

## REGULAR ARTICLE

# Not the right time: why parents refuse to let their daughters have the human papillomavirus vaccination

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## ABSTRACT

**Aim:** To explore why parents refused to allow their 10- to 12-year-old daughters to receive the human papillomavirus (HPV) vaccination from the Swedish school-based vaccination programme.

**Methods:** Individual interviews with 25 parents who had been offered, but not consented to, their daughters receiving the HPV vaccination.

**Results:** Five themes emerged through the interviews: 1) she is just a little girl, 2) inadequate information, 3) not compatible with our way of life, 4) scepticism about the vaccination and 5) who can you trust? The parents made their decisions with their child's best interests in mind. This was not considered the right time, and the vaccine was perceived as unnecessary and different from other vaccines. Mistrust in Government recommendations and a lack of evidence or information were other reasons to decline.

**Conclusion:** The decision-making process was complex. These parents preferred to wait until their daughter was older and believed the information they received from the school health system was insufficient. The results indicate that a more flexible HPV vaccination schedule may improve vaccine uptake. This includes more transparent information about the virus and the vaccine and information about who to contact to get the daughter vaccinated at a later date.

## INTRODUCTION

Many countries have implemented vaccination programmes to prevent infections related to the human papillomavirus (HPV) (1). The quadrivalent vaccine is highly efficient and safe (2), offering protection against HPV types 16/18 and 6/11, which are implicated in most cases of cervical cancer and condyloma (3,4). Although the majority of HPV infections heal spontaneously, persistent infection with high-risk HPV strains can cause cancer decades later (5). As HPV is sexually transmitted, the vaccine should be distributed to girls who have not already been exposed to HPV to offer them the best level of protection (2,6). Vaccine coverage among girls aged 10–14 years differs between countries (1,7–9), from 14.2% in the United States (10) to 92% in Scotland (11). The highest uptakes have been found where publicly funded, school-based vaccination programmes have been implemented (7).

It is up to parents to decide whether their child is vaccinated and this decision is usually made based on the perceived benefits and risks of the vaccine (12). Parents

who refuse to let their daughters receive the HPV vaccination consider that the risks outweigh the benefits. The reasons they give include the fact that the vaccine is too new, there are concerns about long-term safety (13), they are worried about the side effects, they think their daughter is too young (14), or they may not feel that their daughter is at risk of an HPV-related disease, such as cervical cancer. The parents may also feel that they have not been given enough information to give their informed consent (13).

In the spring of 2012, inoculation with the quadrivalent HPV vaccine was introduced into the Swedish school-based

## Key notes

- Interviews were conducted with 25 parents who had refused to let their 10- to 12-year-old daughters receive the human papillomavirus (HPV) vaccination from the Swedish school-based vaccination programme.
- The reasons for refusal were complex; many parents felt that the information they received was insufficient and they preferred to wait until their daughter was older.
- The results indicate that a more flexible approach to the HPV vaccination is needed.

## Abbreviations

HPV, Human papillomavirus; STI, Sexually transmitted infection.

vaccination programme for girls from 10 to 12 years of age. The vaccine is provided free of charge, but parents have to give their consent. The national goal is to reach coverage of more than 90% to achieve herd immunity. In the first year, the coverage was 79% (15). We currently have limited knowledge about why parents refuse to let their daughters receive the HPV vaccine as part of school-based programmes. A better understanding of why they decide to withhold their consent could lead to improve vaccination strategies. The aim of this study was, therefore, to explore parents' reasons for declining the HPV vaccination offered to their 10- to 12-year-old daughters by the Swedish school-based vaccination programme. A qualitative method was used to explore the rationale behind the parents' views on the HPV vaccine.

## METHODS

### Study design and sample

This was an explorative, qualitative study with face-to-face interviews. Parents were eligible for inclusion if they had refused to let their daughter receive the HPV vaccination as part of the school-based vaccination programme and agreed to share their views on the subject.

The heads of the School Health Service of eleven municipalities received information about the study and gave their permission. They informed school nurses, who distributed information letters to parents. Parents who agreed to participate in the study were asked to contact the researchers by email or telephone and were offered a cinema ticket as a reward. A total of 25 parents, representing a wide variety of urban and rural areas, were recruited and agreed to participate. The recruitment continued until no new material emerged from the interviews. The characteristics of the participants are presented in Table 1.

### Interview

Interviews were performed at a place chosen by the parent, who also completed a brief background questionnaire and

gave written informed consent. The main open-ended question during the interviews was as follows: Can you tell me about your reasons for refusing to let your daughter have the HPV vaccine? Additional questions were asked to clarify the parents' statements. The interviews lasted between 30 and 60 min, and the average interview was 40 min. The researchers provided parents with contact details, so that they could ask further questions about the study if they needed to. The interviews were carried out by three of the authors (MG, MO and CS) and were transcribed verbatim.

