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## #5

### **Mini Review**

# Why Can't We Prevent HPV-Linked Preventable Cancers Using HPV Vaccine?



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#### **Abstract**

This study provides a high-level discussion, conclusion, and recommendations on the underutilization of human papilloma virus vaccination (HPVV) in Saskatchewan, Canada, drawing on the findings of individual and group interviews conducted as a part of a qualitative mixed-method study. It is structured in the following way. First, it reiterates key findings from the overall study at the system, provider, and patient levels by locating them in the published literature. Second, it identifies and discusses cross-cutting themes (from the themes identified) at three levels (system, provider, and patient). It then provides a concluding section drawing from our qualitative effort to address the overarching goal of addressing inequitable HPVV uptake by advocating "systems thinking" to enhance overall HPVV uptake. It concludes by providing broad recommendations and implications.

#### Synthesis of findings

In this section, using Engel's biopsychosocial lens that underpins the philosophy of medicine, <sup>1</sup> we synthesize and interpret the key themes from the findings from the patient perspective (migrant parents) and stakeholder perspective (system and provider-level workers in human papilloma virus (HPV) immunization program planning, rollout, delivery, and administration) in Saskatchewan and relate them to the relevant literature reviewed in the earlier phases of the same study under broader context of English Canada. <sup>2</sup> When synthesizing findings, we first introduce each section with a key finding to reflect what the study found as the most significant and needs to be incorporated into the recommendations discussed later in this communication. Alongside this, we use a quotation that resonates with the respective themes and subthemes to set the stage for the discussion.

#### Problem description

Knowing is half the battle—G. I. Joe<sup>3</sup>

**Keywords:** Cancer prevention; HPV vaccination; HPV vaccine; Social determinants of health; Structural determinants of health.

**Abbreviations:** BCG, bacillus Calmette-Guerin; HPV, human papilloma virus; HPVV, human papilloma virus vaccine; PHN, public health nurse; SDoH, social determinants of health; STI, sexually transmitted infection.

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Key finding 1: Information, awareness, and education of HPV infection and HPV vaccine (HPVV). All the study data (reviews, documents, interviews, surveys, and focus group discussions) speak to this very problem, which represented a double-edged sword. Absence contributes to vaccine attitudes that hinder HPVV uptake and presence drives vaccine attitudes that facilitate HPVV uptake. This study finding aligns with the existing literature in several ways. First, the study findings reveal that inadequate awareness or low literacy on HPV infection and HPVV is a barrier to HPVV uptake. Ogilvie et al.4 reported that in 2010, one of the main reasons for not having daughters receive HPVV was insufficient information to make an informed decision. That was when one of the first population-based assessments of factors associated with HPVV uptake in a publicly funded school-based program was conducted in British Columbia. Along similar lines, Fernandes et al.5 examined the attitudes of undergraduate university women toward HPVV in a cross-sectional study in Ottawa. They reported that one of the primary barriers to HPVV uptake identified by nonvaccinated study respondents was a lack of knowledge about the vaccines. Second, our study findings highlight that a better understanding of HPV infection and HPVV is critical to HPVV uptake in multiple ways. (1) It serves to address HPVV-related safety concerns. (2) It handles preconceived notions rooted in cultural or religious perceptions about sexual activity or misconception that their child(ren) is at low risk for contracting HPV. (3) Parents can rationalize why HPVV is given to young children (9 years of age and older) and sexually inactive and address any sexual activity associated with HPV. (4) It equips parents to communicate with their child(ren) on the needs and benefits of HPVV. (5) It alleviates

confusion around contracting HPV infection in a monogamous relationship. (6) It helps parents to make an informed decision (consent for their child(ren) to receive HPVV.

