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Engaging Canadian First Nations Women in Cervical Screening through Education

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Abstract

Recognition of the need to decrease cervical cancer rates in Indigenous populations has been ongoing—yet few successful interventions have been reported. In addition, literature addressing the challenges and barriers associated with designing screening programs aimed to specifically reach Indigenous women is limited. Here, we report findings from a mixed methods cervical cancer research project conducted in partnership with 10 First Nations communities in northwest Ontario, Canada. Individual interviews with community health professionals (the majority of whom identified as First Nations) stressed that awareness of cervical screening benefits is lacking. In contrast, focus group participants (women with no formal health education) emphasized the desire to learn more about the science of human papillomavirus (HPV), and that a positive HPV or abnormal Papanicolaou test need not mean a woman will undoubtedly develop cervical cancer. Both the health professionals and the focus group participants highlighted that sexual health education must start early, in schools, preferably before girls are sexually active and that it has to continue throughout life to create a *screening culture* with a focus on women's wellbeing. Both interview and focus group participants highlighted that sexual health education must start early, in schools, preferably before girls are sexually active and that it has to continue throughout life to

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create a *screening culture* with a focus on women's wellbeing. Health professionals elaborated mainly on special events for *community women* whereas focus group participants also recognized the need to include *community men* in health education particularly for de-stigmatizing the sexually-transmitted HPV infection.

Keywords

Indigenous Health; First Nations Women; Cervical Screening; Human Papillomavirus; Health Education

Introduction

The Papanicolaou (Pap) test was introduced in the 1950/60s and has considerably reduced cervical cancer incidence and mortality by up to 80% in Europe (Anttila et al., 2004). A 60% decrease was reported for the United States after the first 20 years of cervical screening (Marcial, 1977) and a decrease of similar magnitude has been reported in the Canadian provinces of British Columbia (van Oortmarssen and Habbema, 1986) and Manitoba (Choi and Nelson, 1986). Cervical cancer arises mostly in women who are not regularly screened (Albrow et al., 2012; Spence et al., 2007) and its incidence is disproportionately high among Indigenous women in Canada, the United States (Vasilevska et al., 2012; Decker et al., 2015), Australia and New Zealand (Jackson and Ward, 2000; Reath and Usherwood, 1998). Barriers to Canadian Indigenous women attending cervical cancer screening or following-up on abnormal results have been described by us (Maar et al., 2013) and other research (Morgan and Wabie, 2012). These include social, historical and cultural determinants of health, such as the impact of colonialism and social marginalization; structural limitations, such as reduced access to health resources; and reduced income and lower educational opportunities in comparison with the population as a whole. In addition the invasive nature of the Pap test has been cited as a barrier for this group (Maar et al., 2013). Indigenous women often report not feeling respected in the health care system (Spence et al., 2007) and many have experienced culturally inappropriate service provision (Read and Bateson, 2009).

The intersection of social, cultural and historical disparities of health along with a lack of understanding about the purpose and benefits of cervical cancer screening has been identified as a key factor as to why Indigenous women more often develop cervical cancer and die from it than non-Indigenous women (Morgan and Wabie, 2012; Read and Bateson, 2009). Many Indigenous women do not know what a Pap test entails (Hislop et al., 1996) and the link between sexually transmitted infections (STIs) such as human papillomavirus (HPV) and cancer leads to stigmatization (Jackson and Ward, 2000), further exacerbating insufficient screening attendance. Additionally, some Indigenous populations view death as a natural part of the life cycle. Illness is described as an imbalance, and removing a part of the body [like the scraping of cells for a Pap] is considered harmful (Strickland et al., 1999). Hence, it has been reported in some studies that fear of death may not be a motivator for prevention services and may constitute a cultural barrier to cervical screening (Strickland et al., 1996). A recent review (Clarke et al., 2013) that evaluated medical interventions with ethnic minority women showed that the most common strategy for minority health is

education about a disease with focus on the patient as the target, lacking emphasis on community engagement and investigation of the multiple, intersecting levels of the health care system and how they impact screening uptake (Clarke et al., 2013; Morgan and Wabie, 2012; Reath and Usherwood, 1998).

Our study examines the engagement of First Nations women from northwest Ontario, Canada in cervical cancer screening. We hypothesize that increased, regular screening attendance and follow-up of abnormal screening results would reduce the higher cervical cancer burden in this population. We have previously reported screening recruitment strategies with First Nations women and, based on interviews with health care professionals (HCPs), we have reported that education is one of the key factors for increasing their cervical screening attendance (Maar et al., 2013; Maar et al., 2014). To obtain a more representative and comprehensive understanding of the views held by members of our partner communities, we extended our study to include community members without formal health education to ensure that their voices would be heard in the research. Here, we present the data from the individual HCP interviews and the focus groups with community women focusing on potential educational strategies with the future aim to increase awareness for and uptake of cervical screening in Canadian First Nations women.

