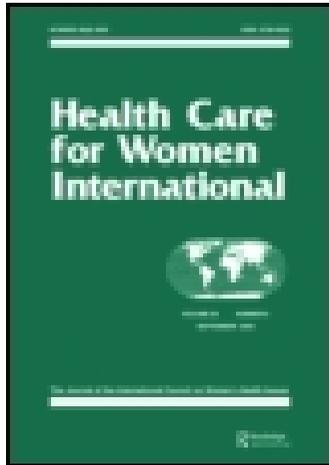


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### Strategies for Increasing Cervical Cancer Screening Amongst First Nations Communities in Northwest Ontario, Canada

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# **Strategies for Increasing Cervical Cancer Screening Amongst First Nations Communities in Northwest Ontario, Canada**

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*The high burden of cervical cancer in Indigenous populations worldwide is due to underscreening and inadequate follow-up. Using qualitative, participatory action research, we interviewed health care staff to identify ways to increase screening recruitment in First Nations communities in Northwest Ontario, Canada. Our*

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*findings suggest the value of a multilevel social–ecological model to promote behavioral changes at the community, health care service and stakeholder, and decision-maker level. Participants emphasized the central role of First Nations women as nurturers of life and for the well-being of their family members. They stressed the importance of building awareness and motivation for cervical cancer screening through various activities including continuous education, hosting screening events specifically for women, improving the attitude and service of health care providers, and promoting screening tools and policies that complement and are respectful of First Nations women.*

Cervical cancer rates are relatively high in Indigenous women worldwide most likely due to “underscreening.” The goal of our study is to engage Canadian First Nations women in the participation of cervical cancer screening. The development of trusting relationships with this population prior to starting the study enabled us to actively engage our participants in the research process. Rather than identifying a best practice approach, we understood from candid dialogues with our participants that a multipronged and multileveled process is essential to reach our goal. We strongly believe that this outcome has great value for other vulnerable populations in any global setting.

Cervical cancer is a significant health problem among Indigenous peoples in Canada. It is the most common cancer in First Nations women living in the Northwest Territories (Corriveau, 1997), and in an Albertan community, the incidence of cervical cancer was 20 times higher than in the province as a whole (Colquhoun et al., 2010). A higher mortality rate than in other Canadian women has also been found in Manitoba (Young, Kliewer, Blanchard, & Mayer, 2000) and Ontario (Marrett & Chaudhry, 2003). This is not solely a Canadian phenomenon: Indigenous women from the United States, Australia, and New Zealand also have higher cervical cancer prevalence than the general population (Dignan et al., 1996; McLeod et al., 2010; Shannon, Franco, Powles, Leng, & Pashayan, 2011; Vasilevska, Ross, Gesink, & Fisman, 2012). Low screening or attendance for follow-up in Indigenous populations may be a significant contributing factor to these disparities. Indeed, screening is the key to cervical cancer prevention through early detection and treatment of precursor lesions, and the majority of new cervical cancer diagnoses worldwide are in women with inadequate or no screening or follow-up (Spence, Goggin, & Franco, 2007).

Two tests can be used for primary cervical cancer screening. The *Pap(anicolaou)* test detects morphological changes indicative of a precursor or invasive lesion. Its sensitivity in detecting high-grade lesions is 51%–70% (Koliopoulos et al., 2007), resulting in false-negative test results due to missed morphological changes or suboptimal sampling (Arbyn, Ronco, Meijer, &

Naucler, 2009). Despite this limitation in its operating characteristics, regular Pap screening in Ontario has decreased both incidence and mortality by 60% over the last 30 years. In settings like Northwest Ontario, however, more than 50% of the women are seldom or have never been screened due to their reluctance to undergo Pap testing (Fehringer et al., 2005) and the challenges of accessing screening services (Maar et al., 2013; Stout, Kipling, & Stout, 2001). The *human papillomavirus (HPV) test* has a sensitivity of more than 95%, high negative predictive value and a specificity of more than 90% for detecting high-grade lesions in women aged 30 and older, allowing longer intervals between screenings (Healey et al., 2001; Kitchener et al., 2009; Ratnam, Franco, & Ferenczy, 2000). The HPV test can be performed based on self-collection, adding convenience to higher sensitivity and affecting screening participation rates positively in underscreened women as shown in several independent studies (Ogilvie et al., 2007; Sanner, Wikström, Strand, Lindell, & Wilander, 2009; Stenvall, Wikstrom, & Wilander, 2007; Stewart et al., 2007; Wikström, Stenvall, & Wilander, 2007). It is currently not standard of care, however, in Canada.

