

Parents' decision-making about the human papillomavirus vaccine for their daughters: II. Qualitative results

Andrea Krawczyk^{1,2}, Samara Perez^{1,2}, Leonora King^{2,3}, Maryline Vivion⁴, Eve Dubé⁴, and Zeev Rosberger^{1,2,3,5,6,*}

¹Department of Psychology; McGill University; Montreal, QC, Canada; ²Lady Davis Institute for Medical Research; Jewish General Hospital; Montreal, QC, Canada; ³Department of Psychiatry; McGill University; Montreal, QC, Canada; ⁴Institut national de santé publique du Québec; Québec City, QC, Canada; ⁵Louise Granofsky Psychosocial Oncology Program; Segal Cancer Center; Jewish General Hospital; Montreal, QC, Canada; ⁶Department of Oncology; McGill University; Montreal, QC, Canada

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Abbreviations: HPV, Human Papillomavirus; STI, Sexually Transmitted Infection; CIN, Cervical Intraepithelial Neoplasia; CAIQ, Commission d'Accès à l'Information du Québec; HBM, Health Belief Model

The goal of the study was to examine the reasons given by parents who accepted or refused the HPV vaccine for their daughters in the context of a free provincial school-based vaccination program. A random sample of parents of 9–10 y old girls completed a mail-in questionnaire. Parents' responses to 2 open-ended questions were assessed using content analysis. Coding themes were derived from the Health Belief Model. 806 parents returned and answered the relevant items. 88% of these parents decided to vaccinate their daughter. The primary reasons for parents' acceptance was the perceived benefits (e.g., health protection, cancer/HPV prevention) and cues to action (e.g., physician recommendation, trusting the school vaccine program). Reasons for parental refusal included barriers (e.g., fear of side effects) and low susceptibility (e.g., their daughter is not at risk). Both groups of parents had unanswered questions, doubts and often inaccurate information. This study provides unique insight into parents' perspectives concerning the decision making process for their daughter. There appears to be a need for accurate and complete information to assure informed HPV vaccine decision-making by parents and to increase HPV vaccine uptake.

Introduction

The Human Papillomavirus (HPV) is the most common sexually transmitted infection (STI) in the world, infecting 3 out of 4 people at least once in their lives.¹ There are over 120 different strains of the virus and although most HPV infections clear up on their own, persistent infections can lead to life-threatening consequences. Certain types of HPV are oncogenic in that they are cancer causing. There is now substantial evidence showing that HPV can be detected in virtually all cases of cervical cancer.^{2,3} HPV is also associated with other types of cancers including vulvar, vaginal, penile, anal, and oropharyngeal (head and neck) cancers.^{4,5} Additionally, 2 non-oncogenic types of HPV are responsible for a significant proportion of genital warts.^{6,7}

Due to the burden of HPV-related disease, 2 vaccines have been developed and approved for use, namely Gardasil[®] (Merck) and Cervarix[®] (GlaxoSmithKline). These vaccines have been evaluated in extensive randomized controlled trials and are nearly 100% effective in preventing new HPV infections (caused by the leading strains), and in turn have an efficacy of >90% in preventing cervical intraepithelial neoplasia (CIN2/3).^{1,8} Because HPV is sexually

transmitted, the vaccine has maximum benefit when given prior to initiation of sexual activity when immunogenicity is the strongest.^{9,10} In Canada, vaccination is currently approved and recommended for females 9 to 45 y of age and for males 9 to 26 y of age.¹¹

In 2007, the Canadian government allocated \$300 million to the provinces/territories for HPV immunization programs.¹² In September 2007, the provinces began introducing free school-based immunization programs for females in grades 5 to 8, and catch up immunization programs in grades 8 to 10 (grades vary by province).^{1,13} However, universal school-based vaccination programs are presently only in place for young girls, with the exception of 2 Canadian provinces (Alberta and Prince Edward Island) who recently (April 2013) announced extensions of vaccination programs to include boys.¹⁴ Because it is encouraged that Canadian children get vaccinated prior to the age of 13,¹⁵ parental consent is critical in the vaccination process.