Methods

Communities and Study Design

We developed a participatory action research (PAR) project, entitled the Anishinaabek Cervical Cancer Screening Study (ACCSS) in collaboration with ten Robinson Superior First Nations communities in northwest Ontario, Canada to address cervical cancer screening in First Nations women (Wood et al., 2014). The demographic characteristics of the partner communities have been described in detail elsewhere (Wood et al., 2014). Our theoretical framework is based on the ethical space concept developed by First Nations scholar Ermine (2007) to create respectful and meaningful communication and dialogue across differing cultural worldviews (Zehbe et al., 2012). Following PAR principles which “aim to democratize the research” and work in partnership with marginalized groups (van den Hoonaard, 2015) First Nations’ partner communities were included at all stages of the research process: from initial project planning, to sampling, data collection and analysis, as well as decisions about dissemination strategies (Esterberg, 2002). Respecting First Nations’ ethical protocols in Canada formal research agreements were negotiated with the Chief and Band members of each of our partner communities after face to face community meetings in addition to obtaining Tri-Council research ethics approval from the Principal Investigator’s host institution.

ACCSS consists of a *qualitative strand* with interviews and focus groups, and a *quantitative strand* with a cluster, randomized two-armed screening trial (Wood et al., 2014). Here, we focus on the theme ‘education’ of the project phase involving *qualitative research*. For healthcare provider interviews, we asked the health directors in each community to select one or more key informants among the professional health care staff. For focus group discussions, the community-based health directors were asked to recruit participants without formal health care education who would be in the target group for cervical cancer screening

and education. Small incentives (in the form of money) were paid to all participants to compensate for their time, as is accepted practice in this context. During the focus groups, the research team provided either lunch or supper, mostly catered by a local community member. Two researchers conducted the interviews and focus groups (Maar et al., 2013; 2014). For focus groups, an assistant helped with audio recordings and note taking during the sessions. The study was approved by the Lakehead University Research Ethics Board (#038 11-12/ROMEO #1462079 and 12-13/ROMEO #1463139).

Participants

We conducted *interviews* (lasting from 40 to 90 minutes) with 18 experienced, younger (under 40 years of age) and middle-aged (above 40 years of age) HCPs from August 2011 to February 2012 (Maar et al., 2013; Maar et al., 2014). We conducted nine *focus groups* (lasting from 80 to 120 minutes and including between 3 to 11 women at each community site) from May to July 2012 and then two additional ones in April and May 2014 to reach saturation with the focus group data. The majority of participants identified as being First Nations. Criteria for inclusion in the focus groups included being female resident of the respective community with no formal health education beyond a secondary school level. The lower age limit of participants was 18. Attendees [altogether 76] were mostly adult women but in some cases, female youth and female elders were also present.

Data Analysis

We used semi-structured interview guides for individual HCP interviews and the community women's focus group discussions. We explored questions related to the providers' perceptions on effective ways to reach First Nations women with screening information, potential or promising strategies and special needs to help motivate them to participate in cervical cancer screening. The community focus group discussions were centered around experience with cancer in general and cervical cancer screening in particular and why women do or do not attend and how to educate women about cervical cancer screening in the community. The interview and focus group recordings were transcribed verbatim, reviewed and coded by multiple team members to identify emerging themes for analysis and triangulation. A process of "open coding" (van den Hoonaard, 2015) was used to identify basic level themes which were then grouped into key themes through team review and discussion of the transcripts. At the request of our partner communities no identifiers other than HCP or Focus group participant are provided in the data discussion to preserve the anonymity of the participants.

Results

The Need for more Awareness of Benefits Related to Prevention and Screening

Ideally, to promote health and wellbeing and to prevent chronic diseases like cancer, a steady flow of health education provided by researchers to HCPs and directly or indirectly to community members is required to create awareness for prevention and screening as part of the community wellness program. As has been noted in an Alaskan study with American Native women (Stillwater et al., 1995), there is little knowledge about cervical cancer and

therefore women do not go for screening. Interestingly, this was emphasized by most HCPs but not by focus group participants:

'I don't feel that they are aware of the screening or if it's just they've put that block up and they don't want to do it, but I don't think that they're educated enough to realize so, you know, if something more can be done is the awareness of screening' (Interview 14).

HCPs can play an active role in clarifying the benefits of cervical screening and they should convey evidence-based information about guidelines and service to community women. For this reason, the flow of knowledge transfer between researchers, HCPs and clients is essential. Indeed, as has also been reported by Strickland et al. (1996), researchers need to ensure that new findings are accessible to HCPs and conveyed to community members as evidenced by the interview below:

'You need to make sure that you train the trainers, like, teach, the, the, the CHRs [community health representatives], and the women in the community that are providing service' (Interview 2).

