Gynecologic Oncology 149 (2018) 93–100

Contents lists available at ScienceDirect

Gynecologic Oncology

journal homepage: www.elsevier.com/locate/ygyno

# First nations people's perspectives on barriers and supports for enhancing HPV vaccination: Foundations for sustainable, community-driven strategies

R.I. Henderson [a,*], M. Shea-Budgell [b], C. Healy [c], A. Letendre [d], L. Bill [c], B. Healy [c], R.A. Bednarczyk [e], K. Mrklas [f], C. Barnabe [g], J. Guichon [f], N. Bedingfield [f], S. MacDonald [h], A. Colquhoun [i], S. Glaze [b], T. Nash [j], C. Bell [i], J. Kellner [k], R. Richardson [l], T. Dixon [m], J. Starlight [n], G. Runner [n], G. Nelson [b]

[a] Department of Family Medicine, Cumming School of Medicine, Calgary, AB, Canada
[b] Department of Oncology, Cumming School of Medicine, Calgary, AB, Canada
[c] Alberta First Nations Information Governance Centre, Calgary, AB, Canada
[d] Alberta Cancer Prevention Legacy Fund, Edmonton, AB, Canada
[e] Rollins School of Public Health, Emory University, Atlanta, GA, United States
[f] Department of Community Health Sciences, Cumming School of Medicine, Calgary, AB, Canada
[g] Department of Medicine, Cumming School of Medicine, Calgary, AB, Canada
[h] Faculty of Nursing, University of Alberta, Edmonton, AB, Canada
[i] Alberta Ministry of Health, Edmonton, AB, Canada
[j] Indigenous Mental Health Program, Calgary, AB, Canada
[k] Department of Pediatrics, Cumming School of Medicine, Calgary, AB, Canada
[l] First Nations and Inuit Health Branch, Alberta Region, Edmonton, AB, Canada
[m] Elder, Eden Valley Nation, AB, Canada
[n] Elder, Tsuut'ina Nation, AB, Canada

## HIGHLIGHTS

- A trauma-informed lens is key to cervical cancer prevention in First Nations.
- Colonization's disruption of family & community ties drives health disparities.
- Ruptured intergenerational ties undermine community capacity for prevention.
- Community-based prevention requires reconciliation with healthcare providers.
- Increased uptake of HPV vaccination requires community engagement.

## ARTICLE INFO

*Article history:*
Received 22 August 2017
Received in revised form 17 November 2017
Accepted 19 December 2017

*Keywords:*
First nations
Human papillomavirus
HPV vaccine
Barriers
Supports
Community engagement

## ABSTRACT

*Objective.* In Canada, Indigenous people have higher human papillomavirus (HPV) infection rates, lower screening rates for cervical cancer, and higher rates of invasive cancer, leading to worse cervical cancer-related outcomes than observed in non-Indigenous Canadian women. Lingering harms from European colonization drive these health inequities and create public health challenges. Policy guidance is needed to optimize HPV vaccination rates and, thereby, decrease the burden of HPV-related illness, including high-morbidity surgical procedures and chemo-radiotherapy. The Enhancing HPV Vaccination In First Nations Populations in Alberta (EHVINA) project focuses on First Nations, a diverse subset of recognized Indigenous people in Canada, and seeks to increase HPV vaccination among girls and boys living in First Nation communities.

*Methods.* Developing an effective strategy requires partnership with affected communities to better understand knowledge and perceptions about cancer, healthcare, and the HPV vaccine. A 2017 community gathering was convened to engage First Nations community members, health directors, and health services researchers in dialogue around unique barriers and supports to HPV vaccination in Alberta. Voices of community Elders, parents, health directors, and cancer survivors ($n = 24$) are presented as qualitative evidence to help inform intervention design.

* Corresponding author at: Department of Family Medicine, Cumming School of Medicine, 3330 Hospital Dr NW, Calgary, AB T2N 4N1, Canada.
*E-mail address:* rihender@ucalgary.ca (R.I. Henderson).

https://doi.org/10.1016/j.ygyno.2017.12.024

*Results.* Key findings from discussions indicate barriers to HPV vaccination include resource constraints and service infrastructure gaps, historical mistrust in healthcare systems, impacts of changing modes of communication, and community sensitivities regarding sexual health promotion. Supports were identified as strengthened inter-generational relationships in communities.

*Conclusions and Future Direction.* Ongoing dialogue and co-development of community-based strategies to increase HPV vaccine uptake are required. The identification of possible barriers to HPV vaccination in a Canadian Indigenous population contributes to limited global literature on this subject and may inform researchers and policy makers who work with Indigenous populations in other regions.



