it. The women’s perceptions about the practices of and encounters with health-care providers influenced their accessing of health services and Pap screening. Women gave examples of when providers’ practices either helped or hindered their accessing of health care. The stories were about their own health-care encounters or those of members of their family or their community. Some women indicated that mainstream health services were not aligned with their needs when accessing Pap screening. Others described negative experiences with providers and gave examples of being discriminated against and not receiving culturally safe and competent care: “They generalize [about] us too much. They think we’re drunks. You’re hung over or something like that. Or . . . pill poppers.”

In some health-care systems, women are receiving culturally unsafe care as a result of the devaluing of Aboriginal knowledge, traditions, and ways. Culturally unsafe nursing care and practices encompass situations in which an action “diminishes, demeans or disempowers the cultural identity and well-being of any individual” (Nursing Council of New

Zealand, 2011, p. 7). The literature reveals instances of Aboriginal women encountering health-care providers whose unsafe practices include stereotyping, discrimination, and racism (Browne et al., 2011; Browne et al., 2012; McGibbon & Etowa, 2009). In the present study, lack of cultural safety was evident in the few Aboriginal pamphlets or teaching tools available or offered in mainstream health-care settings. Not a single participant told of being provided with information about health or health care in her own language.

Although the women seldom used the term “cultural safety” in their stories, they provided examples and expressed a preference for culturally relevant services. A few related positive experiences and described receiving culturally safe care from health-care providers who explained information adequately. For the participants, a key requirement for positive and safe care was relationships built on trust and mutual respect, as well as health-care providers being educated with regard to Aboriginal people and communities.

Educating health-care providers: Our community as teacher. Several participants indicated that health-care providers working in Aboriginal communities need specific knowledge about their culture, history, and language, which can be taught by community members. A few also conveyed the importance of health-care providers being able to talk with community members and listen to their stories as a way of becoming knowledgeable about the community and its members. Thus, health-care providers need to learn to understand nuanced, non-verbal communication and how to address an Elder. They also need to learn how to initiate conversations about sensitive topics like Pap screening and ways to convey information to Aboriginal women. Participants spoke of the need for health-care providers to be educated about the community where they are working, and not just by reading about the community and Aboriginal people: “Get educated and trusted in the community, and learn from the community as opposed to just [from] a book . . . I think that maybe if they [came to] study in here [community] for a bit, they would understand us more.” One woman spoke of the need for health-care providers to be educated not only about the history of Aboriginal people, but also about the family unit, which has changed over time: “I think they should know a little bit about the history. They should also know about family units, [about] how families survive.”

Also apparent was the importance of recognizing the diversity that exists among Aboriginal people and not “essentializing” all Aboriginal people or using a “one size fits all” approach to health care in Aboriginal communities. According to the National Aboriginal Health Organization (2010), health-care providers need to become acquainted with and understand cultural beliefs, attitudes, and practices in order to address

barriers that Aboriginal people confront when accessing Pap screening. Several women mentioned that Pap screening workshops in their community would be helpful in educating women about the procedure, the results, and the importance of regular screening. Some even suggested that these workshops could be enjoyable social events for women by featuring food, presents, and door prizes. Black (2009) also raises the idea of organizing a day or week dedicated to Pap screening in the community, such as Pap Week or Papalooza, with games and prizes as incentives.

The Health-Care System Is Complicating Our Going for Paps

The women perceived the health-care system as influencing and complicating their access to services such as Pap screening.

Confidentiality and privacy issues: I don't want anybody knowing. Women described issues around confidentiality and privacy that they or others had experienced and also fears about lack of confidentiality around Pap screening. For most participants, confidentiality and privacy were major concerns that affected their comfort in accessing screening services. 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 health-care providers who socialized with community members. In both communities, almost half of the women revealed that they did not go to their community health centre for Pap screening for fear of confidentiality and privacy breeches. Instead, they opted to leave their community to access Western health services. One woman stated: "I've never actually been there [community health centre] for a Pap test. . . . The reason is [that] I know my results will come back there. I know my file will be there, everything about me — anybody can look at my file. That's why I won't go there." This woman said that she was uncomfortable with other community members having access to her health file: the community was "so close knit" that everyone knew each other.

According to Bourke et al. (2004), social relations impact confidentiality in rural communities. The lack of anonymity has specific consequences for sensitive health issues such as sexual and reproductive health. Confidentiality is more difficult to maintain in rural and small communities, particularly if the receptionist, patient, and health-care provider have relationships prior to and separate from the health-care encounter (Bourke et al., 2004). In rural communities, people know many of the particulars of each other's lives. Also, community members may have more than one role because of their social position or occupation, which can result in the sharing of personal information about other community members (Bourke, 2001). In a study conducted in British Columbia, confidentiality and privacy concerns were cited as barriers for Aboriginal

women obtaining Pap screening (Black, 2009); women residing on reserve did not want to have Pap screening at their community health centre when outside health-care providers came to the reserve, for the reason that other community members would know their business.