### Data analysis

The interviews were analysed using latent content analysis, according to Burnard (16). First, the transcriptions were read several times according to the aim of the study. This was followed by an open coding session, during which data were named and identified with notes in the margin. Then, the data were coded and grouped together into labelled categories. Each category was checked again by returning to the transcribed interviews. During the final step, themes emerged from the data. The initial analysis was carried out by MG and MO and was validated by the co-authors, who individually read the transcripts and identified the categories. No need for changes was identified during this process, but the categories and themes were discussed among the authors until consensus was reached. Examples of the analytic process are presented in Table 2. The study was approved by the Regional Ethical Review Board in Uppsala, Sweden, D.nr. 2012/048.

## RESULTS

The reasons for the parents' decision were complex. Five themes emerged through the interviews: 1) she is just a little girl, 2) inadequate information, 3) not compatible with our way of life, 4) scepticism about the vaccination and 5) who can you trust?

### She is just a little girl

#### *She is too fragile*

A common reason for declining the vaccination was the daughter's young age. The parents believed that it would be several years before she would become sexually active. There were also concerns about the possible harmful effects on a young, growing body.

And then we feel, well, she is just twelve and not sexually active. She is still just a girl, so we feel that we can vaccinate her later if we feel that there is a need for it. (Interview number 23, mother)

#### *Vaccination would be a problem because of existing health issues*

Another ground for declining the vaccination was related to the child's health. Parents said that they did not want their daughter to be vaccinated because she had medical issues, such as diabetes, asthma or allergies. Their child had

**Table 1** Demographic characteristics of the parents

Characteristics	n = 25
Mean age	44 (range 37–59)
Sex	
Women	23
Men	2
Civil status	
Married	21
Single	4
Highest education	
University/college	17
High school	7
Vocational training/education	1
Country of birth	
Sweden	23
Other European country	2
More than one child	23

**Table 2** Example of the analytic process

Interview transcript	Initial coding framework	Category	Theme
We chose not to take it because she is afraid of needles and I do not think we would have been able to force her, so therefore, we did not.	Decision not to vaccinate due to fear of needles	She is afraid of needles	She is just a little girl
I have received very little information, minimal information. Hardly any at all. And that is why I said no	Insufficient information about the HPV vaccine	We only received a piece of paper	Inadequate information
... we think that if you do not do it before marrying or finding the right man and so on, that you do not have lots of sex with different people	We follow a higher moral code	We do not need to	Not compatible with our way of life
This makes one think... when we vaccinate the children, what happens when it mutates? What will happen to her child that she gives birth to if the vaccine is in her body. Nobody can give an answer to those questions today. The vaccine has not been around for so long	Anxiety about unknown future side effects	This vaccination is different	Scepticism about the vaccination
... one wonders if there are lobby groups behind the decision to do this mass vaccination... And then, the rationale is totally different, then it is not about public health, but somebody who wants to make money	Commercial interest in the vaccination	No trust in the government's recommendations	Who can you trust?

previously been exposed to numerous medical procedures, and they wanted to protect her from yet another one. Furthermore, they were worried about how much a young body could tolerate and whether the vaccination would worsen her existing medical condition.

#### *She is afraid of needles*

Some parents decided not to vaccinate because their daughter was afraid of needles. This was a hard decision, because they wanted the daughter to be vaccinated, but it would not be possible without sedation or the use of force. These girls needed more individual treatment, in a calm environment with a parent present, rather than the quick group vaccination offered by the school. The parents hoped that their daughter would grow out of her extreme anxiety about injections and be able to receive the vaccine later on.

#### *She will make her own decision later*

Some parents felt that, out of concern for their daughter's autonomy, they could not make the decision for her at this time. She was considered too young to fully understand the matter. But because she was involved in decisions regarding other important matters, it was felt appropriate to postpone the vaccination and let her decide for herself at a later date.

#### **Inadequate information**

##### *We only received a piece of paper*

The parents felt that the information they received from the school health authorities was insufficient, as it mainly talked about how the vaccination would be administered and did not talk about the actual vaccine and why it was needed. They wanted transparent, unbiased information about all aspects of HPV and the HPV vaccination, together with links to reliable sources of more information. Some parents contacted the school nurse themselves to

find out more, while others felt it would have been helpful to have had the chance to discuss the matter with other parents.

