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### Colonial legacy and the experience of First Nations women in cervical cancer screening: a Canadian multi-community study

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## Colonial legacy and the experience of First Nations women in cervical cancer screening: a Canadian multi-community study

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Regular Papanicolaou (Pap) screening has dramatically reduced cervical cancer incidence in Canada since the 1950s. However, Indigenous women's rates of cervical cancer remain disproportionately high, a factor which is not acknowledged in national media or in educational materials reporting Canada's new cervical cancer screening guidelines. Here, we present findings from a cervical cancer screening initiative in Northwestern Ontario. Based on participatory action research, we worked with 10 First Nations communities in the Robinson Superior Treaty area to increase awareness of cervical cancer risk, develop culturally sensitive tools for screening and education and test the efficacy of human papillomavirus (HPV) self-sampling as an alternative to Pap cytology. We conducted 16 interviews with health care professionals and 9 focus groups with 69 women from the communities. A central theme for both health care providers (HCPs) and community members was the colonial legacy and its influence on women's experiences of cervical cancer screening. This was evidenced by a strong sense of body shyness, including shame related to sexuality and sexually transmitted infections, concerns about confidentiality in clinical encounters and distrust or caution around HCPs. Reaffirming women's traditional caregiving and educational roles, enhancing mother and daughter communication, improving cultural sensitivity in health care and education and adoption of HPV self-sampling to increase women's privacy and control of the cervical cancer screening experience were endorsed. We argue that education and screening initiatives must reflect the cultural preferences of Indigenous women, empowering them to take control of their experiences of health and body in cervical cancer screening.

**Keywords:** cervical cancer screening; First Nations women; gender and embodiment; colonial legacy; participatory action research

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## Introduction

Cervical cancer, primarily caused by human papillomavirus (HPV) (zur Hausen, 2000), is the fourth most common cancer in women worldwide (International Agency for Research on Cancer, 2013). In 2012, following a national taskforce study, Canadian guidelines for cervical cancer screening were updated with an increase in age for first screen (from 18 to 21) and a longer recommended interval between screens (from 2 to 3 years). National media coverage emphasized Canada's role as a mid-twentieth century pioneer in cervical cancer screening and an exemplar of early detection through regular Papanicolaou (Pap) screening. Citing an 83% drop in cervical cancer deaths in Canada between 1952 and 2006 (from 13.5/100,000 to 2.2/100,000) as reported in Dickinson et al. (2012), the Canadian Broadcasting Corporation noted that 'what was a rare cancer has become rarer still' (2012). Media coverage and health education materials introducing the general public and health care providers (HCPs) to the new screening guidelines did not report the elevated risk of cervical cancer morbidity and mortality among vulnerable populations in Canada (Canadian Medical Association Journal, 2013; Cancer Care Ontario, 2012a, 2012b), leaving the impression that the picture had improved for all groups of Canadian women.

However, current data show that recent migrants (Pottie et al., 2011) and Indigenous (First Nations, Inuit and Métis) women in Canada continue to experience significantly higher rates of cervical cancer incidence, prevalence and death than non-Indigenous women (Shannon, Franco, Powles, Leng, & Pashayan, 2011). Studies in the provinces of Ontario, Manitoba, and Quebec report substantially higher cervical cancer mortality rates for First Nations women than for the population as a whole (Decker et al., 2015; Halseth, 2013; Nishri, Sheppard, Withrow, & Marrett, 2015). In the province of Alberta, cervical cancer incidence has been reported to be as much as 20 times higher for First Nations women than for women in the general population (Colquhoun et al., 2010). These data suggest that cervical cancer remains a substantive health risk for some marginalized populations and that a tailored screening strategy may be warranted to improve screening access and follow-up of screen-detected lesions (Morgan & Wabie, 2012).

Indigenous and postcolonial health analysts have called for closer attention to the historical legacies of colonialism, racism and sexism (Bourassa, McKay-McNabb, & Hampton, 2005), how they influence and intersect with contemporary social determinants of health for Indigenous peoples (Allan & Smylie, 2015), and the ways they are manifested through what Adelson has described as "the embodiment of inequity" (2005, p. S45). The works of de Leeuw and Greenwood (2011) and Browne, Smye, and Varcoe (2007) links the legacy of colonialism with intersectionalities of race, gender and social class to demonstrate how patterns of inclusion and exclusion are created by historic 'social, economic and political circumstances and power relations in health care' and contribute to Indigenous women's higher health risk profiles (Browne et al., 2007, p. 134).

