



Original article

A Qualitative Study of Provider Perspectives of Structural Barriers to Cervical Cancer Screening Among First Nations Women

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Article history: Received 25 October 2012; Received in revised form 25 June 2013; Accepted 26 June 2013

A B S T R A C T

Objective: In Canada, opportunistic screening programs have successfully reduced mortality from cervical cancer; however, minority or disadvantaged groups, as well as women in northern and rural areas, are inadequately recruited by this approach. Hence, we set out to examine the structural barriers that prevent First Nations women's participation in cervical cancer screening.

Methods: Using a participatory action research approach and semistructured interview guides, we conducted in-depth interviews with 18 experienced health care professionals, 12 of whom were also community members. These individuals included nurses, nurse practitioners, community health representatives, social workers and physicians who provide care to women in our First Nations partner communities. In the current report, we explored perceived barriers to cervical cancer screening through the lens of service providers.

Results: Structural barriers to cervical cancer screening for First Nations women included shortage of appropriate health care providers, lack of a recall-based screening system, geographic and transportation barriers; health literacy and socioeconomic inequalities, generational effects, and the colonial legacy.

Conclusion: Existing, opportunistic cervical cancer screening programs do not perform well for First Nations women who experience significant screening-related health inequalities that are largely influenced by structural barriers. Sustainable screening interventions in First Nations communities require approaches that resolve these structural barriers, explore new ways of screening, and provide education for both women and health care providers. Many of the structural barriers are rooted in colonial history. Given the negative impact of the consequences of colonization on indigenous women worldwide, many of our findings strongly resonate with marginalized populations in other countries.

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Introduction

In Canada, provincial screening programs have successfully reduced cervical cancer mortality from 7.3 per 100,000 women in 1969 to 2.2 per 100,000 women in 2000 (Health Canada, 2004). Cervical carcinomas are caused by high-risk types of the human papillomavirus (HPV). Not all women infected with

Funded by the Canadian Institutes of Health Research (CIHR Operating Grant # 257682 to IZ) and Indigenous Health Research Development Program Student Mentorship Program (MM and MY).

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high-risk types of the HPV develop a carcinoma or precursor lesion; however, those with persistent infections are at elevated risk. Currently, the primary method of cervical cancer screening is the Papanicolaou (Pap) test, which detects cell morphological changes indicative of a precursor or invasive lesion (Papanicolaou, 1942).

Most Canadian provinces have not implemented recall-based screening, where a cancer registry identifies eligible women. Instead, most jurisdictions have opportunistic screening programs, which rely on the primary health care provider inviting their patients to participate. There is increasing evidence that this screening approach is inadequate in recruiting marginalized and rural groups who are commonly underserved by primary health care providers.

Two Canadian provinces—British Columbia and Nova Scotia—provide recall-based cervical cancer screening. In British Columbia, their Cervical Cancer Screening Program has greatly increased average screening rates (Band et al., 1992; Hislop et al., 1996). However, the benefits are not realized for Aboriginal¹ women who are estimated to have Pap test rates of only 50% compared with 85% for all ever-screened women (Band et al., 1992; Hislop et al., 1996). In Nova Scotia, Aboriginal women were similarly (1.6-fold) less likely to have had a recent Pap (Johnston, Boyd, & MacIsaac, 2004).

Aboriginal women have 2 to 20 times the risk of being diagnosed with cervical cancer, depending on the Canadian province. In Ontario, cervical cancer incidence is 1.73-fold higher among First Nations compared with the general population with similar differences noted for the mortality rate (Marret & Chaudhry, 2003). In Manitoba, Aboriginal women were found to have 1.8 and 3.6 times the rate of in situ and invasive cervical cancer, respectively, and this rate has been increasing (Gillis, et al., 1991; Morgan & Laing, 1981; Young & Choi, 1985; Young & Frank, 1983). In an Albertan community, cervical cancer was found 20 times more often in First Nations women than in other Canadian women (Colquhoun et al., 2010). Accordingly, the death rate from cervical cancer among First Nations women significantly exceeded the rate among women from the mainstream population: the Relative Risk for women aged 20 to 64 was 5.95-fold higher during the study period from 1953 to 1984 (Band et al., 1992).