As noted by another interviewee and in previous research (Sheridan et al., 2004), by emphasizing that cervical cancer is almost entirely preventable with regular screening, HCPs can share encouraging information with their clients:

'We know that 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. So I think maybe reinforcing that message, that this is 100% preventable' (Interview 4).

While HCPs generally emphasized the need for increased awareness about cervical screening, focus group participants wanted to learn more about the cause of cervical cancer, namely HPV. In particular, researchers need to explain statistics about the frequency of HPV infections in humans [e.g. that it is the most widely spread sexually transmitted agent] and the fact that, despite it being the causative agent for cervical cancer, not all HPV infections lead to cancer:

'You have to explain more about that test because it sounds like if you have HPV you are going to get cancer and most women in the communities will be scared' (Focus Group 6).

Educational Interventions through Public Events

As suggested in previous studies (Read and Bateson, 2009; Reath and Usherwood, 1998; Stillwater, 1999; Subrahmanian et al., 2011) community educational events are a key strategy for health promotion and to increase the health literacy of the public. HCPs and focus group participants both thought that health education has to be on a continuous basis to be successful. The majority of the interviewees recommended events for women, which could also be blended into existing programs:

'The mothers would all come and the grandma's would come and the aunts would come so I would have a big number there and I would go through everything and I,

you know and I, the team would be prepared and I would have guest speakers come in as well and there would be a dinner, a luncheon or a feast of some sort and I wouldn't cook the feast and I wouldn't have anybody in the community cook it, I would bring somebody in because I find that's most intriguing, that you know, and I would bring somebody in who had a little bit of charisma like I would bring in probably a Tai Chi instructor who cooks meals' (Interview 7).

'If we plugged into some existing programming, we got a parents and tots program or, you know, we set up a circle that was going to have some, or a meeting that was going to have something but there was a lunch involved and you know, we could plug some existing groups or programs into it' (Interview 10).

However, and as noted by other research to involve the 'significant other' (Gotay and Wilson, 1998), focus group participants stressed that educational interventions for males and females alike are an important strategy, especially to de-stigmatize HPV infection—to not always put the blame on women being the carriers but to inform that men are also carriers of this virus:

'But you're, it's the truth though because if the men are, if weren't educated an hour ago, who's to say they know anything about this [HPV and that both sexes can be infected], which they probably don't. They know about herpes and all that because it's so publicized' (Focus Group 6).

How to Achieve Success with Educational Events in Schools

As we heard during several interviews and as evidenced by the quote below, the partner communities seem to host regular educational events for high school students as part of their curriculum to ensure the students will attend lessons in sexual health:

'Well, we see, generally we start with uh, with uh, in the school. With the health nurse, um, we go up there, we talk about uh, human sexuality, and um, we do, we invite our high school students, and we come, and they come there, and we talk about STDs [sexually transmitted diseases] and transmission and, um, you know, all, all about the birds and bees, you know, they know we provide condoms and there at the clinic. Uh so you know the kids are pretty open to me, like I guess there is trust there' (Interview 4).

However, the lack of information that HPV, a sexually transmitted agent, causes cervical cancer as a rationale for HPV vaccination was noted, mostly by focus group participants, implying a need for adjustment in the health education focus in Canadian schools:

'My girl came home from school saying you know there's an HPV vaccination, I said well what do you know about it, she said nothing really' (Focus Group 5).

Nevertheless, some interviewees shared with us successful experiences that they have had with their teenage students. This finding supports Read and Bateson's work on achieving positive outcomes of educational interventions (2009), e.g. via culturally sensitive gender dynamics, humour and open-mindedness:

'The regular program for girls meet every second Monday and the boys meet every [word missing], and it's called the Moon Time Girls and it's called the Wilderness Boys, and it's just their group' (Interview 3).

'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, you know, and they'll ask me are you bringing bananas next week, you know, so it was a fun thing' (Interview 6).

'I do the whole spiel, with, STIs you know, including HPV, you know, genital herpes as well as Chlamydia GC. And you know, so the cervical cancer, so they're aware of the need for it, and it's you know, it's a survey and choice, so I go through all that' (Interview 5).

Not all Community Members Can Be Reached through Educational Events

Some of our interviewees and focus group members thought it challenging to entice people to come to educational events but felt that women might appreciate hearing from a cancer survivor or an experienced advocate:

'Maybe a person that already went through it, like you know, I had cervical cancer and obviously beat it, you know, maybe something like that type of speaker' (Focus Group 7).