Existing literature supports our study findings. Grace *et al.*<sup>6</sup> examined perceptions and knowledge of HIV-positive gay men about HPV infection and HPVV. They reported that most of the study participants had not received HPVV and they lacked prior knowledge on the health consequences of HPV for gay, bisexual, and other men who have sex with men. The study concluded by advocating for increased HPV health literacy, especially by reframing the long-standing gender association of HPV. Grace *et al.*<sup>6</sup> reported that the study participants remained uncertain of the current availability of HPVV and believed that their newly acquired knowledge of its importance was too little, too late because of their age and possible previous HPV exposure.<sup>6</sup>

Third, our study findings reinforce that HPV health literacy remains the most influential factor that can optimize HPVV uptake in normal times and during crises such as the COVID-19 pandemic. Our study report increased vaccine skepticism heightened by COVID-19 pandemic-related restrictions and mandates as parents started to question routine vaccines such as HPVV all over again. In contrast, the use of various venues and adopting various strategies has increased public awareness of COVID-19 vaccination and converted some vaccine-hesitant people into vaccine-inclined people.<sup>7</sup>

Dube *et al.*<sup>8</sup> explored the challenges and opportunities of school-based HPVV in Quebec and identified that uptake depended on many interrelated factors at individual and interpersonal levels. The most critical factors were vaccine-related knowledge and attitude toward HPVV. Also, Stanley *et al.*<sup>9</sup> explored attitudes and barriers toward HPVV in a population of male gynecology and otolaryngology surgeons in in Ontario, Canada and reported that the most common motivating factor for HPVV uptake was the sense of personal protection from HPV-related diseases and cancers.

The key finding 1 theme stands on its own merit and urges for HPV health literacy at all societal levels. The findings are consistent with the literature and serve to support and strengthen it, with the exception that there should be a three-way flow and exchange of information and knowledge between HPV administrators/deliverers and parents and youth. While studies have examined determinants of HPVV uptake in different contexts using different study designs, 4,8,6,9,10 we agree with Rubens-Augustson et al. 11 that further research is required to explore informational desires and needs of newcomers to inform strategies for equitable HPVV uptake. The literature is sparse and alludes to the type of knowledge, information, and awareness needed and desired by various population subgroups. Our study adds to the literature in more than one way. It reports what type of information is needed and desired, the key population subgroups to which this information and education should be targeted, and the ways HPV health literacy can be given to the target groups.

#### Problem conceptualization

"It's not what you know; it's what you do with what you know."—Unknown writer; Human Parts: A home for personal stories and perspectives.

Key finding 2: Vaccine-related logistics. Our study reports several interrelated and stand-alone vaccine-related logistical factors that impede HPVV uptake. Very little in the literature describes in-depth the factors that hinder HPVV-related information from reaching consumers despite comprehensive immunization packages being sent home via school-based programs. However, studies that do explore factors that could impede effective HPVV

uptake mostly report health provider's recommendations, nurse practitioner position to collaborate with public health agencies to expand knowledge and coverage across Canada, <sup>12</sup> difficulties receiving agreement from local school boards to administer HPVV in schools, refusal from some catholic schools for HPVV clinics in their school except for certain years/grade, <sup>13</sup> resource constraints and service infrastructure gaps, historical mistrust in healthcare systems, and impact of changing modes of communication and community sensitivities regarding sexual health promotion. <sup>14</sup>

Our study reports that we must consider several factors to increase the likelihood of immunization packages carrying HPVrelated information reaching the hands of parents, ensuring they can read and understand the information provided to them. The immunization packages should be sent home using a hybrid approach (i.e., paper copy as well as electronic forms), as opposed to only relying on a child(ren) to transport the material home and bring it back to school. The material should be translated into various languages to match the needs of the population subgroup it intends to serve. The information material should be in simple English, highlight the main information, provide brief statistics, detail vaccine safety, include a rationale of giving HPVV to younger children, explain why the vaccine is discussed in the context of a sexually transmitted infection (STI) and promote the cancer prevention focus of the vaccine. The findings of our study attempt to answer some of the needs and desires of immigrants and refugees in Canada while remaining inclusive of other population subgroups.