Drawing on this earlier work, we explored how Indigenous women's body perceptions influence their comfort with, and participation in, cervical cancer screening in Northwestern Ontario and their recommendations to address the challenges of women's underscreening and cervical cancer risk. This work, which is based on 16 interviews with health care professionals and 8 community focus groups with a total of 69 lay women participants, is part of a larger public health initiative currently underway with First Nations women in Northwestern Ontario to develop culturally sensitive approaches to cervical cancer screening and to explore the feasibility of self-sampling for HPV as an alternative screening modality to Pap cytology (Wood et al., 2014; Zehbe et al., 2011).

## Methods

### *Study design*

The Anishinaabek Cervical Cancer Screening Study (ACCSS) (Wood et al., 2014), was initiated as a pilot study in 2009 by the principal investigator (IZ), a non-Indigenous cancer biologist, to address inequities in cervical cancer screening and outcomes (Wood et al., 2014; Zehbe et al., 2011). Following Ermine's (2007) principles of ethical space to develop a meaningful dialogue across cultural difference, IZ worked with First Nations leaders and health representatives from 10 Robinson Superior Treaty communities in Northwestern Ontario, Canada, to define project priorities and parameters and optimal ways to *actively* engage community members (Zehbe, Maar, Nahwegahbow, Berst, & Pintar, 2012). A participatory action research framework aimed at democratizing the research process and fostering collaboration between HCPs, community members and academic partners (Esterberg, 2002) has guided all stages of the study.

Formal research agreements between the political leadership of each community (e.g. Chief-in-Council), the supporting institution (Thunder Bay Regional Research Institute) and IZ were negotiated between winter 2010 and spring 2011 (Zehbe et al., 2012). Information sessions were held in each of the communities prior to beginning the study in summer 2011 (Zehbe et al., 2012). Community-based research assistants were hired as project liaisons and a community steering committee with representatives from each community was established to provide guidance on cultural safety as well as ongoing feedback on study progress and challenges (Wood et al., 2014).

Continuous community visits have been undertaken by members of the ACCSS academic team (comprised of researchers in cancer biology, virology, epidemiology, medical anthropology, gender and health sociology, public health, arts-based education and knowledge-translation) to communicate and discuss findings with the community research assistants and partner communities. Regular teleconferences have also enabled participation of members from more geographically distant communities and helped to link communities to one another. An ad hoc publication steering committee was established to review prospective reports and publications with two or three community research assistants and/or steering committee members or delegates recruited as co-authors for each submitted peer-reviewed publication. As negotiated with our ongoing partner communities, the ACCSS team membership remains dynamic, with new partners and areas of specialization added as benefit to the collaboratively evolving project process (Wood et al., 2014).

### *Sampling*

Using purposive sampling to target diverse community perspectives (Teddlie, 2007) two types of qualitative data were collected for the current study. The health directors in each community identified one or two experienced HCPs for individual interviews, and female community members were recruited for focus group discussions. The decision to invite the community members to participate by focus group, rather than by individual interview, was based on the recommendation of our community partners who felt that a focus group setting was more in keeping with traditional 'talking circles' and would enhance women's comfort in participating.

Interviews (10 face-to-face and 6 via videoconference) were conducted with 16 HCPs (between 25 and 70 years of age) during August 2011 and February 2012 (Maar et al., 2013, 2014). The HCP group included nurses, nurse practitioners, health managers/

directors, community health representatives and elders who had worked in their respective communities between six months and 20+ years. The majority had 10 or more years of experience. Twelve HCPs self-identified as First Nations and all but one were female. Interviews ranged from 40 to 90 min. Eight focus groups with a total of 69 female community members were conducted between May and July 2012. The focus groups, which ranged in size from 3 to 12 members (average 8), included adult women from late teens to elders (the majority in the 25–49 age range) and lasted between 80 and 120 min. Both sets of questions centred on experiences with cancer in general, and cervical cancer screening in particular, why women do or do not attend, and how to create awareness of cervical cancer screening in the community.

The HCP interviews and community focus groups were conducted in English, as participants indicated their comfort speaking the language. A note taker was present during focus group sessions and both interviews and focus groups were audio-recorded and transcribed verbatim for analysis. Participants received a monetary incentive (CAD \$75) to compensate for their time. Prior to commencing this research, the study was approved by the Lakehead University Research Ethics Board. Renewal of community agreements has continued throughout the research process.