Using participatory action research (Kemmis & McTaggart, 2000), our collaborative research team has partnered with First Nations communities in Northwest Ontario to explore feasible, community-based intervention strategies for cervical cancer screening. Here, we describe interviews with health care professionals stationed in our partner communities and identified key recommendations to increase cervical cancer screening participation among their clients. These recommendations are best understood and implemented through a social–ecological framework—a theoretical interpretation of health promotion that speaks to the complex relationships among individual, social, and environmental factors (Stokols, 1996). The results obtained will inform our subsequent screening trial, promote knowledge translation with stakeholders, and set future screening guidelines that are better adapted to our target population.

## METHODS

We developed a participatory action research (PAR) project (Kemmis & McTaggart, 2000) in collaboration with 10 Robinson–Superior Treaty First Nations in Northwest Ontario to address cervical cancer screening and ultimately improve its uptake and follow-up by their female population (Zehbe, Maar, Nahwegahbow, Berst, & Pintar, 2012). PAR in this study involved the collaborative effort of a multidisciplinary team (with expertise in tumor biology and virology, medical anthropology, epidemiology, health sociology, and women’s studies and gynecopathology) to *actively* engage participants in the research process ensuring the highest possible benefit to them. This was accomplished by the ratification of Research Agreements between the Political Leadership of each community (e.g., Chief-in-Council), the

supporting institution (Thunder Bay Regional Research Institute) and the principal investigator (I.Z.); meet-and-greet visits to all communities prior to starting the study; hiring community-based research assistants (CBRAs, one for each community); the forming of a Community Steering Committee (CSC, one member of each community, usually the health director of this community); an ad hoc Publication Steering Committee (three members recruited from the CBRAs and CSC members or delegates for each submitted peer-reviewed publication) and continuous community visits to disseminate findings to participants. Northwest Ontario faces service delivery challenges due to its large geographic expanse and dispersed population. The participating First Nations communities range from 70 to 840 members on-reserve and are mostly scattered around the northern shore of Lake Superior or around Lake Nipigon.

This mixed methods project consists of two parts: a *qualitative part* with interviews and focus groups followed by a *quantitative part* with a randomized two-arm screening trial (Wood et al., 2014). In the qualitative research reported in this article, we requested the community-based leaders in each community (usually senior health managers) to select one or two knowledgeable key informants who provide care to women in at least one of the partner communities as previously described by us (Maar et al., 2013).

Two researchers were present at each interview: a medical anthropologist with experience in community-based qualitative research (M.M.) and a tumor biologist and virologist (I.Z.) with expertise in cervical cancer and HPV biology. Using semistructured interview guides, they explored questions related to the providers' perceptions on (a) effective ways to reach First Nations women with screening information; (b) potential or promising strategies to help motivate women to participate in cervical cancer screening; and (c) special issues for First Nations women with respect to cervical cancer screening.

The interviews were audio recorded, then transcribed verbatim, and all transcripts were compared with the audio recording for accuracy. The interview data were then analyzed using NVivo 9 (QSR, 2011). The two interviewers (I.Z. and M.M.) reviewed as previously described and coded all of the interview data using thematic analysis, focusing on factors that affect recruitment (Maar et al., 2013). As we will discuss below, the thematic findings were condensed into three global concepts suggestive of a social–ecological model of health promotion (Stokols, 1996). The study was approved by the Lakehead Research Ethics Board (#038 11-12/ROMEO #1462079).