We haven't received any explanation... no information about HPV has been given. The only thing we got was a vaccination appointment. (Interview number 16, mother)

#### *Overwhelmed and pressured to make a quick decision*

The parents felt that the vaccination programme was rushed, and they felt pressured to make a quick decision. Because the HPV vaccine was considered important, they felt they needed more time to make an informed decision and refused to have their daughter vaccinated for the time being.

#### *Perceived recommendation not to vaccinate*

Recommendations from significant others, such as family, friends or healthcare professionals, had an impact on some parents' decision not to vaccinate.

#### **Not compatible with our way of life**

##### *Encouraging adolescents to wait for sex*

Parents believed that girls today are exposed to sex at an early age and in a negative way through TV, films and the internet. They felt it was important to strengthen their daughters' self-esteem and encourage them to adopt another lifestyle than the one they were exposed to through the mass media. They wanted their daughter to postpone their first sexual experience and to only have a small number of partners.

...to encourage and, so to say, especially strengthen young girls' self-confidence and ability to say no. And in a way I think that this vaccination thing... it can

give a false sense of security.(Interview number 22, mother)

#### *We do not need to*

Religious faith and family values were other reasons to decline. The vaccine was not needed because the daughter was only supposed to have one partner and was not going to lead that kind of life of lax morals. Parents believed the decision to decline the vaccine was right, as long as their daughter lived up to these expectations. Otherwise, it would be preferable to ensure she received the vaccine.

#### *Important to inform her about preventing STIs*

Parents felt it was important that their daughters were well informed about preventing sexually transmitted infections (STIs) before she became sexually active. This included the importance of using condoms and related health advice, such as taking part in future cervical cancer screening programmes. It was felt that offering the girls the HPV vaccine, without such information, could give them a false sense of security. Parents thought discussions about STI prevention should take place at home, as well as at school, where they would prefer them to be led by a teacher or a school nurse.

#### **Scepticism about the HPV vaccination**

##### *This vaccination is different*

The HPV vaccine was considered to be different to the other childhood vaccines, with possible, new, unknown side effects and a perceived lack of evidence. In contrast, the other childhood vaccinations were considered to be more reliable, because they had been used for a long time. Parents were worried that the HPV vaccine could have negative effects on the daughter's future health, such as causing autoimmune diseases or decreasing fertility. Furthermore, the parents questioned how long the vaccine would remain effective.

##### *Do we really have to vaccinate against everything?*

Some of the parents declined the HPV vaccine because they were suspicious about vaccinations in general. They believed that vaccinations were unnatural and that their child's health would be improved, and their immune system strengthened, by having flu or the usual childhood diseases. Although most of the parents who took part in the study had let their daughter have the normal childhood vaccinations, some had declined all of them.

...if you get diseases then the body's own immune defence will build much better defence afterwards than a vaccine can ever do.(Interview number 17, mother)

#### **Who can you trust?**

##### *No trust in the government's recommendations*

Some parents did not trust the recommendations of the Swedish government and believed that mass vaccinations

were a way to exert control over the population, a Big Brother phenomenon that told peoples what to do. They also questioned how much government money had been spent on the HPV vaccination and felt that the money could have been put to better use in the healthcare system.

##### *Narcolepsy as a side effect of the vaccination against the swine flu*

The government-supported mass vaccination against (A) H1N1, the so-called swine flu, was later found to have caused or precipitated narcolepsy. This was a commonly cited reason for not trusting the governments' recommendations this time. The mass vaccination for swine flu was described as hysterical, and all the parents drew a parallel between the two vaccinations. They were worried that a similar thing could happen again.

##### *The individual knows best*

Parents felt that the decision about whether to vaccinate was a personal one and that they could make up their own minds about what was best for their child. Most of them were confident that they had made the right decision at this time. They felt that most of the other parents had just vaccinated their daughters without thinking about it.

But it feels as if most of the others haven't really thought about it but just followed the flock.(Interview number 19, mother)

##### *The school nurse was not supportive enough*

Some parents said that they did not trust the school nurse. She or he did not give the family enough support, or they did not feel the nurse was competent enough to provide adequate information. Parents who requested more, and better, information about HPV and the vaccination did not feel that the school nurse could fulfil that need.

#### **DISCUSSION**

The results of our study indicate that the parents who did not agree to their daughter receiving the vaccine went through a complex decision process that included a number of important factors. Some parents believed their daughter was too fragile at the time and was not physically or psychosocially mature enough. They declined the HPV vaccination, as they believed it was the correct decision at the time and in the best interests of the daughter's health and well-being. This rationale is similar to the barriers faced by the former hepatitis B vaccination campaigns for adolescents (5,17,18). As parents are responsible for, and are the legal guardians of, the child, it is not difficult to understand that they made the choice with their child's best interests in mind (19).