### *Analysis*

Three levels of qualitative analysis were employed to analyse the data for this paper. Interview and focus group transcripts were manually coded by three researchers (PW, BW and IZ) using ‘open coding’ (van den Hoonaard, 2015) to identify basic themes which were then grouped into key themes through collective review and discussion. We shared our findings and obtained feedback from the study participants via an educational workshop held in Thunder Bay, Ontario, October 2012 (interviewees) as well as via discussions and meetings during visits to the partner communities in Winter 2013/2014 (focus group members).

No disconfirming evidence or conflicting data were identified. An NVIVO analysis of de-identified data conducted by a researcher, extra to the ACCSS team, assisted us to more comprehensively identify the multiple locations and contexts in which the basic and key themes appeared in the transcripts. Two publication steering committee members reviewed the findings as well as early drafts of the paper. They provided substantial community insights for finalizing this paper, which resulted in their co-authorship. Due to the strong concordance between the HCP and focus group participant responses for the themes addressed in this paper, and their shared environment shaped by colonial legacy, we have chosen to simultaneously discuss the findings of the two data-sets. We have, however, endeavoured to highlight similarities and differences between the two groups where relevant. Interestingly, the HCPs often moved between the subject positions of HCP and community member in their responses to our interview questions. For some, this seems to have related to their multiple subjectivities as HCPs and as Indigenous or long-term community members whose experiences and reflections are as both insiders and outsiders to the community, an issue which should be explored in more depth in future research (Battiste, 2013; Berryman, SooHoo, & Nevin, 2013). As requested by our community partners, participants’ quotes are tagged only by ‘HCP interview’ or ‘focus group’ number in order to protect the identity of participants, most of whom live and work in small face-to-face communities.

## Results

An important theme in the discussion of women's experiences of body, sexual health and cervical cancer screening was the legacy of colonization. Colonization and the historical trauma which it produced (Walters et al., 2011) has destabilized traditional gender relations, reduced women's status in many First Nations communities and disrupted the transmission of culture and knowledge between generations (Browne et al., 2007; de Leeuw & Greenwood, 2011). The extent of such trauma is embodied and subsequently reflected in inequities in population health (Krieger, 2005) such as the different prevalence of cervical cancer incidence between Indigenous and non-Indigenous women.

### *Negative body perception*

#### *Shame and the female body*

The negative implications of colonial legacy for Indigenous women's sexual health continue to resonate and are eloquently summarized in the following quote from one focus group participant:

Being raised with residential school and colonization throughout our history, you know, [pause] things have changed for us in the last couple of hundred years. Women are, we used to be maternalistic, what do you call that, a matrilineal society and we're not anymore, we're a patrilineal as a result of colonization and because of that, the men, have got this perception that they are the, head of the household now. [Ar] ... one time we were the head of our households ... we had the power also to give birth, so, when the doctors came along, they took that away from us as women and, we took care of each other, our families, ... we were the educators, the socializers, and we had a great big role as a society. And we don't have that anymore and so that, so, so because ... we've been impacted by alcohol and now today, drugs, there's this, you know, some of us might have grown up to having been sexually molested. I can say that I was molested as a child and it impacted my sexuality ... as a woman and, I believe that, there are others that probably think that way so if we have issues about our sexuality as a, as women, we're going to, we may be shame based, you know. (Participant of focus group 1)

The following exchange between an interviewer and a HCP reflecting on her own family experiences illustrates the legacy of colonization and abuse, and its impact on women's comfort with their bodies and the shame of physical exposure:

- HCP: I think it's *dirty* to talk about your body, well, not me, but I mean, for her [my mom], it was, it was dirty, you don't talk about that, you know. We were, even as growing up as kids, we had to button our shirts right up to the top, and had to wear the long pajama pant bottoms, or a housecoat that was almost at the floor, you know, covering our ankles. You had to be always, your body was always covered, and –
- Interviewer: Is that part of your tradition?
- HCP: I don't think so, because, no, I honestly, I don't think that's so much cover, part of the tradition, I think a lot it came from the abuse from the residential school (HCP interview 2).