The development of the HPV vaccine has led to the emergence of a new era in cancer prevention. However, HPV vaccination programs for children have generated great controversy among the general public, including parents. The literature on parental HPV vaccine decision-making cites several barriers to vaccination including: a lack of research on the long term efficacy and side effects of the vaccine, the age of vaccination administration being too young, mistrust of pharmaceutical companies, and fears that the vaccine would promote early sexual activity and/or reduce self-protective

*Correspondence to: Zeev Rosberger; Email: zeev@psych.mcgill.ca
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sexual behaviors – also referred to as sexual disinhibition or risk compensation.¹⁶⁻¹⁸ In addition, the cost of the HPV vaccine (which is approximately \$450 CAD for 3 doses) has been reported as one of the principal barriers to vaccination.^{19,20}

Implementation of publicly funded HPV vaccination programs across Canada removes the barrier of cost, thus allowing unhindered exploration of other factors that impact parental attitudes and beliefs concerning vaccination.²¹ Correspondingly, the purpose of the present study is to examine the reasoning underlying parents' decisions to either accept or refuse HPV vaccination for their daughters within this provincial HPV vaccination program. Specifically, this study aims to understand parents' subjective perceptions regarding the risks and benefits of vaccination, including the factors parents believe influenced their decision whether or not to vaccinate their daughters. In turn, this information can better guide public health policies as well as the development of educational interventions for parents making health decisions for their child.

Results

The sample was composed mostly of mothers (95.6% female) and the average age of participants was 40.2 y (*SD* = 5.36, range = 26–73). Most of the sample was married or in a common law relationship (80.2%) and there were on average 4.14 members (*SD* = 1.03, range = 2–8) in a given household. The majority of the sample spoke French as their first language (83.5%) and were born in Canada (90%). In terms of the socio-economic status of the sample, 82.7% were employed and slightly more than one third (36.6%) reported their annual household income to be less than \$60,000. Detailed demographic and sample characteristics can be found in **Table 1**.

Of the 806 parents that provided qualitative responses, 708 (88%) parents accepted and 98 (12%) refused the vaccine for their daughters. A detailed listing of reasons associated with parental acceptance or refusal of the vaccine along with corresponding example quotes can be found in **Tables 2 and 3**. It is important to note that some parents gave more than one reason for their decision [in their open-ended answer]; therefore, there are more reasons cited than there are parents.

Of those parents who accepted the vaccine for their daughters (see **Table 2**), the majority (*n* = 499) cited benefits of vaccination as the reason for their decision. Benefits of HPV vaccination included: general health protection (*n* = 287), associating the vaccine with HPV or cancer prevention (*n* = 104 and *n* = 33, respectively), general positive attitudes toward vaccinations (*n* = 62), and the belief that the benefits of vaccination outweigh the risks of HPV (*n* = 17).

The second most common factor that influenced parents' decisions was cues to action (*n* = 214). Specifically, cues to action included: trusting the school vaccination program and/or public health organizations (*n* = 71), receiving a doctor's recommendation (*n* = 60), parents' personal experiences with HPV/abnormal pap tests (*n* = 29), being influenced by the media (*n* = 21), having a relative experience HPV or cancer (*n* = 17) and pressure to comply with social norms (e.g., other parents accepting the vaccine for their

Table 1. Sample Characteristics (*n* = 806)

Characteristics	n (%)
Language	
French	673 (83.5)
English	61 (7.6)
Other	70 (8.7)
Ethnicity	
White / European	711 (88.2)
Arabic / Middle Eastern / North African	15 (1.9)
Black / Caribbean / African	15 (1.9)
First Nations/ Metis / Aboriginal	16 (2.0)
Other	23 (2.8)
Religion	
Christian	671 (83.3)
Jewish	5 (0.6)
Muslim	11 (1.4)
Eastern non-Christian	23 (2.9)
Other	90 (11.1)
Family Income (CAD \$)	
Less than \$30,000	82 (10.2)
\$30,000–\$59,999	213 (26.4)
\$60,000–\$99,999	239 (29.7)
\$100,000 or higher	245 (30.7)
Marital Status	
Single	73 (9.1)
Married/Common Law	647 (80.2)
Divorced/Separated	72 (8.9)
Widowed	11 (1.4)
Educational Attainment	
Elementary school or some high school	36 (4.5)
High school graduate	96 (11.9)
CEGEP or professional school	295 (36.6)
Some university	84 (10.4)
University graduate	292 (36.2)
Ever had or know anyone close who has had an STI	
Yes	259 (32.1)
No	541 (67.1)
Ever had or know anyone close who has had cancer	
Yes	545 (67.6)
No	260 (32.3)

Note. Sums do not always equal 100% as not every participant completed each item.

daughters; *n* = 10) were all important prompts governing the decision to accept the vaccine for their daughters.

