

# The domino effect: adolescent girls' response to human papillomavirus vaccination

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School-based vaccination programs are an efficient mechanism for offering protection against a variety of vaccine-preventable diseases to large cohorts of adolescents.<sup>1</sup> Historically, such programs have demonstrated both higher vaccine uptake and higher completion rates for a three-dose vaccine than are achieved by traditional vaccine delivery.<sup>1,2</sup> This is likely to be due to ease of access, as relatively few adolescents routinely attend medical clinics compared with other age groups.<sup>2</sup> Currently, Australia, Canada and the United Kingdom are offering school-based delivery of human papillomavirus (HPV) vaccine to adolescent girls, and European countries are considering or launching school-based programs.<sup>3</sup> Some countries have concerns about the acceptability to parents of mass school-based vaccination against HPV.<sup>4</sup>

During the early implementation phase of HPV vaccination in Australia, reports of fainting and of mass psychogenic reactions were widely publicised internationally.<sup>5,6</sup> Fear of vaccination, including fear of pain, was also noted in a pilot study in the UK.<sup>7</sup> Fear and collective distress in response to a perceived threat can cause headache, fatigue, hyperventilation and syncope, and females are disproportionately affected.<sup>6</sup> Symptoms can spread quickly by "line-of-sight" transmission.<sup>6</sup> Such responses are not uncommon in school settings<sup>8,9</sup> and could adversely affect attitudes toward and acceptance of HPV vaccination.

Fear and distress caused by vaccination have been assessed in children,<sup>10</sup> but not in adolescents. Mass vaccine delivery to adolescents in a school setting presents additional challenges; fear may heighten or spread as a result of rumours distorting the threat of the vaccine.<sup>5</sup>

As part of a larger study that aimed to examine experiences, decision making and factors influencing consent and vaccination uptake in the 2008 and 2009 HPV school-based vaccination program in New South Wales,<sup>11-13</sup> we present data pertaining to the experience of and response to fear, among adolescent girls being offered HPV vaccination.

## ABSTRACT

**Objectives:** To examine the experience of fear, the fear response, and factors affecting fear in adolescents undergoing school-based human papillomavirus (HPV) vaccination.

**Design, participants and setting:** A purposive sampling strategy and qualitative methods, including observation and face-to-face interviews. Focus groups comprised adolescent girls who were involved in HPV vaccination in 2007 at schools in Sydney, New South Wales. Individual interviews were conducted with parents, teachers and vaccination nurses.

**Results:** Data from observing vaccination days at three schools and from interviewing 130 adolescents in 20 focus groups, 38 parents, 10 teachers and seven nurses were included in the analysis. All participants discussed the issue of fear and distress experienced by adolescent girls in relation to HPV vaccination. Observations corroborated the focus group and interview data. Our results indicated that fear was promoted by witnessing the fear reactions of peers; perceived judgement by peers; lack of information or misinformation; and being vaccinated later in the day. Fear was moderated by procedural factors, the support of peers, appropriate knowledge, and nurses' distraction techniques or approach. Fear also affected acceptance of HPV vaccination.

**Conclusions:** Fear of HPV vaccination was a near universal experience among adolescents in the school setting and was often associated with significant distress that had an adverse impact on the vaccination process. School vaccination could be improved by proactively managing fear and distress.

MJA 2011; 194: 297-300

## METHODS

### Sample

A purposive sampling strategy was used to approach potential participants from a broad range of vaccination experiences, including those fully vaccinated, incompletely vaccinated and not vaccinated. To facilitate this, schools with high and low vaccination uptake, determined by data from the 2007 vaccination program, and schools from different sectors (public, Catholic and independent) across Sydney were approached. Ten schools were contacted and nine elected to participate; the 10th was unable to accommodate our research within the school year. The participating schools had three-dose vaccine completion rates ranging from 64% to 90% of all eligible girls.

### Ethics approval

The study was formally approved by the human research ethics committee at the Children's Hospital at Westmead and the NSW Department of Education and Training research approval board. In addition, the

study was supported by the Association of Independent Schools in NSW and the relevant local Catholic Diocese.

### Data collection

A subsample of three schools was selected for observation on vaccination days. Two researchers visited two school sites each, conducting a lone and a joint observation each, for a total of three observations. Their observations described the context, which included the environment, procedures and processes, and comments of students, teachers and nurses.