A similar point was raised by other HCPs who noted taboos about body and sexuality particularly for older community members. As one HCP stated:

One of the barriers would be trust, um, especially for the older ... people, um, because they're coming from the Indian residential school system and you know, and it's taboo to talk about sex and ... you shouldn't be touched there. (HCP interview 9)

### *Stigma of sexually transmitted infections*

Fear of stigmatization related to HPV (Jackson & Ward, 2000) as a sexually transmitted infection (STI) was expressed by some HCPs and relates to the stereotype of the Indigenous, 'sexually immoral woman' (Carter, 2000), further impacting negatively on women's body perceptions:

Definitely there's always going to be a stigma about any kind of thing that's an STD [STI], because people think it's dirty or whatever. Like I've had people come in, like, even the girl I just saw with genital warts and she just couldn't believe it, and couldn't like fathom who she would have got it from because everyone she's been with has only been with her. Right? (HCP interview 8)

Another HCP noted the impact of stigma on people's willingness to be tested and their concerns about charting:

Actually in the last 6 months that I've been there, I've had uh, a minimum of 5 people who have come to me who um, have been concerned about contracting STIs and did not want me writing it into their chart for fear that it would leak into the community ... they're afraid of the stigma surrounding that so and a lot of times too I wasn't able to do any [cervical] screening. (HCP interview 16)

The problem of women being blamed by their partners for transmission of STIs was voiced by several of the focus group participants. For others, however, as illustrated in the quote below, the expressed fear was contributing to an already negative stereotype about First Nations people as a group:

Health centers on reserves, don't want to spread it out too much how many people have HPV. I know how the stereotype works if we pass on the information in non-native communities they will say all native people have HPV. (Participant of focus group 2)

### *Body shyness*

Shame associated with the female body and STIs, coupled with the unease of Pap screening due to its invasiveness and the physical discomfort involved in taking a cervical sample, may be the reason some women do not attend cervical screening. As reported in other research (Black, 2009; Kolahdooz et al., 2014; Morgan & Wabie, 2012), this was a concern expressed by several of our focus group participants and described in terms of feeling shy or vulnerable:

I remember feeling so vulnerable, just so extremely vulnerable and, and I remember at one point he [the male physician] was talking on his phone while I was up in the stirrups and I thought uh, you know, I wonder how many other patients feel like this .... There's got to be a better, kinder, gentler, more humane way to do it. (Participant of focus group 1)

A common statement of local women, with or without formal health background, was that they were only comfortable getting Paps done if they had developed a trusting relationship with their doctors, and many preferred female doctors:



Oh, and the thing is, when the doctor asks me specifically well, we could do a Pap test. No, I have my own gynaecologist because that's my private area, you know, and I don't want just anybody looking around down there or poking around down there, so I feel, well, with my, with my gynaecologist, do, to do that kind of screening. So and I think a lot of women feel, feel that way. (HCP interview 4)

If you don't trust men, you're not going to go see a doctor and uh, the way we have to be checked by a doctor, it's so in-, even me, I, I think I'm pretty open about my sexuality as a woman, when I go see the doctor, I don't like it and I don't think any woman likes it whether what culture they come from, but if you're a culture that has been impacted by residential school, colonization, all the more it's going to be more, 10 times harder for us to go to a male doctor to open up, you know what I mean? (Participant of focus group 1)

Building trust is essential for First Nations women because of the past Canadian residential school system with its physical, sexual and emotional abuse by teachers and institutional moral authorities (Miller, 1996) and was similarly emphasized by HCPs and focus group participants:

They have been sexually abused, too, and I know like, in the past residential schools, that kind of thing, those people are just not comfortable because of their experiences in the past ... I will be here for a long time and whenever you need to see me, to come see me, so that even just that little thing and then when they do come I do see them, hopefully that trust builds up and I think that's a big piece with the First Nations. (HCP interview 2)

I think one of the biggest issues um, [short pause] the barriers that prevents people from going to and maybe it's cause it's taboo is because they've been sexually abused. (Participant of focus group 9)

### ***Negative experience with governmental health services***

#### *Distrust of health authorities*

Distrust of health care provided by the Canadian government was cited as part of the legacy of colonization. Control over health services has been paternalistically managed by federal authorities, with communities and individuals often feeling excluded from decisions about their own health and well-being (Kolahdooz et al., 2014; Kurtz, Nyberg, Van Den Tillaart, Mills, & the Okanagan Urban Aboriginal Health Research Collective, 2008). The HCPs interviewed indicated an awareness that many women seem to experience the surveillance and management of the body in screening and physical examinations as intrusive. Elders' memories of residential schools or stories they had been told continued to shape their own discomfort with and distrust of cervical cancer screening and other preventive health interventions, as some interviewees noted:

She [HCP] thinks it's her [that they don't like], 'like, why is no one coming [for screening]' ... 'it's not you, it took me 20 years to get to where I'm at now, and I *still* get people that don't trust me.' (HCP interview 3)

I guess they were told about some kind of vaccine or something, like years ago, and it was something just, to try to get rid of the Native people. (HCP interview 13)

Other participants noted that developing trust relationships between HCPs and community members takes time, and is negatively impacted by the frequent turnover of physicians in

many northern communities. A participant of focus group 5 expressed the discomfort she experienced as a result of the change in physicians with this statement:

My doctor who I had since my oldest was born, she just up and quit, so when my next appointment, I had this guy looking at me, it's like [pause] right, so it's not like they stick around here.