An additional 15 parents consented to the HPV vaccine because they felt that their daughters might be susceptible to increased and/or earlier sexual activity. Seventeen parents made their decision based on anticipated regret. In other words, they accepted the vaccine because they feared they would otherwise feel regret if their daughter contracted an HPV infection in the future and they had refused the vaccine.

Parents who refused the vaccine for their daughters reported that their primary reasons for doing so were common barriers (*n* = 71, see **Table 3**). Some of the more specific barriers reported were concerning vaccine protection. As an example, some parents had doubts about the safety of the vaccine (*n* = 14), the effectiveness of the vaccine (*n* = 10) and the duration of vaccine protection (*n* = 8). A few parents feared potential long-term side effects associated with the vaccine (*n* = 12) while a

Table 2. Reasons given by parents who accepted vaccination (n = 708)

Benefits (n = 503)	Sample Quotes:
General health protection (n = 287)	<i>I want to protect my daughter from anything that may cause her harm. Since I cannot be with her 24/7, at least a vaccine can immunize a potential risk.</i>
Cancer prevention (n = 104)	<i>To give her some protection against one of the many forms of cancer existing in our society today.</i>
General Positive attitude toward vaccinations (n= 62)	<i>For my husband and I, vaccines are there to improve the quality of life for everyone.</i>
HPV prevention (n = 33)	<i>I decided to get [my daughter] vaccinated to protect her against HPV. Why risk her contracting this virus?</i>
Benefits of vaccination vs. risks of HPV (n=17)	<i>I decided to get [her] vaccinated because the promises of benefits and protection exceed the potential dangers to me.</i>
Cues to Actions (n = 214)	
Trusting school vaccine program/public health organization (n = 71)	<i>Because I trust in the health system of our country/ province. I believe that their primary objective is the health of people and I do not believe they would risk offering us vaccination programs that haven't been fully studied and proven.</i>
Physician recommendation (n = 60)	<i>My gynecologist and my daughter's pediatrician strongly recommended to have my daughter vaccinated.</i>
Personal experience with HPV/abnormal pap tests (n = 29)	<i>Because I was diagnosed with HPV. I want her to not have the chances to be infected.</i>
Influence of the media (n = 21)	<i>Television publicities rapidly convinced me that I have to get my daughter vaccinated.</i>
Relative's experience with HPV and/or cancer	<i>My mother and mother-in-law [both] had uterine cancer and underwent removal of the uterus.</i>
Social norms (n =10)	<i>If this is to prevent infection, why not? And when all other children are getting vaccinated, why not my daughter?</i>
Perceived Susceptibility (n = 15)	<i>... I cannot guarantee that my daughter will engage in safe sexual relationships. So, this vaccine will at least protect her against HPV and eventually cervical cancer.</i>
Anticipated Regret (n = 17)	<i>I had my daughter vaccinated because if she ever got cervical cancer from not getting the vaccine, I would never forgive myself, if I could of prevented it.</i>

Note. 708 parents gave at least one reason for accepting the vaccine for their daughters. In total 808 reasons were coded, as some parents gave more than one reason in their answer.

small minority (n = 2) questioned the actual severity of HPV or felt that their daughter should decide for herself (n = 3). Some parents reported being against vaccines in general (n = 5) while others reported not having enough information about the vaccine (n = 11) or were suspicious that pharmaceutical lobbying was behind HPV vaccine campaigns (n = 11).

The second most common factor related to vaccine refusal was susceptibility (n = 32) whereby parents felt that their daughters were not at risk for HPV. Specifically, some believed that the age of vaccination is too young/daughter is not yet sexually active (n = 25), or that their daughters were instilled with moral values surrounding abstinence/other modes of protection (n = 10). Cues to action were not generally cited as reasons for vaccine refusal. For example, only 4 parents reported that a doctor recommended against the vaccine. Similarly, only 3 parents acknowledged negative media attention (about the HPV vaccine) as being the source of their decision.