Similar disparities are found internationally. Indigenous women in Australia are 2.4 times more likely to develop cervical cancer, with a mortality rate five times the Australian average (Shannon, Franco, Powles, Leng, & Pashayan, 2011). In New Zealand (McLeod et al., 2010), Māori women have poorer cancer specific survival than non-Māori women (mortality hazard ratio, 2.07). Cervical cancer incidence in American Indians and Alaska Natives is also significantly elevated (relative risk, 1.25; 95% confidence interval, 1.11–1.39; Espey et al., 2007).

The causes of these disparities are still poorly understood, but likely involve the multiple social barriers experienced by low-income, multicultural populations (Sorensen et al., 2003). Research on the “intersecting roles of multiple sources of disparities” and the origin of observed health inequalities is urgently needed to improve cervical cancer screening among Aboriginal women (Sorensen et al., 2003).

To elucidate the factors that influence participation in cervical screening by Aboriginal women, we conducted qualitative research with 18 key informants possessing extensive

experience in providing sexual health-related services to First Nations women in Ontario, Canada. We particularly focused on the structural barriers to cervical cancer screening in this population. This research is part of a larger study, entitled “Engaging First Nations Women in Cervical Cancer Screening: Assessing Factors Related to Screening and Uptake of Self-sampling.” This study is designed to identify viable, culturally acceptable cervical cancer screening approaches, with the long-term goal of increasing screening and reducing cervical cancer among Aboriginal women.

Methods

Our project is based on participatory action research (PAR) methodology involving research partnerships with 11 First Nations communities in rural Northwest Ontario. These communities are culturally and politically aligned with the Anishinaabek Nation Northern Superior Chiefs and the Robinson Superior Treaty. They lie within a 500 km radius of Thunder Bay, the major urban and medical center of Northwest Ontario. Communities range in population size from 70 to 840 individuals and share many social determinants of health with other First Nations communities in rural Canada.

Consistent with Canadian guidelines for research with Aboriginal people, we employed a PAR approach (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). As such, formal research agreements were developed with each partner community, outlining processes for involving the community stakeholders as valued partners in the design and implementation of the study. The research partnership between our academic team and the community stakeholders has been described in detail elsewhere (Zehbe, Maar, Berst, Nahwegahbow, & Pintar, 2012). Local community-based research leads (usually senior health services managers, composed mostly of community women) were identified by the chief and council, the political leadership body who had approved implementation of the research in the respective community. Through application of the collaborative research principles on which PAR is based, local research leads were consulted in all phases of the research. The leads often consulted further with additional community stakeholders on research design and methods.

The result of this collaborative relationship was that study design was strongly influenced by the perceived sensitive nature of HPV infection and cervical cancer prevention in First Nations. In their role as community-based co-researchers, research leads identified the connotation of HPV with shame and stigma in their communities as well as related factors such as sexual abuse histories and drug use. These issues may either prevent community women from engaging with this research or, under the worst circumstances, even further psychologically harm participants. Therefore, consensus was reached between the academic and community teams that for the current project phase, the research would focus on structural barriers to cervical cancer screening by exclusively interviewing health care and social services providers. These women, most of whom were also community women, had professional training and long-term experience dealing with sensitive health topics and related social issues within the community. Future participation by the general population of community women and exploration of more personal topics than structural barriers will have to be

¹ The term “Aboriginal” is used to be consistent with the Canadian constitution and includes the indigenous people of Canada whose ancestry is First Nation, Inuit, or Métis.

negotiated after the community leadership has evaluated their community's experience with this HPV research.

Using purposive sampling, the community-based research leads were responsible for recruiting one or two key informants experienced in providing or arranging sexual health-related services at each location. Because of the close cultural, political, and geographic affiliations between the communities, this sampling strategy was deemed ideal to cover the perspectives within the communities. We conducted in-depth interviews with 18 experienced health care professionals (17 female, 1 male), including nurses, nurse-practitioners, community health representatives, social workers, and physicians who provide services to women in at least one of the First Nations partner communities. Twelve of the participants were First Nations women who lived in our partner communities and their responses were therefore informed by their own lived experience as well as the experience of providing services to their clients. The interviewees had worked in the communities between 6 months and 15 years.