#### *Lack of confidentiality and privacy*

Related to concerns about distrust were issues of confidentiality and privacy with the health care system, particularly in small face-to-face communities where gossip travels quickly (Black, 2009; Shoveller et al., 2009). While discussing concerns about confidentiality, the women mentioned the organization of space in community health care clinics, the practices and dynamics of clinic encounters and the ways in which personal information was readily available to those within earshot, as the following comment from a participant of focus group 2 demonstrates:

You know what, just sitting in the waiting room, the receptionists are phoning people telling them, we've got your results, you need an, you know, make another appointment, they say the name right out loud, they say what the test is.

The above statement highlights a shared sense that personal information is not protected in the clinical encounter either in terms of the way in which health staff address people and their needs, or the ways the physical layout and data collection systems make test results and reasons for medical appointments public – a sentiment also echoed by a HCP:

Privacy, a small town, I mean, you can hear through the walls, you know, walls talk because there's, it's all in one building and coming in here and everybody sees the first person coming in here, they come to see me, they come to see welfare, they come to see housing, they're going and everybody knows everything. (HCP interview 3)

A focus group participant framed her concerns about anonymity in small face-to-face remote communities this way:

Being in reserves, a lot of people know people's business and a lot of people get worried about that when you're trying to keep something personal. I mean the teddy bears talk, the leaves talk, the hydro lines talk. (Participant of focus group 5)

#### ***Role of family (mother–daughter) relations***

Strong, positive family relationships, in particular mother–daughter bonds, were talked about by both groups of respondents as being important in promoting positive ideas about the female body and sexuality as well as in improving women's comfort with cervical cancer screening (van Herk, Smith, & Andrew, 2010–2011). The women emphasized the importance of communication between mothers and daughters and also the need to foster strong connections among wider groups of women. Many also reflected on the ways in which ideas about First Nations women's embodiment and sexuality were changing with younger generations and how these changes were, for the most part, positive. Though some interviewees' own mothers did not want to talk about sexual health, they themselves made an extra effort to do so with their own children.

The following quote from a focus group interviewee expressed commonly stated sentiments in both focus group discussions and HCP interviews:

I just taught them that sex isn't, it's not what you call dirty, you know, but there's a certain way you got to go about having, like for sex with a partner, you know, you got to explain that part to them, but to talk openly about sex, it's not what you call a dirty subject, yeah. If you want to know something just feel free to ask. (Participant of focus group 1)

An HCP reflecting on her own experiences of socialization and how she is trying to educate her daughter differently, expressed it this way:

Like my mother, you know, was the kind of woman that ... when I first got my period, I didn't know what it was because that was something you don't talk about, your body like that. It's you know that's your own personal, private, so when it happened, I had absolutely no knowledge what was going on in my body ... And with my daughter, I didn't want her to have that feeling, so I mean, of course I changed and I explained everything but, and then that's the way things are now, women are more informed than they have been in the past. (HCP interview 2)

### ***Self-collected sampling as a way of increasing women's control of cervical screening***

Self-collected vaginal samples have helped to increase screening attendance among under-screened or never-screened women (Ogilvie et al., 2013). Moreover, our pilot study with one partner community has shown that close to 90% of the women would prefer self-sampling over Pap testing (Zehbe et al., 2011). For a number of HCPs interviewed, the idea of HPV testing through self-sampling was appealing and would not compromise their relationship with their patients. Instead, they suggested it would increase women's control of the timing and place of testing, thus alleviating many concerns about privacy and body discomfort during Pap examinations. It would also allow for more confidentiality during the release of results, as this interviewee's comment suggests:

I think it [self-sampling] would be, I think it would be great, because it provides them with some autonomy and allows them to take control of the situation. That would be really great actually .... I think it would increase [education opportunities] actually, yup, because it's a lot less clinical right, cause like you say, it's a lot less you know, stripping down and you know, allowing someone else to do the scraping of the cervix, you know, the whole uncomfortable procedure of going through a Pap opposed to doing it privately in the bathroom on your own is a huge difference. (HCP interview 16)

Focus group members also thought that self-sampling would be a good idea as it would allow them more control over the privacy and comfort of the experience as the following participants note:

I think it would definitely be more private ... They wouldn't be so embarrassed ... all kinds of people are easily embarrassed. (Participant of focus group 2)

It's simple, it's not like you are having forceps in you. (Participant of focus group 6)

## **Discussion**

In interviews with HCPs and in focus groups with community women, we identified two primary themes grounded in colonial legacy demonstrating a general, negative body

perception and negative experience with formal or governmental health services. The women's embodied experiences of gender, racialization and marginalization in a post/colonial world (Browne et al., 2007), together with issues of trust with care providers and the formal health care system were prominent themes. For many women, the colonial legacy of cultural disruption and silencing, as well as negative portrayals of Indigenous women's bodies and sexuality continue to be barriers to self-care. While some women did not have direct experience with residential schools, most had witnessed its intergenerational effects and stressed its negative consequences (Miller, 1996). The enduring colonial legacy and its impact on screening and HCP and client relationships were also strongly emphasized by the HCPs interviewed.

The stigmatization of Indigenous women's bodies and sexuality from colonial times to the present, as well as negative stereotypes of Indigenous women (Carter, 2000), have impacted many women's experiences of *body* and *sexual* health. In this study, many of the focus group participants talked about their discomfort with physical examinations, a sense of shame and stigma in relation to sexuality and STIs (Jackson & Ward, 2000), and expressed concerns about confidentiality and privacy in the management of their personal health information (Black, 2009; Shoveller et al., 2009). These themes were also noted in the HCP interviews, where participants often moved between the subjectivities of care provider and community member in reflecting on and responding to the questions. Jacklin and Warry (2012) draw connections between negative experiences with formal authorities (including physicians) and scepticism or distrust of surveillance and services provided by non-Indigenous HCPs. This was supported by our interviews and focus groups where issues of trust and distrust between patient and care provider were emphasized. Our study suggests that such embodied legacies of colonial history may explain, at least in part, women's reluctance to participate in Pap screening and supports other research exploring this topic (see Black, 2009; Kolahdooz et al., 2014; Morgan & Wabie, 2012).

Despite the negative impact of the colonial legacy, both interview and focus group participants affirmed a strong need to reassert and valorize the traditional roles of women as family health educators, caregivers and advocates, as well as the importance of fostering strong mother–daughter and intergenerational relationships to *decolonize* and strengthen women's wellbeing in subsequent generations. This could lead to a more positive attitude towards sexual health and may have a beneficial outcome for cervical screening attendance (van Herk et al., 2010–2011). The prospects of offering self-collected vaginal samples to First Nations' women as an alternative to Pap cytology (Ogilvie et al., 2013; Zehbe et al., 2011), thus allowing them to conveniently take their own sample at home, was favourably acknowledged. Self-sampling for HPV would also eliminate other screening barriers such as long distance to the nearest health centre as well as lack of transportation and child care facilities (Maar et al., 2013).

## Conclusion

Important advances have been made in reducing cervical cancer incidence for the majority of Canadian women, but populations such as Indigenous women remain at a disproportionately high risk of cervical cancer morbidity and mortality. An important strategy in decolonizing Indigenous women's bodies and health is to heighten the *visibility* of their health inequities and challenges in policy and practice guidelines. Policy-makers must ensure that cervical cancer screening and educational initiatives reflect the experiences and preferences of First Nations populations, and incorporate

their voices in a meaningful fashion. It is also crucial to support Indigenous women's roles as educators and advocates for their own and their families' health in this generation and for generations to come.

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### References

- Adelson, N. (2005). The embodiment of inequity: Health disparities in aboriginal Canada. *Canadian Journal of Public Health, 96*(Suppl 2), S45–61.
- Allan, B., & Smylie, J. (2015). *First peoples, second class treatment. The role of racism in the health and well-being of indigenous peoples in Canada*. Toronto: Wellesley Institute.
- Battiste, M. (2013). *Decolonizing education. Nourishing the learning spirit*. Saskatoon: Purich Publishing.
- Berryman, M., SooHoo, S., & Nevin, A. (Eds.). (2013). *Culturally responsive methodologies*. Bingley: Emerald Publishing.
- Black, A. T. (2009). Cervical cancer screening strategies for aboriginal women. *Pimatisiwin, 7*, 157–179.
- Bourassa, C., McKay-McNabb, K., & Hampton, M. (2005). Racism, sexism and colonialism: The impact on the health of aboriginal women in Canada. *Canadian Woman Studies, 24*, 55–58.
- Browne, A., Smye, V., & Varcoe, C. (2007). Postcolonial feminist theoretical perspectives and women's health. In M. Morrow, O. Hankivsky, & C. Varcoe (Eds.), *Women's health in Canada: Critical perspectives on theory and policy* (pp. 124–142). Toronto: University of Toronto Press.
- Canadian Broadcasting Corporation. (2012). Cervical cancer screens may offer little value before age 25. Retrieved from <http://www.cbc.ca/news/health/cervical-cancer-screens-may-offer-little-value-before-age-25-1.1200546?cmp=rss>
- Canadian Medical Association Journal. (2013). Recommendations on screening for cervical cancer. *CMAJ, 185*, 35–43.