Among the 138 supplementary comments that were provided by the parents who accepted the vaccine, over 70% parents (n = 100) still had questions about HPV and the HPV vaccine. For example, some parents (n = 13) still had remaining doubts about vaccination safety, specifically with regards to the long-term efficacy or necessity of the vaccine (n = 8). Others were apprehensive about vaccinating their daughters at such an early age (n =

13) and some were uncomfortable with the pressure from vaccination campaigns (n = 9) to vaccinate their daughters. Furthermore, a very small subgroup of parents who accepted the vaccine later expressed regretting their decision (n = 6).

Discussion

In our sample, the majority of parents participating in the Quebec vaccination program reported accepting the vaccine for their daughters. The principal reason reported for acceptance was the perception that the vaccine would be beneficial for their daughters' health. However, some parents who accepted the vaccine also expressed having remaining concern, lingering questions and/or regret. Providing appropriate and continuing education and resources to parents may help to increase confidence in decision-making. This approach may be critical to ensure completion of the vaccine regimen (2 dose regimen in grade 4 in Quebec, at the time of present study).

The HPV vaccine has been the subject of much controversy, mainly due to public fears that receiving the vaccine would encourage sexual promiscuity, elicit sexual activity at an earlier age, and/or reduce self-protective sexual behaviors. On the contrary, several studies have found no association between the HPV

Table 3. Reasons given for parents who refused vaccination (n = 98)

Barriers (n = 71)	Sample Quotes:
Vaccine not sufficiently tested (n = 14)	<i>The vaccine has not been on the market long enough</i>
Fear of side effects (n = 12)	<i>I had read many warning on the internet about serious side effects. My son has autism. I was afraid my daughter might be one of the few with serious side effects too</i>
Not sufficiently informed (n = 11)	<i>The lack of information makes me hesitate.</i>
Suspicious of pharmaceutical lobbying (n = 11)	<i>Because I do not have a lot of confidence in the pharma-ceutical industry. I think rather that their primary purpose is not the health of people but a way to make big money</i>
Doubts concerning efficacy (n = 10)	<i>The HPV [vaccine] does not protect against all forms of cancer.</i>
Duration of protection (n = 8)	<i>The duration of the vaccine efficacy, if I remember correctly, is 3–4 years. . .</i>
Anti-vaccine attitudes (n = 5)	<i>. . . it seems that every 6 months for several years, a new vaccine appears. It seems to me that at some point, it becomes [confusing] for the immune system.</i>
Low susceptibility (n = 32)	
Daughter is too young/ not sexually active (n = 25)	<i>. . . my daughter is extremely unlikely to begin sexual activity before age 16–17 because she is not given any opportunities to really meet boys.</i>
Upheld family values (n = 10)	<i>Since pre-marital sex is forbidden in my religion, I believe that my daughter will choose to live her life as I am teaching her, and as such will not have many sexual partners.</i>
Other mode of protection (n = 10)	<i>I prefer the use of condoms and regular Pap test.</i>
Low severity (n = 2)	<i>. . . The percentages of people with cervical cancer, are there high enough to make the vaccine a necessity?</i>

Note. 98 parents gave at least one reason for refusing the vaccine for their daughters. In total 120 reasons were coded, as some parents gave more than one reason in their answer.

vaccine and sexual promiscuity.^{18,20,22–24} In fact, the vaccine has actually been shown to be associated with more responsible and safer sexual behaviors, such as condom use, regular Pap screening and STI testing.^{25,26} In line with this, while the majority of parents in our sample who refused the vaccine reported several concerns regarding the effectiveness and safety of the vaccine, no parents reported concerns about the impact of vaccination on riskier or earlier sexual activity. This result highlights that claims made by some parents and/or the media suggesting that HPV vaccination will lead to risk compensation or younger sexual activity may be over exaggerated, and are not necessarily a legitimate post-vaccination concern among parents.^{18,27,28} Importantly, some parents who accepted the vaccine did so based on the premise that earlier sexual activity is commonplace among today's generation, which suggests that (earlier) sexual activity was not a consequence of HPV vaccination, but rather a precursor. This issue warrants further investigation.

The HBM considers 5 distinct factors: perceived threat and severity of a disease, benefits and barriers (e.g., beliefs in the efficacy of the preventive measure) and cues to action. The results suggest that the potential benefits of vaccination were important for acceptors. This may suggest that the more finite points (e.g., how susceptible your daughter is to HPV) is less of an influential factor than general health protection and/or cancer prevention. For the refusers, the influencing factors were more varied and consisted of both barriers (e.g., questions about safety, duration of protection) and susceptibility (e.g., contrary to acceptors, these parents saw no need to vaccinate their daughters since they were not yet sexually active.)