## RESULTS

### Seven Ways to Promote Cervical Cancer Screening in First Nations Women

From the interviews, we identified seven key themes to promote cervical cancer screening in First Nations women in our partner communities. These

themes illustrate methods that can shape individual behavior by influencing the beliefs and actions of individuals and their support system of family, friends, and health care providers.

*Explain the value of cervical cancer screening.* The majority of interviewees stressed that to make cervical cancer screening a success, comprehensive information about cervical screening, its importance (for example, why it has to be done regularly to be effective) and its benefits (for example, regular screening can prevent cancer almost entirely) have to be clearly stated:

Explain [what the Pap test is] then they accept the value of early diagnosis: I find that once I explain to them the importance of early detection and [that] it can be treated, they're more agreeable to [a Pap test]. (*Informant #1*)

Despite the fact that Pap cytology has been used for many decades as primary screening, many Indigenous women in our study area do not seem familiar with what it entails or why it is done. In particular, it has not been made clear that it only screens for cervical cancer. Clearly, more efforts need to be taken to explain the exact nature of gynecological screening to women seeking this service. To improve education by a trusted health care provider is therefore a much-needed approach to create awareness for screening services:

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 they have it. (*Informant #2*)

The message that regular cervical screening can almost entirely prevent cervical cancer must also be emphasized:

We know cervical cancer is 100% preventable, and I know because I read stats and see statistics that Aboriginal women are the number one on the list for dying from this. (*Informant #4*)

*Motivate through specific educational strategies and capacity building.* All interviewees emphasized that education at different levels, including capacity building with professional health staff, is an important factor to raise awareness for cervical cancer screening and to develop and sustain a good screening culture. Health education should be tailored to the various needs of women in the community, and various strategies to get the word out to the women were suggested. Initially, the screening interventions should focus on building local capacity for client education of health care professionals stationed in our partner communities:

You need to make sure that you train the trainers, like teach the CHRs [community health representatives], and the women in the community that are providing service. (*Informant #1*)

Participants also identified important roles for community women to participate in educating other community women. In particular, champions in the community, who have survived [cervical] cancer, were seen as potentially powerful educators:

I think if there was someone just sharing stories. If a woman was willing to share her story that she's had this and got screened early. Girls like to listen to things like that, and the women like to listen to things like that. I beat this and I did that. Something like that would motivate them. (*Informant #1*)

Within the extended family, role modelling was seen as another educational approach that could include mothers, aunts, and grandmothers:

Well, my mother, you know, always went for her physicals; thus I learned that I was to go for my physicals. . . the families that do have it, you can see that progression of preventative health care. (*Informant #5*)

For the younger generation, however, early education is needed in schools:

Start early, in school already: we should get our younger girls out there, and have that part as [education], at [grade] 8, and I know they're doing great in the school, getting it out there, about STDs. (*Informant #6*)

Regular workshop sessions were suggested as a good way to provide information to community women where they gather for work lunches or in waiting rooms:

Workshops, information sessions: I have lunch and learns. That's a start. There's all different venues bringing that into the community. (*Informant #1*)

To complement the active interventions, participants also suggested passive interventions to reach all community members. Newsletters and flyers at doctor's offices, health centers, or nursing stations can be used in combination with social networking:

You could even [do] something as simple as Facebook. Everybody's on Facebook. (*Informant #1*)

Participants stressed the important role of humor within the culture and its role in health education:

We didn't specifically talk about HPV, but we talked about STDs [during the education session]. Yeah, I think they got it because they still, when they see me on the streets here, we kind of giggle about it because we used bananas [for the sex education], you know, and they'll ask me: "Are you bringing bananas next week?" You know, so, it was a fun thing. (*Informant #6*)

Some women may appreciate being talked with in their own language:

I have a sweet little old lady, she's probably close to 80; she won't speak it, she won't speak English, she understands you, she can speak English, but she would rather speak in her own language. (*Informant #9*)