Focus groups were conducted among adolescent girls aged 12-16 years during the school year when they were offered the HPV vaccine, with each group comprising girls of similar age (eg, 12-13 years). All parents of focus group participants had received information about the HPV vaccine and had already consented to or declined vaccination. The girls had been given the opportunity to have at least one vaccine dose.

Individual interviews were conducted with parents, who were not necessarily parents of girls who participated in the focus

## 1 Number of study participants in focus groups and interviews, and number of focus groups, by school type

Type of school (no.)	Adolescent girls (no. of focus groups)	Parents	Teachers	Nurses*
Catholic (3)	53 (7)	12	4	na
Independent (3)	35 (6)	15	3	na
Government (3)	42 (7)	11	3	na
<i>Total (9)</i>	<i>130 (20)</i>	<i>38</i>	<i>10</i>	<i>7</i>

na = not applicable. \* Total only given, as nurses were employed by an area health service and did not belong to a particular school.

groups. Interviews were also conducted with teachers and vaccination nurses. Focus group and interview prompts were informed by the literature and, subsequently, by data analysis in a dynamic way to ensure all potential themes were explored.

The following topics were explored in relation to HPV and HPV vaccination: attitudes, decision-making processes, knowledge and understanding, experience of vaccination, discussion with family and friends, and any questions and concerns raised by participants. Examples of prompts used included, for adolescents, "Can you tell me about what happened when you went to have the vaccine?", and for teachers, "How do the students in your school respond to the vaccine program?"

### Data analysis

Focus groups and interviews were digitally recorded, transcribed verbatim, and analysed using the qualitative software package QSR NVivo 7 (QSR International, Melbourne, Vic). Two of us (DMB, SCCR) completed the primary analysis, using an inductive approach and constant comparison.<sup>14</sup> Conceptual saturation was reached when no new codes were generated.<sup>15</sup> Details of our analytical approach have been published previously.<sup>11</sup>

## RESULTS

Data from observing three schools and from interviewing 130 adolescents in 20 focus groups, 38 parents, 10 teachers and seven nurses were included in our analysis (Box 1). Quotations given in the following sections are followed by code letters denoting schools, and the number of the focus group (FG) or nurse interview (N).

### Experience of fear

Fear was a common emotion experienced with regard to vaccination. The girls' fear

consisted of three main features: fear of pain, fear of having the needle pierce the skin, and fear of vaccine content and possible side effects. Parents were often aware of their daughters' fear and some had discussed it with their daughters. Other parents did not have a discussion or expected the school to address this issue.

Fear of pain was the most frequent concern mentioned, and this fear was often specific to HPV vaccination. Most girls believed that HPV vaccination hurt more than other vaccinations. This was consistent for vaccinated and non-vaccinated girls.

Girls were also fearful of the moment when the needle would pierce the skin. They were especially fearful of the sensation associated with the vaccination.

I really have a phobia of needles. It's just the way they feel when they go into you and you feel the actual liquid going in ... (I, FG 2)

Fear of the vaccine's content and side effects was linked to possible short-term side effects, such as fainting, as well as potential longer-term adverse reactions.

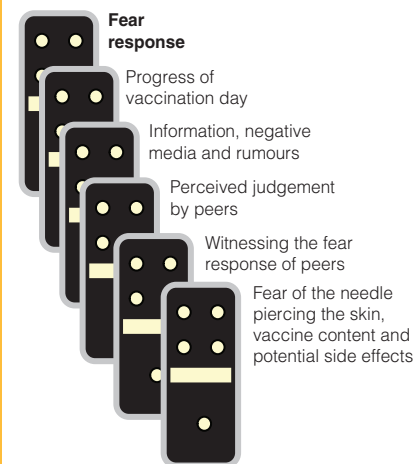
### Intense fear reaction

Girls, parents, teachers and nurses all discussed the intense fear response of some girls to vaccination. Our observations supported statements that some students experienced a more severe reaction than others, which included sobbing, screaming, and fainting. One adolescent's intense reaction seemed to lead to others experiencing this same intensity.

We saw these two people ... pouring their eyes out and so our class got ... freaked out ... Like, "Are we going to get hurt?" So we were all ... really scared and everyone was crying and getting all nervous. (D, FG 2)

Parents talked about the intense fear reactions of their daughters and of other adolescent girls, as described by their daughters.