The trust established with the First Nations communities during the partnership development (Zehbe et al., 2012) was instrumental in setting the stage for a rich and candid dialogue. An experienced qualitative researcher (M.M.) led each interview. To maximize community benefit resulting from this PAR research project, community research leads requested that the interview process should additionally serve to raise health care provider awareness of HPV infection, testing, transmission, and vaccines. A tumor biologist specializing in HPV research with focus on cervical cancer prevention (I.Z.) therefore attended all interviews and provided information about cervical cancer and HPV as questions arose or clarifications were required. Twelve of the interviews were conducted face to face and six were conducted by video conferencing to accommodate scheduling difficulties associated with winter travel in rural Northern Ontario. Interviews ranged from 40 to 90 minutes and were conducted during the fall and winter of 2011 and 2012.

Using semistructured interview guides, we explored the perceived community attitudes about 1) cancer and 2) cervical screening, as well as 3) barriers to and 4) potential facilitators of screening. All interviewees were informed about the study prior to conducting the interviews and thereafter were required to sign an informed consent sheet. The interviews were audio recorded, transcribed verbatim and analyzed using NVivo 9 software (QSR, Burlington, MA). All transcripts were compared with the audio recording for accuracy.

Coding was predominantly deductive and focused on structural barriers commonly reported in the sexual health literature, including cultural, geographic, socioeconomic, and policy barriers, that discourage women from accessing health services (Dang, Giordano & Kim, 2012; Sabatino et al., 2012; Sumartojo, 2000). M.M. and I.Z. independently reviewed and coded all of the interview data using thematic analysis. The coded data were then reviewed during in-person meetings and a consensus was reached on any discrepancies. Member checking is another important aspect of both qualitative analysis and PAR. It ensures high levels of data accuracy, credibility, and validity, especially in cross-cultural research, by feeding research results back to community stakeholders for validation. To accomplish this, we presented the results and preliminary analysis to the community health care providers for comment and verification both at a workshop on October 16, 2012, and in writing. No changes were requested. The study was approved by the Lakehead University Research Ethics Board (#038 11-12/ROMEO #1462079).

Results

Shortage of Appropriate Health Care Providers

Participants identified a shortage of health care providers who are trained to do Pap tests as a barrier to cervical cancer screening in rural areas. In addition, participants believed that many First Nations women are shy about their bodies, particularly in medical examinations, and are consequently very uncomfortable with pelvic examinations when performed by male providers:

The girls are always looking for female doctors or nurse practitioners, because they're more comfortable. Like, my daughter's doctor is male, and she's like, I want a female doctor. But they won't take any more patients! So for her, that's a barrier. (Participant 1)

During the interviews, we were told repeatedly that "women just don't want *anyone* poking around down there," and that they required a trusting relationship with a familiar provider to undergo this procedure. Even women who had regular Pap tests in the past may stop screening altogether if there was a turnover in health care providers.

Lack of Recall System

Primary care providers try to remind women about screening as they come into their office presenting with other issues. None of the rural systems we studied had an official system to recall women for regular Pap testing.

From my experience as a woman, no, they don't contact anybody [regarding screening]! (Participant 2)

Many women in the studied communities seemed to be unaware of the importance of cervical cancer screening and the lack of a recall system was therefore a major barrier for screening. Furthermore, regional primary care providers such as physicians and nurse practitioners who provide care in clinics in the mainstream Canadian health system did not share patient information with community-based First Nations workers. A community-based reminder system, although feasible in some communities in terms of staffing, was impossible owing to the lack of agreements for the sharing of health information between on- and off-reserve service providers which are necessary to comply with federal and provincial privacy laws.