There is an ethical dilemma between personal autonomy, the individual's right to make decisions and the need for societies to achieve herd immunity (20). Should the obligation to help others be more important than the

individual's right to consent or not consent to the vaccination (20)? Due to concerns for their daughters' autonomy, some parents believed that they could not make the decision to vaccinate, at least not now. Their focus was on the best interests of their child, as argued by Dawson (19,21). The interests of society at large, and the private and intimate nature of the HPV vaccination, which is a behavioural vaccine, can be difficult to accommodate (22). As the decision was considered to be a family matter, the parents felt that the common good of herd immunity was of minor interest compared with the best interests of their daughter.

The HPV vaccination was not considered compatible with some families' way of life. The parents believed that it was important to discuss alternative methods of prevention and to strengthen the girls' self-esteem and courage to wait for their first sexual experience, despite the pressure they faced from the mass media. This is discussed by Verweij and Dawson, who claim that alternative protection, such as information regarding safer sex practices, should be considered when looking at vaccines against STI (23). The information from the school health service included the information that HPV is a STI. Some parents found it difficult to recognise the benefit of the vaccination at this time, as it is a vaccine that protects girls against an infection transmitted by sexual contact. Some parents were reluctant to face the fact that their young daughter would eventually become sexually active. Yet, it is important to emphasise that the HPV vaccination is prophylactic (6). One way to bridge the gap between the parents' perceptions that their daughters are too young, and the public health perspective to achieve a high coverage rate, is to offer vaccinations later if parents were concerned about their daughter's young age. Such a strategy could improve uptake, but it would impact on the effectiveness of the immunisation programme, as vaccination prior to sexual activity is essential to prevent HPV infection.

All the parents who were interviewed were deeply affected by the mass vaccination against A (H1N1), the so-called swine flu, which coincided with Sweden's implementation of the HPV vaccination programme. Approximately 60% of the Swedish population were vaccinated, because the A (H1N1) virus was considered to pose a severe threat. Unfortunately, the vaccine had severe side effects, and a few hundred new cases of narcolepsy, many of them among children, were linked to the vaccine (24). Massive media coverage contributed to mistrust in the government's recommendation. This is quite a new phenomenon in Sweden, as the government had received almost universal trust on healthcare matters up to that point. Public trust in government recommendations is an essential factor for successful vaccination programmes, and a lack of trust can be hard to recover (23).

In contrast to another study about parental decision-making regarding the HPV vaccination (25), most of the parents in this study actively looked for information and had found out more about the vaccine. But they still did not feel they were well informed. This limited knowledge was a key factor for declining the HPV vaccination (13,14,26).

Parents wanting adequate information about the HPV vaccination had previously been pointed out as an important factor (13,27). The policy-makers are responsible for identifying risks and benefits (20) and should therefore provide adequate information (23). The distribution of more transparent, factual and unbiased information, as well as the chance to discuss the vaccine with healthcare experts and other parents, would also help to meet the parents' needs. This would hopefully regain public trust and increase vaccine coverage.

An additional strategy could be to offer more individualised vaccination opportunities to families with extra questions and concerns. This would also be an option if the child was very scared of needles and afraid of the actual vaccination procedure.

A limitation of this study was the characteristics of the informants. Most of them had a university degree and were born in Sweden. This selection bias is also found in other studies (26,27). We do not know whether highly educated parents are more or less prone to consent to HPV vaccinations, but one could assume that they are more willing to participate in interview-based studies. It might also be that more motivated parents participated. Only two parents with an immigrant background volunteered to take part. This could be due to language barriers, as the interviews were carried out in Swedish. Nevertheless, the focus in this study was parents who had not consented to the vaccination. The authors had previously explored immigrant women's beliefs and views on the prevention of HPV and found that they were strongly in favour of the HPV vaccination for their daughters (28). One reason why mainly mothers, and not fathers, volunteered to participate might be that mothers are usually the ones who decide whether their daughter will receive the HPV vaccination (29).

It was difficult to recruit parents, as the vast majority of Swedish parents accepted the need for the HPV vaccination and few volunteered to participate. The problem of recruiting parents who refuse vaccinations is well known (30). The sample was small, but as in all qualitative research, the aim is not to generalise. It is for the reader to decide whether the findings can be transferred to another context.

## CONCLUSIONS

Parents who refused to let their daughter receive the HPV vaccine preferred to wait until she was older and considered that the information they received from the school health system was insufficient. There are a number of strategies that may improve the vaccine uptake in the future. These are a more flexible vaccination schedule, more transparent information about the virus and the vaccine and information about who to contact to get the daughter vaccinated at a later date.

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