*Embed cervical cancer screening into community events.* Most informants agreed that screening should be integrated within a community health-and-wellness-promoting event specifically designed for women and embedded into community life and First Nations culture. The event could range from a women's wellness day, honoring the role of women in the community, to the more mundane day-to-day activities that are important and enjoyable to the women in the community, such as a sewing circle or the community kitchen:

So if you're having something that they're able to come and access, [like a] sewing circle, or community kitchen, something that they're gonna get, then they'll come. (*Informant #2*)

Cervical cancer screening can be planned around events that honor women like Mother's Day:

I would concentrate on a day that's important to the women, like Mother's Day. The mothers would all come and the grandmas would come and the aunts would come. I would have guest speakers come in as well and there would be a dinner, a luncheon, or a feast of some sort. I would bring somebody in who had a little bit of charisma like a Tai Chi instructor who cooks meals. (*Informant #7*)

Combining cervical screening events with a small incentive would likely increase excitement related to the event and participation:

It's hard to get people coming unless we have food and incentives. (*Informant #10*)

*Health care providers need a trusting rapport with women.* Health care providers have an important role in inviting women for screening. Their attitude and rapport with women is crucial for developing a good screening culture in the community. Several informants stressed that to encourage women to attend cervical screening, warm, personal, and friendly relationships are essential. The women have to feel comfortable with the health care provider:

The women are, you know, fairly open once they're comfortable. (*Informant #1*)

Likewise, the women have to be able to trust their health care provider:

It's all about trust and relationships, like if you can't build a relationship you're not gonna get anywhere, you might not even see them again. (*Informant #8*)

*Integrate cervical cancer screening recruitment into existing health care services.* A few interviewees pointed out that to make cervical cancer screening more convenient, health care system level interventions will need to be considered to increase screening participation. Women can be recruited for cervical cancer screening when they come to the office for other reasons. This would add flexibility to the screening culture and help establish the importance of preventive health care into the existing culture. Providers suggested prompting women during visits:

"Well, since you're here, you know, we haven't screened for this, and when was your last Pap and what about colon cancer screening?" (*Informant #8*)

Such service could also be brought into the communities in the near future using mobile services for breast cancer screening:

*Create a dialogue on cervical cancer screening in day-to-day activities.* Once screening awareness and recruitment opportunities are improved, the screening culture in the communities has to be sustained by engaging with women on a personal level. Participants had several suggestions for sustaining a screening culture within the health center staff:

For our little group of work girls, [the] service team, we always tend to remind each other as well, like, "Hey, is it time for your check-up yet, like?" (*Informant #13*)

A good way of getting cervical cancer screening into a routine would include several (friendly) ways by which women can remind one another: the health care providers remind their women clients, and community women and the

female staff remind one another. Word of mouth is a powerful approach to spread the message on an ongoing basis:

I think it's just sort of word of mouth, spreading things around, and just kind of bringing it up, you know, all the time. (*Informant #8*)

Another participant suggested an even more proactive word-of-mouth approach:

I call four people and then each one of the people I call, they call four people and it's something that we're trying to work on. (*Informant #14*)

*Incorporate First Nations gender perspective on body and preferred screening techniques to enhance privacy and comfort.* We received various suggestions how cervical screening could serve as one vehicle for women to reclaim their role as teachers of health and well-being, which is congruent with First Nations' notion of women as nurturers and givers of life. Participants suggested that First Nations women's traditions such as Moon Time Teachings include education on women's wellness and could incorporate screening education:

The regular program for girls meets every second Monday, and it's called the Moon Time Girls. (*Informant #3*)

Using a holistic approach for cultural integrity, women's unique role as givers of life could be used as a motivation to take care of their bodies:

Well, word it a way to have to do with childbearing, [which] is a sacred gift that's only given to women, let's keep our bodies healthy by getting annual check-ups, and you use some culturally appropriate like pictures, or something. (*Informant #4*)

The prospects of including the novel and noninvasive screening approach, namely, HPV self-sampling, was received enthusiastically because it is consistent with First Nations teachings on personal responsibility for caring for your body. As such it has the potential to further empower women to collect their own samples in privacy giving them control over how and when they participate in screening:

*Informant #14:* I think that's the best idea that has come out of anything, like it's not invasive, you do it in your own home, at your own time. . .