- Cancer Care Ontario. (2012a). Ontario cervical cancer screening guidelines update. Retrieved from <https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=13104>
- Cancer Care Ontario. (2012b). Information for health care providers on cervical cancer screening. Retrieved from <https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=132392>
- Carter, S. (2000). Categories and terrains of exclusion: Constructing the “Indian woman” in the early settlement era in Western Canada. In C. A. Cavanaugh & R. R. Warne (Eds.) *Telling tales. Essays in western women’s history* (pp. 60–81). Vancouver: UBC Press.
- Colquhoun, A., Jiang, Z., Maiangowi, G., Ashbury, F., Chen, Y., Drobin, W., ... Yacoub, W. (2010). An investigation of cancer incidence in a first nations community in Alberta, Canada, 1995–2006. *Chronic Diseases in Canada, 30*, 135–140.
- Decker, K. M., Demers, A. A., Kliewer, E. V., Biswanger, N., Musto, G., Elias, B., ... Turner, D. (2015). Pap test use and cervical cancer incidence in first nations women living in Manitoba. *Cancer Prevention Research, 8*, 49–55.
- de Leeuw, S., & Greenwood, M. (2011). Beyond borders and boundaries: Addressing indigenous health inequities in Canada through theories of social determinants of health and intersectionality. In O. Hankivsky, S. de Leeuw, J. Lee, P. Vissandjee, & K. Kharlou (Eds.), *Health inequities in Canada: Intersectional frameworks and practices* (pp. 53–70). Vancouver: University of British Columbia Press.
- Dickinson, J. A., Stankiewicz, A., Popadiuk, C., Pogany, L., Onysko, J., & Miller, A. B. (2012). Reduced cervical cancer incidence and mortality in Canada: National data from 1932 to 2006. *BMC Public Health, 12*, 992. doi:10.1186/1471-2458-12-992
- Ermine, W. (2007). Ethical space of engagement. *Indigenous Law Journal, 6*. Retrieved from <http://hdl.handle.net/1807/17129>
- Esterberg, K. (2002). *Qualitative methods in social research*. Boston, MA: McGraw Hill.
- Halseth, R. (2013). *Aboriginal women in Canada. Gender, socio-economic determinants of health, and initiatives to close the wellness gap* (Report). Prince George: National Collaborating Centre for Aboriginal Health. Retrieved from [http://www.nccah-ccnsa.ca/Publications/Lists/Publications/Attachments/77/Aboriginal\\_Women\\_EN\\_web.pdf](http://www.nccah-ccnsa.ca/Publications/Lists/Publications/Attachments/77/Aboriginal_Women_EN_web.pdf)
- International Agency for Research on Cancer. (2013). *Latest world cancer statistics. Global cancer burden rises to 14.1 million new cases in 2012: Marked increase in breast cancer must be addressed* (Press release No. 223). Retrieved from [http://www.iarc.fr/en/media-centre/pr/2013/pdfs/pr223\\_E.pdf](http://www.iarc.fr/en/media-centre/pr/2013/pdfs/pr223_E.pdf)
- Jacklin, K., & Warry, W. (2012). Decolonizing first nations health. In J. C. Kulig & A. M. Williams (Eds.), *Health in rural Canada* (pp. 373–389). Vancouver: University of British Columbia Press.
- Jackson, L. R., & Ward, J. E. (2000). An analysis of resources for Indigenous women in NSW about cervical screening. *Australian and New Zealand Journal of Public Health, 24*, 327–330.
- Kolahdooz, F., Jang, S. L., Corriveau, A., Gotay, C., Johnston, N., & Sharma, S. (2014). Knowledge, attitudes, and behaviours towards cancer screening in indigenous populations: A systematic review. *The Lancet Oncology, 15*, e504–e516.
- Krieger, N. (2005). Embodiment: A conceptual glossary for epidemiology. *Journal of Epidemiology and Community Health, 59*, 350–355.
- Kurtz, D. L., Nyberg, J., Van Den Tillaart, S., Mills, B., & the Okanagan Urban Aboriginal Health Research Collective. (2008). Silencing of voice: An act of structural violence. Urban aboriginal women speak out about their experiences with health care. *Journal of Aboriginal Health, 4*, 53–63.
- Maar, M., Burchell, A., Little, J., Ogilvie, G., Severini, A., Yang, J. M., & Zehbe, I. (2013). A qualitative study of provider perspectives of structural barriers to cervical cancer screening among first nations women. *Women’s Health Issues, 23*, e319–e325.
- Maar, M., Wakewich, P., Wood, B., Severini, A., Little, J., Burchell, A. N., & Ogilvie, G. (2014). Strategies for increasing cervical cancer screening amongst first nations communities in north-west Ontario, Canada. *Health Care for Women International, 6*, 1–18.