Our study also reports that due to the COVID-19 pandemic, already scarce resources (time, money, and human resources) are stretched thin. There were no existing preplanned ways to keep the routine immunizations running. The staff is burned out due to workload, lack of recognition, and little help in clearing out the backlog of immunization of three streams of child(ren) (those who are eligible now, those who were eligible during the COVID-19 pandemic-related school-shut down, and those who will qualify in due course). Here, we quote a participant's voice who described the problem better than we could.

"There are two things. It is, yes, of course, funding. To pay the salaries and more money, but then, the other step is just the resource. I'm going to say everyone above me, in general, is not treating healthcare personnel very well, and you have many, many people leaving the healthcare field because of this. Finding the people to put them into the positions will also be a struggle because we do not feel appreciated or valued, and it is a huge factor in the welfare, availability, and functioning of healthcare workers as we see them today."—(Provider-level participant, initial interview six).

From our standpoint, there is a complex intellectual, theoretical and motivational turn that occurs when all or most of the problems are defined as a problem rooted in the social determinants of health (SDoH) because the solution to this problem is often conceptualized as needing to happen in HPVV consumers regardless the problem was conceived as a responsibility of the patient, the provider, or the system? In our view, this individualist and all-encompassing expression of the SDoH, in some ways blames the victim and blurs reflection of the complexities of HPVV end-users lives, hence obscuring the need to identify the structural determinants of health to intervene in health inequities.

Zooming into examining the structural<sup>15</sup> determinants of health and relevant drivers can help to understand the context and background of HPVV underutilization among various population subgroups. While interviewing patient, system, and provider-level

Table 1. Summary of factors under the theme of information, awareness, and education about HPV infection and HPV vaccine

Barriers	Facilitators
Inadequate information, awareness and education about HPV infection and HPVV	Adequate information, awareness and education about HPV infection and HPVV
Never knew what HPV is (infection?)	Awareness about the HPV infection, and vaccine
Uncertainty about vaccine safety	Information about HPV vaccine safety and efficacy
Religious and moral inclinations: Their kids will abstain sexual activity until marriage	Dismantle myths and educate parents and youth esp. about uncertain social circumstances of kids' future partner, etc.
Belief: Not the right age for HPV vaccine	Educate: Parents and youth
HPV vaccine would provide a license to sex/ promiscuity (early involvement, risky behavior)	Educate: Parents, youth, teachers, and other school staff
Insufficient venues for information exchange with parents and youth	Create multiple venues for information exchange with parents and engaging youth at school
Will never contract HPV in monogamous relationship	Education of parents, youth, and school staff
Is HPV vaccine same as BCG?	Provide clear understanding of the HPV vaccine
PHNs and immunization staff find HPV vaccine skepticism challenging	Periodic refresher courses and training of immunization staff

BCG, bacillus Calmette-Guerin; HPV, human papilloma virus; HPVV, human papilloma virus vaccine; PHN, public health nurse.

participants, we found a sharp contrast in the viewpoints of people coming from different levels of the hierarchy and talking about the potential drivers of the same problem (i.e., HPVV underutilization). For example, on one hand, parents complained that they were not given the desired information on HPV infection and the vaccine, due to which they failed to consent to HPVV. On the other hand, system-level workers stated that parents were not reading the information, so they might not know what the HPVV is about. At the same time, provider-level workers believed there was a gap in accurately communicating the message to the parents, especially to those subgroups willing to learn about HPV infection and HPVV. Our study has itemized several factors that need to be addressed

to tackle vaccine-related logistics while ensuring the right information reaches HPVV consumers and end-users. Tables 1 and 2 provide a summary of important factors.