Indigenous communities across Canada experience a significant burden of disease associated with the human papillomavirus (HPV). Higher rates of infection compared to the non-Indigenous population [1–5] are complicated by lower cervical cancer screening rates [6], increased burden of disease [7,8], and related hospitalization [9]. In 2010, the rate of cervical cancer among First Nations women was around double the rate among all women in Alberta (15.4 vs. 8 per 100,000, respectively [10, 11]), while data from Ontario indicate that survival after cervical cancer diagnosis is lower among Indigenous women [12]. This parallels cancer burden more broadly, which in Alberta in the past decade has reached as high as 20 times the incidence compared to non-Indigenous populations [4]; with recent reports indicating cervical cancer among First Nations and Inuit women in the province is 2.3 times higher than among non-First Nations and Inuit counterparts [5]. While data on HPV vaccine uptake among Indigenous people is lacking (e.g., [13]) and while the impact of vaccination according to variability in rates of uptake remains speculative [14], there is evidence to suggest that vaccination is lower in Indigenous populations [15]. These data suggest that there may be barriers to care at distinct levels of prevention and treatment, driving disparity in cervical health outcomes for Indigenous people. Policy guidance that addresses health inequities is urgently needed to optimize HPV vaccination rates, thereby decreasing HPV-related illness and its sequelae, including colposcopic/surgical procedures and chemo-radiotherapy.

Developing an effective strategy to increase HPV vaccine uptake requires partnership with Indigenous communities, as well as recognition of their diversity and unique determinants of health. In particular, what do affected communities know about HPV and its health impacts? How (and how well) have healthcare providers and systems reached this diverse population for sexual health promotion? And, what insights might communities have for improving preventative care? This article addresses such questions, focusing on a specific Canadian Indigenous population, First Nations (FN) people within the province of Alberta. FNs are not only descendants of the original inhabitants of North America, but as nations form administrative units and function with official status recognized by the federal government. The stakeholders in this project included primarily Elders from FN communities; FNs encompass a population of approximately 118,00 people in Alberta, representing 14% of FN people in Canada [16]. Elders are individuals recognized in distinct ways by their communities as having accumulated knowledge and skills with which they mentor and/or lead others for the benefit of their culture and communities [17]. Their perspectives were gathered at an event that took place in 2017 to inform the EHVINA initiative, a university, health services, and First Nations partnership aimed at Enhancing HPV Vaccination In First Nations Populations in Alberta.

The current study contributes to a larger EHVINA project goal of identifying and validating known barriers and supports to HPV vaccination among FN people in Alberta. The EHVINA study also aims to establish baseline HPV vaccination rates among people living in FN communities in Alberta, as existing data are fragmented. Many FN communities in Alberta have been allocated at least one 'reserve' (i.e. a geographic area designated for use by a FN).[1] While the Alberta provincial government tracks childhood vaccine uptake off-reserve [18], only recently have the provincial government and some FNs (i.e., 3–4 of 48 FNs in the province, which encompass a total of 140 reserves communities) begun to link it to data on vaccines delivered to populations on reserve (see Box 1: HPV Vaccination in Alberta). Findings reported here will contribute evidence around barriers and supports to HPV vaccination identified by community members, helping to inform the development of evidence-based, theory-informed, and context-sensitive/population-based intervention strategies [19–21]. Findings may also provide relevant information for jurisdictions in other geographic regions with large Indigenous populations. The upstream, community-oriented social determinants approach employed here is aligned with recent findings by the Truth and Reconciliation Commission (TRC) of Canada, specifically Call to Action number 18 of 94, which states that "the health of Aboriginal peoples is [recognized as] a direct result of previous Canadian government policies" [22]. Among Canadian government policies that affect Indigenous health is the residential schools system that, for most of the twentieth century, forcibly removed Indigenous children from their homes and communities with the intent of assimilation [23].

## 1. Methods

In order to ensure EHVINA's alignment with community experiences and perspectives on cervical cancer, in June 2017 the team brought together partnered FN knowledge holders and the research team. Insights learned from FN community members who attended the gathering (i.e., Elders, health directors) form qualitative data shared here. The narrative and exploratory nature of findings are relevant to health services and

Box 1
HPV Vaccination in Alberta.

Vaccines preventing HPV infection have demonstrated long-term effectiveness and acceptable safety profiles (2), also preventing other cancers, namely HPV-associated vulvar, vaginal, penile, anal, and oropharyngeal (i.e., mouth and throat) forms (3). In Alberta, the Gardasil vaccine has been provided by the province through a school-based program to grade 5 girls since 2008 and boys since 2014, with a catch-up for un-vaccinated peers in grade 9. Health Canada, which is the federal department responsible for food inspection, pharmaceutical patent review, as well as public and FN health provision, funds the vaccine to FN children living on reserve. National HPV vaccination strategies have reduced the incidence of associated sexual infections, such as genital warts, but at lower rates in Indigenous populations (76% versus 87%, respectively) (7; 8). This is related, at least in part, to decreased likelihood that on-reserve children will be vaccinated. As cervical cancer is a recognized problem in FN communities, designing and implementing effective intervention strategies to increase HPV vaccination rates is critical to addressing this disparity.

[1] From the Canadian Department of Justice: http://laws-lois.justice.gc.ca/eng/acts/I-5/page-1.html?txthl=tract+lands+land#s-2.