*I.Z.:* Whenever you, you know, are ready for it and. . .

*Informant #14*: I think that with education along with it that this is what it is, I think that the success rate will be phenomenal with it because it's in their own home.

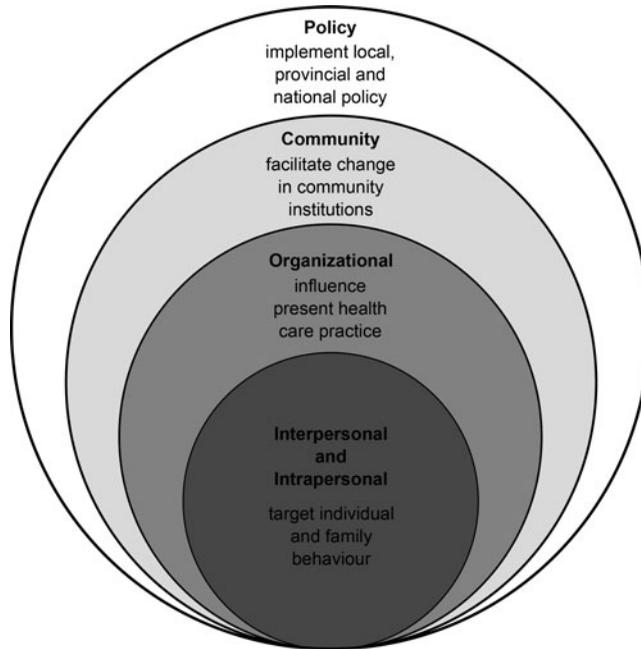
The fact that one self-sampled swab could test for several STIs (including HPV) makes self-sampling even more attractive:

If it [other STI testing] can be done on the same swab [as self-sampling], I would say, the value of that would be huge. (*Informant #15*)

The Pap test is seen as being very invasive, requiring exposure of the most private parts of the body to the health care professional. This poses a problem for many First Nations women, particularly when the health care provider is male. Instead, female staff should be involved whenever possible to ensure women's comfort with the screening process or to explain the self-sampling technique: "The girls are always looking for female doctors" (*Informant #13*).

### Three Global Concepts to Promote Cervical Cancer Screening in First Nations Women

The seven key themes suggested by our interview participants indicated that screening recruitment would have to be a multilevel process: (a) to target women and their families; (b) to promote preventive care with current, local health care services, and (c) to motivate individual behavior change with community-based strategies. These global concepts closely align with the social-ecological model of multiple levels of health promotion and acknowledge the interdependency between individual behavior and the surrounding environment (Division of Cancer Prevention and Control & National Center for Chronic Disease Prevention and Health Promotion, 2013; Stokols, 1996). The social-ecological model is based on the premise that addressing screening barriers at multiple levels will have the greatest impact on individual behavior toward cervical cancer screening. Figure 1 illustrates this interdependency as a multilevel approach to increase cervical cancer screening in First Nations women. Figure 2 elaborates on the global, social-ecological levels by exploring thematic networks based on the seven key themes from above. The innermost level of the social-ecological model represents the knowledge, attitude, and behaviors of First Nations individuals and their support system of friends and family corresponding to themes 1-3 (Figure 2A). Surrounding the interpersonal and intrapersonal circle of the social-ecological model is the organizational level, which includes health promotion through local professionals and organizations. Involving local health care providers and promoting screening within the local health care centers, as discussed in themes 4 and 5, are two key interventions that could help improve cervical screening uptake in First Nations communities