Strengths and limitations

One important limitation to consider is that the overall response rate was relatively modest (33%). Despite this, our sample size was large for a qualitative study. Another limitation is that only a small proportion of our sample had refused the vaccine for their daughters, yielding only a modest amount of data for this group. Similarly, our sample was composed mostly of mothers, thus the perspectives of fathers are not represented. Notably, in our study, the proportion of parents who refused the HPV vaccine compared to those who accepted, as well as the ratio of mothers to fathers, is similar to the proportions reported in other studies of parental acceptance of the HPV vaccine.^{17,29} In fact, many studies have acknowledged that mothers/female guardians are often the primary decision-makers when it comes to health-care decisions in the household,^{30,31} and a large representation of females is typical in Quebec vaccine coverage studies.³²

An important limitation with open-ended questions is that respondents can only mention influences of which they are aware. Furthermore, respondents are more likely to verbalize salient or immediate influences, while leaving out those that are more distant and less conspicuous. As an example, although past compliance to other childhood vaccinations had an effect on their decision to vaccinate,³³ parents rarely mentioned this as a reason when asked open-endedly. This example supports the utility and value of a mixed methods design.

Lastly, it is important to note that many parents who accepted the HPV vaccine for their daughters consented to the initiation of the vaccine series, but may not have necessarily completed the

2-dose regimen at the time of the study. Accordingly, over the course of 5 y (first 2 doses administered in grade 4 and a booster dose first planned but finally not administered, based on a decision by the government of Quebec, in Grade 9), parents may be exposed to other factors in the interim that influence their initial and final decision. However, since there is now evidence to suggest that 2 doses of the HPV vaccine may be sufficient to bolster immunity,^{34,35} the province of Quebec has opted to administer 2 doses.¹⁵

Research implication and future directions

Future research directions should better address the informational needs of parents not only prior to vaccination, but also following vaccination since parents in our sample seemed to desire more information after having made their decision. This was true regardless of whether they accepted or refused the HPV vaccine for their daughters. Another important issue is that although parents are the ones deciding to vaccinate their children, young girls are the ones receiving the vaccination. The literature suggests that at the time of vaccination, many girls have not heard of HPV or the HPV vaccine and several may not even be aware that they have been vaccinated against HPV. For this reason, examining parent-daughter communication is another important area of research that will be crucial for understanding how information about sexual health is transmitted from the consenting party (the parent) to the recipient of the health behavior (a minor). Specifically, does the child even understand why she is receiving the vaccine (to prevent a sexually transmitted infection which causes genital warts and cancer)? Further, recipients of the HPV vaccine need to be made aware of certain health practices that should still be adopted despite being protected from certain strands of the HPV (e.g., regular Pap/HPV screening, safe sex practices including condom use, STI testing, etc.).

In summary, within the context of a school-based program, most Quebec parents accepted the vaccine for their daughter, citing general health benefits and/or cancer/HPV prevention as the most commonly reported reason. Cues to action such as a recommendation from a physician, a relative or from the child's school were also important reasons given for those who accepted. On the other hand, vaccine refusers cited barriers that can be conceptualized as a lack of or inadequate knowledge. This included fears about side effects, concerns about safety and vaccine efficacy/protection. Parents who refused also felt that their daughters were not susceptible or at risk to get HPV and/or that she was too young to receive the HPV vaccine. Interestingly, neither group of parents reported that giving the HPV vaccine would lead their daughter to have sex at an earlier age, or lead to increased and/or riskier sexual behaviors. In fact, some parents believed that "kids these days" are having sex at an earlier age and therefore wanted their daughters to be protected. The results of these qualitative analyses largely coincide with our quantitative findings,³³ therefore providing convergent validity. The parents' comments provide both nuance and breadth, with rich details of their subjective perspective on decision-making; such details are often lost in a purely quantitative analysis.

Both groups of parents had remaining questions, doubts and often inaccurate information. Parents who refused the vaccine

require supplementary information as well as clarification of misconceptions to adequately decide whether or not to vaccinate their daughters. Parents who accepted but expressed concerns or regret, require further education to guarantee completion of the vaccine regimen. Providing parents' with information to address their reported lack of knowledge will help increase confidence in their decision for their daughter and perhaps their other children when they reach the appropriate age for HPV vaccination. This highlights the need to disseminate to parents information that is accurate, appropriate and sufficient.