Transportation Barriers

To facilitate access to health services that are locally unavailable, community health clinics have arranged transportation to urban or larger rural medical clinics using a locally operated medical transportation van. Yet, "transportation is still a huge barrier for many First Nations women" (participant 2) living on-reserve, especially those on social welfare:

Barriers to access [include] the transportation to and from the city. Most [non-Aboriginal] people don't have to travel 2.5 hours on a bus to then get dropped off at their appointment and then not get picked up till after 4 o'clock in the afternoon... You drop them off at their appointment but they have no money to purchase a lunch for themselves or to feed themselves during the day, so a lot of times they won't go

because they have no way of providing themselves with a meal when they're in the city. (Participant 3)

Study participants indicated that transportation barriers affected employed women as well: Women who worked locally were frequently unable to afford to take a whole day off from work for a medical appointment (vehicles leave the community early in the morning and return in the evening). Therefore, many women wait to seek care until they experience acute illnesses with clear symptoms. Furthermore, many women do not have reliable child care at home and children are only permitted in the medical van if there is spare room. One provider described a frequently occurring scenario:

Say I'm a client, I have four kids, I'm a single parent, I can't find child care, I have to take all four of my kids with me, I would go early enough and let the referral clerk know that "okay, it's going to be me and my four kids." And then, the referral clerk says well if we have a full van and they're all medical appointments then your children won't be able to go with you.

We have single moms with newborns ... the babies are given priority, but if they're not being breastfed and they do have a full van then baby can be left behind and we have had to do that in some cases. Again, you're not going to leave your baby or you're not going to leave your children if it's just for a Pap smear. (Participant 4)

In most communities, medical escorts or relatives were also not eligible for transportation to accompany women seeking Pap tests. This is a barrier, especially for older and very young women who may require moral support for this procedure, which is seen as invasive and intimidating by many women.

Education and Socioeconomic Inequalities

Many participants agreed that "education is the biggest thing" (participant 5) in terms of facilitating a woman's decision to engage in cancer screening. They discussed education in terms of a woman's attendance at a formal school system, but also from the perspective of health literacy, including a woman's specific knowledge related to HPV transmission, knowledge of how to use and access health services, comfort level of navigating health services, and knowledge of cervical cancer prevention. Participants felt that many Aboriginal women were disadvantaged in these areas:

As far as education, you know, we're not exactly up to par. I'm not speaking about the young people but maybe adults, you know, like the middle-aged women who might not have had the chance to go to high school or college. It's not that they're incapable of understanding, but just to give them that little extra knowledge, cause some people might not want to say, 'well I don't understand' because who wants to really admit that they don't understand something. (Participant 6)

Furthermore, community members with low health literacy and a lack of awareness of why cervical cancer screenings are performed were unlikely to subject themselves to a Pap test. Lack of culturally appropriate health education was therefore seen as a factor:

The biggest motivation is education, I think. You know, just, teach them, let them know that the service is there, that they need to take it, it's important that ... it's constantly out there. (Participant 7)

Formally educated women usually did not experience the same degree of language or health literacy barriers. These women had become reasonably experienced or even comfortable with mainstream institutions, although cultural barriers persisted to some degree. According to participants, these educated women were more likely to be proactive about their health and possessed the self-efficacy to navigate the health system. They were usually in a higher socioeconomic class and more easily able to make their health a priority.

I think there's more empowerment in women here [in the community], because more women are employed here. I'd say employed First Nations [women] are more apt to be coming in [for a Pap test]. Yeah, that would make a difference: Educational standards! (Participant 8)

Conversely, the poverty experienced by many families on-reserve was perceived to affect health screening negatively:

[This is] a very poor community and I think poverty also keeps people just focused on when the cheque's coming and what they can do to get the kids fed. (Participant 9)

Generational Effects

Providers described generational differences with respect to screening reluctance among First Nations women. One shared sentiment was the following:

It's difficult, with the older women, and then the really young, newly sexually active girls are a little reluctant to get their Pap. (Participant 10)

However, there seemed to be a sense that many younger women eventually became used to screening in early adulthood:

It's older women who probably don't go as often [for screening], and younger women, are a little bit more proactive with their health. (Participant 11)

Participants believed that the reason for this was primarily that older teenagers are exposed to health education in schools and consequently many are concerned about sexually transmitted diseases. Pap tests are often required to refill birth control prescriptions and young women generally comply. Often, these young women became more informed about sexually transmitted disease prevention and more open to accepting screening than their older counterparts in the community:

The young ones ... seem to be more open to the fact that this is important with regards to their health care ... whereas I find with the older generation they are very set in their ways and they're a bit more difficult to get through to with regards to health teaching and prevention. (Participant 3)

Women at the end of their childbearing years were described as often believing cervical cancer screening was not necessary because they may have undergone hysterectomies, they were in monogamous relationships, or they were not sexually active. Elders often experienced additional barriers:

It seems that the older that they are, the more they keep to themselves and they think that automatically cancer just means you're going to die so they don't try to get the help that they can ... most of the older ones are not trying to help themselves and they feel that it would be selfish of them to put the burden onto someone else. (Participant 2)

A fear of leaving the community and the potential of being kept in hospitals far from their communities owing to abnormalities that might be found in a Pap test was perceived as another concern for elders:

The older clients, they don't want to leave the community for testing and they don't want to go out for appointments because again, they've seen some of our elderly leave the community and not come back home... They're silent on a lot of their health issues until it's pretty much too late for them to be diagnosed. (Participant 4)

One reason for their apprehension may be related to feeling helpless and uncomfortable in medical encounters owing to cultural and language barriers (elders often only speak English as a second language). Participants also described the behavior of older women to be commonly rooted in the history of the often negative relationship between First Nations and mainstream society:

That history, that went on there that really still has such an impact! We think that we've made things user friendly, and to us it is, but to others, to them, it isn't, you know. For some of the older generation, they may not necessarily have been through mainstream education, and they don't know what questions to ask, and, they are, just very intimidated by it, and so they just avoid [mainstream health care] altogether. (Participant 12)

An additional complication noted was that the vast majority of primary care providers were non-Aboriginal and turnover rates were high. The colonial legacy of oppression surfaced in most interviews and is further explored below.

Colonial Legacy

Providers explained that past governmental assimilation policies, such as the residential school system, still contributed to the mistrust held by some Aboriginal people toward mainstream Canadian institutions, including the health care system. Many Aboriginal women still experienced racism:

A lot of First Nations, they've had really bad experience with Caucasian people, so to come to a clinic, which is viewed like an organization sort of like a residential school ... building that trust is very difficult. (Participant 13)

Another legacy of residential schools was high rates of sexual abuse in Aboriginal communities and the resulting emotions of shame and shyness about sexuality. One provider recounted her personal experience:

As we were growing up as kids, we had ... a housecoat that was almost at the floor, you know, covering our ankles. ... Your body was always covered ... I honestly, I don't think that's so much cover was part of the [First Nations] tradition, [instead] I think a lot [of] it came from the abuse from the residential schools. (Participant 7)

Many providers linked reluctance to cervical screening with the destructive environment experienced by some Aboriginal women in residential schools that included strict taboos related to sexuality or sexual abuse.

Discussion

Aboriginal women experience significant health inequalities in cancer screening that are, based on our research, less

influenced by personal risk behaviors and more by broader societal forces (Blankenship, Friedman, Dworkin, & Mantell, 2006; Spence, Goggin & Franco, 2007). These structural factors are centered in sociohistoric and environmental conditions that influence women's health behaviors, deter women from cervical cancer screening, and are exacerbated by health system limitations. Similarly, a recent systematic review (Sabatino et al., 2012) provided preliminary evidence that structural barriers are intertwined with cervical screening behaviors in study populations in the United States, Canada, and Australia. Furthermore, research in the United States and Canada supports our finding that health care providers' attitudes and abilities to establish trusting relationships greatly impacts First Nations women's willingness to undergo Pap testing (Hislop et al., 1996; Smith, Christopher, LaFromboise, Letiecq, & McCormick, 2008).