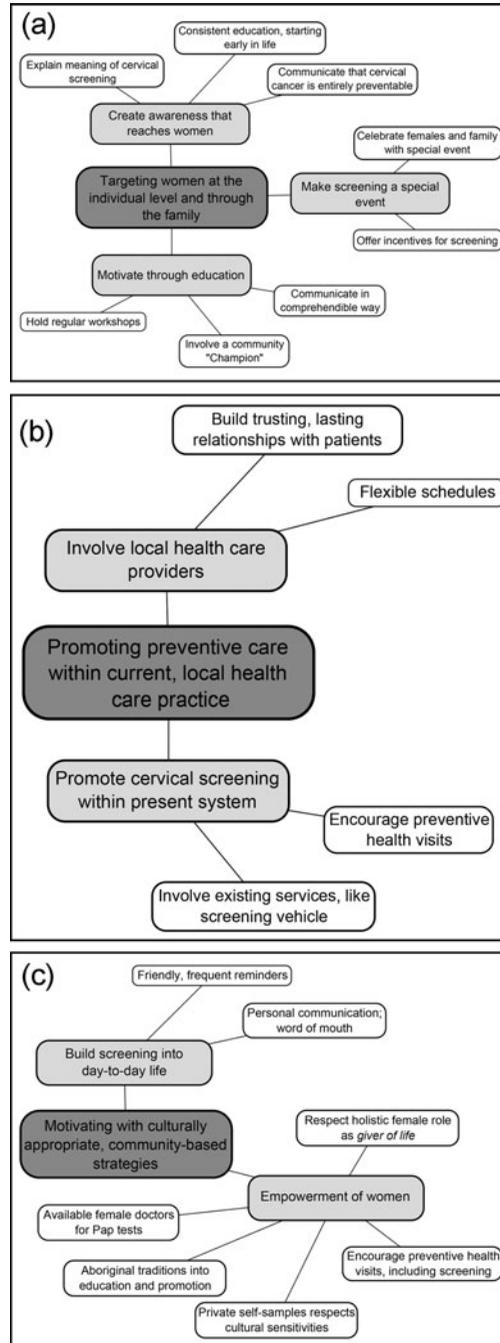


**FIGURE 1** Concentric bands indicate the relationships between the levels of influence. At the core of the diagram are individual and family attitudes, knowledge, and behaviors toward cervical cancer screening. Encompassing the individual and family level interventions is the organizational level of cervical screening approaches. The third band represents the community level adaptations that can help influence cervical cancer screening uptake by integrating culturally appropriate practice into the communities and into mainstream medicine. The outermost band depicts policy and society level changes that occur after sufficient evidence has been reviewed by stakeholders.

(Figure 2B). Integrating cervical screening promotion in First Nations culture and beliefs is crucial for having a long-lasting impact on individual health behavior. By creating a routine with cervical screening and incorporating a First Nation female gender perspective into cervical screening efforts (themes 6 and 7), these community-level approaches, along with the aforementioned interventions, should contribute to a comprehensive health promotion strategy promoted by decisionmakers (Figure 2C).

## DISCUSSION

Research elucidating cervical cancer screening recruitment approaches has been conducted in a few Canadian provinces and territories, for example, British Columbia (Black, 2009; Bottorff, Balneaves, Sent, Grewal, & Browne, 2001; Clarke et al., 1998; Hislop et al., 1996) and Nunavut (Healey et al., 2001; Moeller, 2007), but not in Ontario. Pasick, Hiatt, and Paskett concluded in 2004 that none of the interventions work within all populations, for all cancer



**FIGURE 2** (a) Thematic network for “targeting women at the individual level and through the family”—the innermost circle, *individual and family level*, of the social–ecological model. (b) Thematic network for “promoting preventive care within current, local health care practice”—the second level, *organizational level*, of the social–ecological model. (c) Thematic network for “motivating with culturally appropriate, community-based strategies”—the third level, *community level*, of the social–ecological model.

screening tests or in all settings, based on their review of 16 meta-analyses of cancer screening interventions worldwide. They argued that research is needed to fill critical gaps in knowledge regarding which interventions work for different populations, screening tests, and settings, which is in line with our investigation. Our deduced seven themes, based on community health provider interviews, were connected to become a *holistic screening recruitment strategy* that uses principles from the social–ecological model of health promotion. This novel, qualitative, and interactive framework has not been reported earlier. Instead, several studies conducted worldwide, reviewed in Black and colleagues in 2002 and focusing specifically on cervical cancer screening, reported success on *targeted recruitment components* such as mass media campaigns, individual strategies, education using lay health educators, or letters of invitation.