- Miller, J. R. (1996). *Shingwauk's vision: A history of native residential schools*. Toronto: University of Toronto Press.
- Morgan, L., & Wabie, J. L. (2012). Aboriginal women's access and acceptance of reproductive care. *Pimatisiwin*, 10, 313–325.
- Nishri, E. D., Sheppard, A. J., Withrow, D. R., & Marrett, L. D. (2015). Cancer survival among first nations people of Ontario, Canada (1968–2007). *International Journal of Cancer*, 136, 639–645.
- Ogilvie, G. S., Mitchell, S., Sekikubo, M., Biryabarema, C., Byamugisha, J., Jeronimo, J., ... Money, D. M. (2013). Results of a community-based cervical cancer screening pilot project using human papillomavirus self-sampling in Kampala, Uganda. *International Journal of Gynecology and Obstetrics*, 122, 118–123.
- Pottie, K., Nolen, A., Topp, P., Torres, S., Welch, V., & Durand, N., for the Canadian Collaboration for Immigrant and Refugee Health. (2011). Appendix 19: Cervical cancer: Evidence review for newly arriving immigrants and refugees. Guidelines for immigrant health. *Canadian Medical Association Journal*. doi:10.1503/cmaj.090303
- Shannon, G. D., Franco, O. H., Powles, J., Leng, Y., & Pashayan, N. (2011). Cervical cancer in indigenous women: The case of Australia. *Maturitas*, 70, 234–245.
- Shoveller, J., Johnson, J., Rosenberg, M., Greaves, L., Patrick, D. M., Oliffe, J., & Knight, R. (2009). Youth's experiences with STI testing in four communities in British Columbia, Canada. *Sexually Transmitted Infections*, 85, 397–401.
- Teddlie, C. (2007). Mixed methods sampling: A typology with examples. *Journal of Mixed Methods Research*, 1, 77–100.
- van den Hoonaard, D. K. (2015). *Qualitative research in action. A Canadian primer* (2nd ed.). Don Mills: Oxford University Press.
- van Herk, K. A., Smith, D., & Andrew, C. (2010–2011). Identity matters: Aboriginal mothers' experiences of accessing health care [online]. *Contemporary Nurse*, 37, 57–68.
- Walters, K., Mohammed, S., Evans-Campbell, T., Beltran, R., Chae, D., & Duran, B. (2011). Bodies don't just tell stories, they tell histories: Embodiment of historical trauma among American Indians and Alaska natives. *DuBoise Review*, 8, 179–189.
- Wood, B., Burchell, A. N., Escott, N., Little, J., Maar, M., Ogilvie, G., & Zehbe, I. (2014). Using community engagement to inform and implement a community-randomized controlled trial in the anishinaabek cervical cancer screening study. *Frontiers in Oncology*, 4, 27. doi:10.3389/fonc.2014.00027
- Zehbe, I., Moeller, H., Severini, A., Weaver, B., Escott, E., Bell, C., & Paavola, N. (2011). Feasibility of self-sampling and human papillomavirus testing for cervical cancer screening in first nation women from Northwest Ontario, Canada: A pilot study. *British Medical Journal Open*, 1, e000030–e000030. doi:10.1136/bmjopen2010-000030
- Zehbe, I., Maar, M., Nahwegahbow, A. J., Berst, K. S. M., & Pintar, J. (2012). Ethical space for a sensitive research topic: Engaging first nations women in the development of culturally safe human papillomavirus screening. *Journal of Aboriginal Health*, 8, 41–50.
- zur Hausen, H., (2000). Papillomaviruses causing cancer: Evasion from host-cell control in early events in carcinogenesis. *Journal of the National Cancer Institute*, 92, 690–698. doi:10.1093/jnci/92.9.690