Sustainable screening interventions in Aboriginal communities must clearly go beyond the individual educational and behavioral approach to focus on eliminating structural barriers. Historical structural factors such as past Canadian governmental assimilation policies and, particularly, the consequences of the forced relocation of Aboriginal children to residential schools (Milloy, 1999) still contribute to power imbalances, subsequently impeding access to health care for Aboriginal women. Moreover, jurisdictional divisions between on-reserve (First Nations community) and off-reserve (mainstream community) providers result in a lack of access to health information by community-based Aboriginal workers and impede the development of locally controlled, First Nations, recall-based screening systems. Mainstream providers often have difficulties connecting with First Nations women on reserves owing to cultural barriers and the high mobility of First Nations people. As organized screening is developed, providers will need to take into account that many women who are living in poverty do not have access to phones. This may require personal contact from on-reserve providers, who are not currently working with mainstream providers and do not have access to patient health information because of privacy laws. Hence, policy development in the area of patient data sharing is urgently needed.

In the interim, new policies to support innovative screening approaches may be warranted: Structural barriers including transportation issues and the pervasive distrust of unfamiliar health care providers might be effectively mitigated by the provision of alternative methods to cervical cancer screening, such as the HPV self-sampling test. As demonstrated in previous studies (Ogilvie et al., 2007; Zehbe et al., 2011), there is emerging evidence that self-sampling may indeed be acceptable to Aboriginal women as well as other women who were less likely to attend Pap tests in the past. The HPV self-test can be conveniently and privately administered in a woman's home, but under current health policy, this test is not financially covered by the health care system. Similarly, self-sampling may also apply to women who are reluctant to undergo cervical screening because of a history of abuse, excessive shyness, insufficient familiarity with the provider, or discomfort with the power imbalance between themselves and the health care providers—issues that our research indicates act as significant barriers to cervical cancer screening among Aboriginal women.

Awareness campaigns are necessary and require a focus on culturally appropriate and empowering messaging. Education programs are also needed to inform primary care providers about the unique barriers to screening, discovered in this study, that are faced by Aboriginal women.

Implications for Practice and Policy

There is a gap in the Canadian health care system regarding Aboriginal women and cervical cancer screening, and qualitative research studies such as this one demonstrate the need for viable, culturally based approaches. For example, in our study, health literacy and self-sampling emerged as the main facilitators of cervical cancer screening within the current service landscape of opportunistic Pap screening. Aboriginal communities require culturally appropriate education materials to raise awareness that cervical cancer is preventable with regular screening. Community education campaigns must be developed in concert with Aboriginal women. Educational strategies must also reach primary care providers, to ensure that they are sensitized to the many historic and systemic barriers to cervical cancer screening that Aboriginal women may face and that they avoid labeling these patients as noncompliant or disinterested in their health. Transportation issues could be addressed by adding a cervical cancer screening service to the already operating and successful breast cancer screening mobile coach that visits nearly 30 communities throughout Northwest Ontario.

Offering HPV self-sampling tests as an alternative to a Pap test may further address barriers related to discomfort with pelvic examinations, lack of qualified or trusted health care providers, and transportation barriers. Changes to health policies are required to gain coverage for this procedure under government health insurance. HPV testing and self-sampling may potentially even lead to savings in the health system of rural and remote areas as specialized primary care providers are not required to facilitate the testing. However, with HPV-based testing, jurisdictions will need centralized services to prevent overscreening and to avoid harm. Better coordination and integration of on- and off-reserve health care systems, especially in the area of health information systems, will be required in the long term to ensure that Aboriginal women are seamlessly followed up regarding test results, monitoring, aftercare, and regular invitations for screening.

Although a limitation of our study is that we included only 11 communities from similar cultural groups in Canada, it is clear that Aboriginal women elsewhere, and even Indigenous women worldwide, share similar colonial experiences and socioeconomic disadvantages. Therefore, many of our findings likely also apply to Indigenous women in other countries. Additional qualitative research with Aboriginal women is urgently needed to gain a deeper understanding of the psychosocial and cultural factors relevant to inform the development of culturally safe, strength-based, and community-led educational and screening programs.

Acknowledgments

The authors gratefully acknowledge the participation of Northern Superior First Nations communities in Northwest Ontario for facilitating this research and for reviewing this paper prior to publication. Marion Maar is corresponding author for the qualitative part of the study while Ingeborg Zehbe is corresponding author for the clinical part involving cervical cancer biology and HPV. We thank Lisa Boesch for transcription and support in preparing the manuscript.

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