The conflicting views of stakeholders and patients suggest that some ideological differences and limitations arise from how stakeholders think the problem should be addressed versus the patient belief that the problem would not exist had it been planned well and possible issues anticipated. Although stakeholders believe that it is an authority mandate that the existing information sheet be maintained, that could mean that it is up to the parents to ensure they understand what is provided. In our view, these differences hold

Table 2. Summary of factors under theme of vaccine-related logistics

Barriers	Facilitators
Vaccine-related logistics as roadblocks	Vaccine-related logistics in place
Vaccine information sheet is too wordy and technical	Create simple version of vaccine information material
Vaccine sheets are too busy (text heavy)	Include Q & A to highlight main information
English as a second language	Translate vaccine material in different languages
Disproportionate emphasis of STI vs. cancer prevention	Balance the emphasis and promote HPV-linked cancer prevention related success
Many needles in grade six	Needle spacing or periodic reoffer in high schools
Filing consent form is akin to writing an exam	Consent form should be made easy to fill
Paper copy of the information material is difficult to track	Consider hybrid approach of sending immunization packages home (i.e., electronic and paper copy)
Child as a medium of transportation for immunization packages (potential of loss, etc.)	Immunization packages should be sent electronically followed by paper copy (vice versa)
Inadequate reminder/notification from school about vaccine day	In addition to school letter, notification via email or school app EDSBY
No HPV vaccine make up day for missed opportunities	School is the best medium for needle administration, so more opportunities at school for HPV vaccine

HPV, human papilloma virus; HPVV, human papilloma virus vaccine; Q & A, question and answer; STI, sexually transmitted infection.

exciting possibilities for acting on the drivers of HPVV uptake. Among the migrant parents interviewed, there was tremendous interest in learning about HPV infection and HPVV. This finding of our study strongly supports those of Rubens-Augustson *et al.*<sup>11</sup> and calls for informational desires and needs from newcomer perspectives to inform strategies for equitable HPVV uptake. Our study findings also partly align with Wilson *et al.*<sup>16</sup> for devising language-appropriate resources to help newcomer parents make informed decisions in consenting for their child(ren) and promoting HPVV uptake. Unlike Wilson *et al.*<sup>16</sup> study, we did not find any cultural-related factors that impede HPVV uptake.

#### Problem solving by identifying cross-cutting themes

"A problem well put is half solved."—John Dewey<sup>17</sup>

"Solving a problem for which you know, there is an answer is like climbing a mountain with a guide along a trail someone else has laid. In mathematics, the truth is somewhere out there in a place no one knows beyond all the beaten paths. And it's not always at the top of the mountain. It might be in a crack on the smoothest cliff or somewhere deep in the valley."—Yoko Ogawa, The Housekeeper and the Professor

This study highlights several related and unrelated barriers to and facilitators of HPVV uptake, revealed by examining perspectives at three levels (patients, providers, and the system). Without exception, the participants at all levels communicated a common potential facilitator (the adoption of the COVID-19 vaccine model), which qualifies as a cross-cutting theme from among the two key themes discussed above due to the reasons mentioned below. The cross-cutting themes are topics (areas or factors) that gain importance concerning the objectives of development cooperation that should be considered and integrated well into all development interventions and policies. 18 These topics are the issues that (1) cannot be neatly separated into individual interventions because even projects or programs targeting other areas have a direct or indirect impact on them. 18 (2) They should not be separated because by separating them we could lose synergies that we can leverage and benefit from. Cross-cutting themes intersect throughout the main project and can serve as an effective tool for explaining the impacts of a targeted factor in one area and can have a much wider impact on other areas. 19 In the context of this study, the cross-cutting theme (topic or factor) is the one that serves to inform how the uptake of HPVV can be optimized in a way that educates people about HPVV and results in successful vaccine uptake. Such an approach translates to the adaptation of the COVID-19 vaccine model in the vaccine uptake continuum.<sup>20</sup>