The intervention techniques identified in this article could contribute to a widespread change in cervical cancer screening standard of care, and this multilevel health promotion strategy could have a great impact on women's health in First Nations communities in diverse locations. The self-collection of vaginal samples for cervical cancer screening is associated with convenience and privacy, enabling women to take their own sample when and where it is suitable to them. This screening approach seems more “culturally sensitive” than the Pap test. In line with “cultural sensitivity” and as reported earlier by other groups from Australia (Reath & Carey, 2008) and the United States (Lantz et al., 2003; Smith, Christopher, LaFramboise, Letiecq, & McCormick, 2008), our community informants were adamant about the need for female rather than male health care providers. The role of health care providers in building trusting relationships cannot be emphasized enough. Considerate interaction between knowledgeable health care providers and Indigenous women impacted positively on screening rates as reported in several Canadian studies (Moeller, 2007; Zehbe et al., 2011), a fact that was further underlined by our informants.

In line with several other studies from the United States (Hodge, Fredericks, & Rodriguez, 1996; Strickland, Chrisman, Yallup, Powell, & Squeoch, 1996; Wilson & Orians, 2005) and Australia (Manderson & Hoban, 2006), *continuous* education acknowledging cultural values is essential for a successful screening program. As reported in an Australian study (Black, 2009), we understood from our interviewees that education about cancer prevention has to start early, that is, at school, and different generations can positively influence each other. While information and education often is passed from the older to the younger generation in a role model (for example, from mother to daughter), it could also pass in reverse and include extended female family members, such as sisters, aunts, and grandmothers. The older women who seem to be the hard-to-reach group could also get gentle reminders by their younger family members. As also noted in a study from the United States (Lantz et al., 2003), we learned that role models could

also be “Champions” who are cancer survivors and therefore have a story to tell.

Like in an Australian (Manderson & Hoban, 2006) and U.S. study (Scarcinci et al., 2010), our informants mentioned that cervical screening service and reminders could be conveniently integrated into other programs: well women clinics, mobile facilities such as screening vans providing service within the community, and into the daily routines in doctors’ offices when women come for other health issues.

## CONCLUSION

While our study supports findings from the quantitative studies of cervical cancer screening deficits among Indigenous populations in the United States and Australia, it also contributes uniquely to this important field of study. Our use of a qualitative PAR model with Canadian First Nations communities and their health care providers has allowed us to identify specific concerns and feasible solutions as evidenced by the seven themes to foster cervical cancer screening in First Nations women. Cervical screening service needs to be flexible, personal, friendly, comfortable for, and respectful of First Nations women. Screening recruitment should be approached as health promotion in a holistic manner and acknowledge the Indigenous woman’s role as a key giver of life and facilitator of good health for her family. Screening recruitment should be a multipronged process on the community, health care service, and stakeholder as well as individual decision-maker level as described above in the social–ecological model. Personal relationships with and trust in health care staff are particularly important in First Nations communities. Repeated education cycles are necessary to create and sustain awareness for and participation in cervical cancer screening. Self-sampling as a screening technique enables privacy and may be a good choice for “culturally sensitive” cervical cancer screening.

In line with the social–ecological model, our findings suggest adapting a holistic approach to health promotion by placing the focus of attention on the women and their roles as nurturers of life and caretakers of their families’ and their communities’ health. Research studies such as this one can also positively influence local, provincial, and national cervical cancer screening guidelines, the final band of the social–ecological model. Our interviews with community-based health care providers indicate that to ultimately change individual behavior in First Nations women, cervical screening promotion needs to be implemented at multiple, culturally compatible levels.

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