A few participants also mentioned that community medical drivers could be related to them and want to know why they were going for a certain appointment. In order to be paid, the drivers had to submit medical forms stating why the person required medical transportation.

Yet not all women had concerns about confidentiality or privacy in their community health centre: "I have [had] Pap smears there [community health centre] and there were no issues around privacy or confidentiality."

Health-care accessibility: We need more services. Some women identified issues within mainstream health-care systems that impact Aboriginal women's access to Pap screening. Several reported a lack of Pap screening services, timely appointments, transportation, and interpreters. Accessibility issues were compounded by the confidentiality concerns discussed above. Even when health services were available, they were not accessible to all Aboriginal women: "We need more services. I like the idea of women's clinics and women's health days that would be accessible for everyone."

For the few who spoke primarily Mi'kmaq, there were literacy issues and a lack of translators available for services provided outside the community. One Elder said, "Each hospital should have an interpreter." The women also viewed mainstream health-care systems as inflexible, unwelcoming, indifferent, and not always considerate of their wishes. These findings indicate that the needs and preferences of Aboriginal women are not always the same in terms of Pap screening. To respond to the differences, health services should be available both within the community and outside it. Barnett et al. (2002) propose that health-care scheduling be not only flexible and convenient for Aboriginal women but also responsive to their diverse needs so that the right services are being offered to meet their specific needs and life contexts.

Strengths and Limitations of the Study

The use of PAR approaches, Indigenous principles, talking circles, and in-depth interviews enabled respectful and trusting relationships to be developed between researcher and participants. This approach fostered open dialogue and the opportunity to share diverse and rich stories about Pap screening in the context of Mi'kmaq women's lives. Many of the participants said that they had not previously talked about their experiences with Pap screening. Thus, it is evident that this research provided women an opportunity to give voice to their experiences.

Although the sample represented a broad range of ages, having only two women over the age of 60 is a study limitation. Also, the inclusion requirement that women speak, read, and understand English may have been a deterrent to participation. Women under 21 years of age and women who had never had Pap screening were excluded from the study; therefore, the findings may not be transferable to their experiences or perspectives.

Health-Care Practice and Policy Recommendations

It is evident from the results that health-care providers need to take account of the social determinants of health and the contexts of Aboriginal women's lives when considering why they are or are not accessing Pap screening. It is also vital that providers appreciate the impact of historical trauma, interpersonal violence, and trauma-informed care for Aboriginal people while at the same time being aware that Aboriginal people have strengths to counter traumas and violence. A "one size fits all" approach to health care will not be effective; it is essential that Pap screening practices with Aboriginal women be individualized. Health-care providers must acknowledge the limitations of mainstream standards and best practice guidelines and the fact that these may not always apply to Aboriginal people. It is critical that time be invested in building relationships in communities prior to the initiation of screening. Health-care providers should enhance education and knowledge about Pap screening with Aboriginal women in ways that acknowledge the women's realities, needs, and requests and that include opportunities for them to share their stories, perceptions, and experiences with other women. This would raise awareness of the importance of screening and honour storytelling as an authentic method for sharing knowledge. Also, Pap screening should be offered consistently in communities, with extended clinic hours and personal reminders, in order to increase access for Aboriginal women.

We need policies to address the complex determinants of health that contribute to major disparities in access to health care and Pap screening for Aboriginal women. We need to formalize confidentiality and privacy policies with Aboriginal communities and to educate health-care providers and all workers in community health centres about patients' right to privacy and confidentiality. We also need to develop and implement confidentiality policies for medical drivers who transport Aboriginal women to health services, including Pap screening. In addition, we need policies that clarify jurisdictional responsibilities for funding and screening supplies in Aboriginal communities. Finally, Aboriginal women and community members should be consulted on policy development, implementation, and evaluation related to Pap screening.

Conclusion

This qualitative study explored Mi'kmaq women's experiences with Pap screening in two First Nation communities in eastern Canada and considered the historical, economic, and sociopolitical contexts that shaped these experiences. It is important to recognize that some Aboriginal women are accessing Pap screening regularly in spite of challenging circumstances. In general, epidemiological data alone do not provide insight into women's experiences with Pap screening nor identify reasons why women are or are not accessing screening. There are multiple factors, such as history, politics, socio-economics, health-care providers, and health-care systems, that impact women's access. It is critical that nurses and other health-care providers be aware of these diverse factors and how they influence women's access to Pap screening. Health-care providers need to consider the social determinants of health and the contexts of women's lives when considering why they are or are not accessing screening and need to individualize care, while offering consistent and convenient screening services. Building relationships with communities, creating safe spaces for screening, educating women, and providing trauma-informed and culturally safe care are also vital in encouraging Aboriginal women to access Pap screening. Improving Pap screening services for Mi'kmaq women requires multifaceted, culturally safe nursing approaches that are developed in partnership with the women themselves and their communities.

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