HPVV uptake efforts can follow or adopt the COVID-19 vaccine model in terms of vaccine program planning, rollout (including spreading awareness using multiple approaches), and vaccine delivery and administration. For example, public messaging in dimensions of knowledge translation and dissemination of HPVV should be delivered on the patterns in which COVID-19 vaccine-related information was translated and disseminated. The COVID-19 vaccines were described as life-saving interventions, and this information was widely distributed using a number of forums. COVID-19 information packages and on-site pamphlets contained information that was short, simple, and easy to understand, with a question-and-answer section to facilitate understanding. HPVV information should be delivered in similar ways. In line with the themes described by Khan *et al.*<sup>2</sup> as a framework for access to care and prevention and overlaps with the elements of the vaccine uptake continuum, the efforts to

improve HPVV uptake rates will include:

- 1. creating awareness of the HPV-disease-related health threat (i.e. HPV-linked cancers);
- making HPVV available to all age groups in addition to schoolaged children;
- 3. improving HPVV accessibility through programs in addition to the school-based immunization program;
- enhancing affordability removing the age cap for HPVV and by informing people that HPVV is available through publicly funded school-based programs and public health outlets;
- raising HPV health literacy levels to create HPVV acceptability to effectively meet the challenge of suboptimal HPVV uptake.

#### Recommendations

Drawing on the study's findings, we provide high-level recommendations keeping the system thinking approach in the background.

#### Recommendation 1

A multicomponent or multistrand intervention remains instrumental in enhancing HPV immunization rates. That is, an educational campaign that involves educating parents who consent for their child(ren) to get HPVV, the children receiving the vaccination, and the staff providing HPVV. The multicomponent intervention will involve educating the three key groups involved in the HPV vaccine uptake continuum (children receiving HPVV, parents consenting to it, and staff providing it (public health nurses) and helping to provide it (school admins and teachers).

#### Recommendation 2

Create and distribute a user-friendly immunization guide. That is, one that is simple, brief, translated into different target languages, captures information in the context of children having an HPV vaccine and has a cancer prevention focus. This recommendation offers the opportunity to follow the COVID-19 vaccine model as an example.

#### Recommendation 3

Use a person-centered approach in terms of educating parents and those who need HPV vaccines on dimensions of the needs of individuals. This approach allows us to focus on the needs of individuals using the person-centered approach. An example is educating them in multiple dimensions based on their needs, which could involve giving the right information, dismantling myths, handling misconceptions, and addressing specific questions, concerns, or fears. The person-centered approach is recommended over the patient-centered approach because we aim to achieve the main goal of person-centeredness, which is a meaningful life for the person over a functional life for the patient.<sup>21</sup>

#### Conclusions

Current awareness and education strategies are ineffective, do not convey the information in a way that can easily be understood by the parents, and do not enable them to provide informed consent for their child(ren) to get the HPV vaccine. Vaccine-related logistics are equally important as HPV vaccine information, awareness, and education. Therefore, the logistics of HPV vaccine information delivery should be reconsidered. The logistics of information delivery need to be revisited in the context of a hybrid digital and analog world. Culture is not as significant an issue as considered. A systems-level thinking approach that centers the patient and family

is needed, in which we need to look at all levels of the systems to understand and improve HPV vaccine uptake. Regardless of the quantitative or qualitative division of the ways of inquiry, the systems-level thinking approach at the heart of population health science carries the desire to intervene to make the population healthier. The persistence of disparity in the uptake of the HPV vaccine serves to add to the health gap, contributing to health inequities in Saskatchewan and globally.

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#### **Author contributions**

Conceptualized and designed the conduct of the review, conducted data collection, sorting, organization and interpreted data and prepared and revised the manuscript (AK), contributed to the conceptualization of the review, its design, and results interpretation and reviewed and revised the manuscript (CN), contributed to the conceptualization of the review, its design, interpretation of the results, manuscript review and revision (SyA), contributed to the study conceptualization, reviewed the manuscript and provided feedback (ShA), reviewed the manuscript, offered edits and provided valuable insights and feedback overall (SG).

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Khan A. et al: Barriers and facilitators of HPV vaccine uptake

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