## 2 Factors promoting a fear response in adolescent girls offered human papillomavirus vaccination



Themes mitigating fear are not included in this figure, and girls did not necessarily progress through all of these to an intense fear response.

Teachers also discussed how girls' fear responses exacerbated the responses of their peers, suggesting that girls were most stressed when waiting in large groups for vaccination. Teachers explained that some were so anxious while waiting that they intentionally left the vaccination area before being vaccinated. These girls may or may not have received the vaccine at a later time.

Nurses commented on how girls could influence one another:

One girl fainted, [and] we had gym mats, and because one went down, girls asked, "Oh, could you vaccinate me lying down please?" and so it really was a domino effect. The entire year had heard what was going on. (N 4)

### Factors affecting fear

Factors both promoting and mitigating fear were identified; some factors influenced fear in more than one direction (Box 2).

#### Witnessing the fear response of others

Use of privacy screens and the number of girls waiting in an area before vaccination were important procedural factors.

Some schools assembled large groups of girls to be vaccinated. This meant that girls waited together for long periods, which appeared to cause greater collective anxiety and fear.

When we had the whole year down there, I thought people got more scared,

because everyone was talking about how it was and stuff. (C, FG 2)

Vaccinations usually took place in a large room with a separate entrance and exit. Some schools positioned a screen at the entrance so the waiting group could not watch the process.

Lack of privacy screens was observed to exacerbate fear as it provided an opportunity for line-of-sight transmission of anxiety. While girls were generally not permitted into the vaccination area until immediately before being vaccinated, some amount of vaccination preview occurred: either immediately before being vaccinated, or by girls prematurely trying to gain access into the vaccination area.

The disadvantage [of school versus a private doctor] is that you see other people really traumatised ... they are really scared and they all start freaking out. Your heart just starts racing and it's like you are scared and you don't want to get it done either. (I, FG 1)

#### **Perceived judgement by peers**

Concern among girls about their possible reactions in front of their peers seemed to amplify fear in some cases.

I was really scared that I'd faint and everyone would laugh at me. (C, FG 2)

Some students, although admitting to being fearful, were able to suppress the expression of their fear, as they were extremely concerned about their peers judging them.

You put on a brave face when you are 'round your friends. You will try not to cry, and say it doesn't hurt, when you are with your friends. (B, FG 1)

#### **Information, negative media and rumours**

A few girls who had read the parent information brochure said that reading about possible side effects made them more fearful.

I know the side effects are, like, good to have on the sheet so it can warn you, but then when girls heard about it they got even more scared. (D, FG 2)

Most girls knew very little about the vaccine, and their fears were often intensified by rumours or misinformation from friends, relatives and the media. Many rumours about extreme side effects and adverse reactions specific to the HPV vaccine circulated among the girls. Parents commented on the rumours they felt triggered their child's intense fear response: for example, a rumour about someone who had died after having received the HPV vaccine.

Many girls described how an understanding of why they were being vaccinated and of the benefits of HPV vaccination would help to reduce their fear.

Well if I know what it [the vaccine] is, or what it's actually doing to me and it's good, then I would take it, like, I would do the dose. (G, FG 2)

Nurses agreed that lack of information played a role in girls' responses to vaccination. They suggested that parents who discussed the vaccination helped to prepare their adolescent for the experience.

#### **Support of peers**

Many girls discussed the benefit of having their friends available in the room to support them by holding their hand or talking to them.

It was just all the girls and it was like everyone supporting each other and stuff. If you were anxious, you had your mates there holding your hand. (H, FG 1)

#### **Nurses' interactions with girls**

Girls discussed distraction techniques that nurses used and how these helped to make the girls feel more comfortable.

It's better when [the nurses] talk to you because then you're distracted ... They had some balls and they gave you one of those to squeeze and you didn't feel the needle going in. (E, FG 2)

Schools had different policies about what distraction methods were appropriate. For example, certain schools allowed the use of iPods during vaccination days, while other schools did not. Some nurses used creative puzzles or different distraction tactics to soothe girls' anxieties.

Girls in a selection of schools reported how negative interactions with nurses increased their fear.