While educational events may attract individuals who normally socialize in their community, we learned, mostly from interviewees, that there are others that shy away from attending:

'We've done lunch and learns on it [cervical cancer screening] but we don't have like, a lot of people that come out, where they share their stories, or, whatever they learned with other community members. We usually have the same people coming all the time, so it's, we're not hitting all the target risk' (Interview 13).

One potential reason why health education may be difficult to deliver to adult community members is due to the legacy of historical trauma and social determinants-related challenges, as communicated by several HCPs:

'It's always the same people. Then we thought, maybe, there's, like problems on reserve with pills and stuff like that so, we're thinking those families just don't wanna be involved in anything' (Interview 13).

Another reason for non-attendance may be related to age:

'The older generation they are very set in their ways and um, they're a bit more difficult to um, to get through to with regards to health teaching and prevention' (Interview 16).

Potential Strategies to Engage Hard-to-Reach Women for Cervical Screening

To reach women who do not normally attend educational events in health, the use of traditional [pamphlets, radio, TV, advertisement] and new social media [website, Facebook, Twitter], as reported in other research (Christopher et al., 2005) and outlined by several focus group participants and HCPs, could be a useful option:

'I think um, you have to gear some of your uh, your media stuff to make it for certain age groups. Um, like pamphlets, you, make them look more teen friendly or something like that and very short sentences and do points, like to the point and then uh, maybe for the older generation' (Focus Group 9).

'Everybody's on Facebook' (Interview 1).

While the above approach is rather *impersonal*, another way of involving hard-to-reach women would be on a *personal* face-to-face level. As described in previous investigations with Nganampa Aboriginal women in South Australia (Reath and Usherwood, 1998), urban American Native women in North Carolina (Dignan et al., 2005) as well as Cherokee women in the Northern Plains of America (Subrahmanian et al., 2011) and as suggested by health disparities intervention researchers (Clarke et al., 2013), most of our interviewees and some focus group members thought that developing personal relationships would make a difference in drawing people to educational sessions. Various suggestions, involving the HCP encouraging the client or the HCP going door-to-door, as well as family members or friends and colleagues [peers] reminding each other on a word-of-mouth basis, were provided:

'I think I'd have to go, someone would have to go door-to-door and we'd have like a list of what age group you're looking at and then we can go and pick certain individuals that we know that would probably participate and then get the group together and speak about it' (Interview 9).

'See like my niece, I went for a Pap test there like a couple of months ago and she, I was like go do a Pap test and she was like what is that, and I told her, you know, it could cause this and this, you know, and she's like, um no I don't feel like it. That's my great niece and she has a baby and I told her got to get regular checkups and she's like do you? I was like yeah. She ended up going for a Pap test though' (Focus Group 8).

Discussion

Continuous health education for men and women is needed to steadily develop and maintain a *screening culture* framed by the idea of women's health and wellbeing rather than by preventing diseases such as cancer. Notably, disease prevention *per se* is not traditionally part of Indigenous framing of health for many communities. This can only be achieved 'long-term' through an ongoing dialogue which builds trusting and collaborative relationships between Indigenous peoples, researchers and HCPs using well-grounded ethical principles based on Indigenous values. Researchers must facilitate and promote such interactions as well as provide feedback to the public and stakeholders. Stakeholders that are responsible for screening guidelines must be open-minded and willing to adapt them for the benefit of Indigenous peoples as necessary.

It seems challenging to reach under-screened women and convince them of the benefits of cervical screening. Gotay and Wilson (1998) argue that women with strong social ties have higher screening rates than women with troubled or undeveloped social networks. Therefore, strategies involving personal face-to-face dialogues between researchers and HCPs as well

as between HCPs and their clients need to be pursued to improve the present educational environment and screening habits (Clarke et al., 2013, Dignan et al., 2005; Reath and Usherwood, 1998; Subrahmanian et al., 2011; Zehbe et al., 2011). Combined with interventions generally directed toward improving access to the health care system, which other research has already called for (Reath and Usherwood, 1998), we infer such strategies will reach more women in their communities.

Future ACCSS directions include new educational approaches such as arts integration (Russell and de Leeuw 2012) to attract more women to attend screening. Integrating the arts as a teaching method in educational settings has demonstrated increased learning engagement (Burnafurd et al., 2000; Gelineau, 2004). Art making in the research process produces various works, which can then be purposefully used to mobilize knowledge across the audience spectrum and as teaching tools for students in formal and informal educational settings (Cole and Knowles, 2001; Sameshima and Sinner, 2009). Being mindful of the potential stigma around HPV, we note the importance of being transparent that HPV infection impacts most humans at some point in their lives. In addition, the effects and benefits of the HPV vaccination for both sexes should be discussed. Such clarifying teachings can be more effective when attendees participate in embodied learning, *e.g.* with audio-visual tools and anatomy models (Sameshima, 2008) and substantiated through first-person stories of survivors, peer teaching and community engagement.

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