The current findings can be used to help inform the development of and testing of interventions to allay the fears of parents who may refuse HPV vaccination as well as to reassure parents who agreed to vaccinate but still want more information and/or expressed some regret post-vaccination. With the evidence and/or development of new and existing vaccines that prevent other HPV-related cancers (including vulvar, vaginal, anal, penile and head and neck cancers), it is critical to ensure that the unique informational needs of parents are addressed in order to assure informed, educated decision-making regarding the HPV vaccine.

Methods

Using the Régie de l'assurance maladie du Québec database (Quebec's public health care system), Quebec parents of girls in grade 4, typically 9–10 y old, were randomly selected ($n = 2500$).^a Parents were mailed an invitation letter to participate in the study, a consent form, and a questionnaire composed of quantitative and qualitative questions. A modified Dillman's Total Design method³⁶ was employed using a reminder post card at 1 week and replacement surveys at 4 weeks to maximize the response rate. Data were collected from January 25, 2010 to July 25, 2010. The study protocol was reviewed and approved by the Commission d'accès à l'information du Québec (CAIQ) and the McGill University Research Ethics Board.

The present article focuses on the qualitative component of the study where parents were asked to explain why they did or did not have their daughter vaccinated in an open-ended format. Parents were asked in either English or French: 'In your own words, why did you decide to vaccinate or not vaccinate your daughter?'^b Parents were also invited to leave any additional comments with the following item: 'If you have any additional comments that you would like to share, please feel welcome to do so below'. For both of these open ended items, respondents could fill up to 4 double spaced lines. The quantitative results are presented in a separate manuscript.³³

Eight-hundred and thirty four parents responded and returned the questionnaire. Eight hundred and six answered the open-ended questions and 138 entered additional comments. These responses were transcribed and analyzed using NVivo 10. A primary coding scheme was developed and discussed with the research team. The Health Belief Model (HBM) was selected by the authors as the theoretical framework through which to analyze parents' responses. The HBM is a conceptual framework consisting of beliefs and attitudinal constructs that seek to explain the adoption of health

behaviors (e.g., cancer screening, smoking).³⁷ It is a useful tool for understanding the role of factors that are thought to explain and predict the adoption of a specific health behavior (e.g., decision to vaccinate). The HBM has been used in numerous studies examining HPV vaccine decision-making.³⁸⁻⁴⁰

Two frames were developed: one for the parents who accepted the vaccine and one for the parents who refused the vaccine. The HBM proposes that the likelihood that a certain health behavior will be adopted is influenced by 5 key constructs: perceived susceptibility to the disease, perceived severity of the disease, benefits and barriers of performing the behavior, and cues to action which is defined as any external source (e.g., doctor recommendation, media reports) that have the potential to instigate the behavior in question.⁴¹

Content analysis is a method used to extract and reduce data from a body of qualitative material by systematically and objectively identifying specified characteristics of the material in order to better understand their meaning.^{42,43} The present content analysis was performed using NVivo 10 software. All comments were read by 2 authors (ED, MV). Data codification was performed by MV. The data was then organized into themes, which were chosen a priori by the authors, based on the theoretical constructs of the HBM. Conceptual categories were then created and concepts belonging to a similar dimension were regrouped. On an iterative basis, these conceptual categories were updated and revised until saturation was achieved, in other words when no new properties, dimensions or relationships emerged during subsequent analysis. After coding a few of the comments, the coding tree was discussed by the authors (ED and MV) and adjusted.

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Ambiguous comments were discussed and consensus was achieved among the authors (ED, MV, SP and LG).

Disclosure of Potential Conflicts of Interest

Dr. Rosberger reports personal fees, outside the submitted work, as a consultant at a workshop on behavioral science issues for Merck in November 2012. All other authors declare no additional conflict of interest.

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Notes

^aA school HPV vaccination program for females enrolled in fourth grade, was established in the Quebec schools in 2007. The Quebec health care system gave us access to all parents who had a daughter aged 9–10 years old.

^bIn French, parents were asked “Dans vos propre mots, pourquoi avez-vous décidé de vacciner ou non votre fille?”

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