The nurses could be nicer. They were mean. Like, we were there and we were scared ... shaking, and they go, "If you are not going to sit here and get it done properly, you can go to the doctor's" ... like, really forceful. (C, FG 2)

#### **Time of day**

Our observations indicated that girls who were vaccinated in the morning were calmer on entry to the vaccination room than those vaccinated later in the day. In the afternoon, many girls were sobbing even before entering the room. This appeared to be due to conversations held while they waited: about whether the vaccination was painful, girls having fainted and certain nurses having

caused more pain than others. As the day and rumours progressed, many girls' fear increased. Additionally, the time taken for nurses to vaccinate each girl lengthened over the course of the day.

## **DISCUSSION**

Our results suggest that anxiety related to vaccination at school is commonplace for adolescent girls, and this was evident for HPV vaccination.

While anticipatory fear is associated with vaccination in other settings,<sup>16</sup> anticipatory and experienced fear may be particularly intense for girls vaccinated in a school setting. Severe responses, such as mass psychogenic reactions that have been seen in mass vaccination settings,<sup>6,17-20</sup> were not noted in our study. Our data suggest that when anxiety and fear were at increased levels, the process of vaccination either slowed or did not occur.

In this study, fear seemed to be linked to anticipatory anxiety, which can be an important predictor of perceived pain in children and adolescents.<sup>21</sup> Fear of the needle piercing the skin, watching a nurse prepare an injection, and observing others receiving injections have been associated with increased anxiety in other settings.<sup>16</sup>

Methods of soothing younger children receiving venepuncture include having a parent present,<sup>22</sup> but our research suggests that in school-based vaccination, appropriate peer support may assist some girls. Peers are extremely important for adolescent girls as a source of support and as a preferred resource for dealing with health concerns.<sup>23,24</sup>

Other effective interventions used for management of pain and distress are distraction and cognitive behaviour interventions.<sup>25-27</sup> Our research indicated that wider use of distraction methods, such as allowing girls to listen to iPods, could be effective.

A nurse's approach while providing vaccination can affect a vaccine recipient's response. An empathic approach elicits more positive behavioural responses than a directive approach.<sup>28</sup> This supports our study's findings that girls' perceptions of the nurses' approach contributed to their experience. It may be appropriate for some vaccination nurses to receive training in managing adolescents' fears related to vaccination.

Preparation for injections and vaccinations can result in lowered perceptions of pain.<sup>29</sup> Our data suggest that being informed and well prepared may reduce the

propagation of myths, rumours and other fear-promoting factors. This would then reduce fear and, potentially, refusals of vaccination. Appropriate education for girls, either through discussions with parents, teachers and nurses, or through specifically designed educational and self-management strategies, may provide adolescents with a more positive experience of vaccination.

Anticipatory fear is a normal response to a perceived threat,<sup>30</sup> but is an unnecessary psychological trauma when no real threat exists. Vaccination providers have a clinical, moral and ethical obligation to minimise the anxiety and pain associated with vaccine delivery.<sup>31,32</sup> Guidelines have prioritised preventing and treating procedural pain and anxiety related to medical procedures in children and adolescents.<sup>33</sup> Given the nearly universal finding of fear in this study, these should be priorities for school HPV vaccination programs. Mitigating girls' experience of fear is likely to promote acceptance of the vaccine and improve the efficiency of the vaccination process. Promoting higher levels of understanding, offering peer support, and careful examination of procedural factors that alleviate distress during vaccination at school should be considered, particularly as school-based vaccination becomes more common internationally.

## ACKNOWLEDGEMENTS

We thank NSW Health for their cooperation with this study and their invaluable advice and feedback on the results. We acknowledge CSL Ltd, Australia for partial funding of this research, in the form of an unrestricted research grant. We acknowledge the invaluable input of the parents, adolescents, teachers and nurses who participated in this study, and each of the schools that allowed the onsite research to be undertaken.

## COMPETING INTERESTS

Spring Cooper Robbins has received travel grants for meetings organised by CSL. Kirsten McCaffery has received a speaker's fee from CSL and a consultancy fee from GlaxoSmithKline (GSK). Rachel Skinner has received travel and research support from GSK and CSL to attend conferences to present data, and in the past has received honoraria from GSK and CSL for participating on advisory boards and educational seminars. She has been principal investigator for GSK on clinical trials of their HPV vaccine.

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(Received 10 Aug 2010, accepted 19 Dec 2010) □