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Adolescent-Parent Dyad Descriptions of the Decision to Start the HPV Vaccine Series

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Introduction

The human papillomavirus (HPV) is the most common sexually transmitted infection in the United States (U.S.) for both females and males.¹ Over half of high school seniors in the U.S. report ever having sexual intercourse which puts adolescents at risk for HPV infection.² Clinical trials have demonstrated the safety and efficacy of the HPV vaccine which has been licensed in the U.S. to prevent genital warts in females and males; HPV-caused cervical, vulvar, vaginal, and anal cancer in females; and anal cancer in males. HPV is also associated with other genital and oropharyngeal cancers. Despite national guidelines for routine administration to adolescents in order to reduce the burden of disease, HPV vaccination rates remain low among both females and males, particularly in comparison to other routine adolescent vaccinations.³ There are numerous barriers to adolescent vaccination against HPV including lack of a strong provider recommendation, parental fear of side effects, parental uncertainty about vaccine safety and effectiveness, and lack of parent understanding about HPV infection.^{4–6}

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It is known that a strong provider recommendation^{7–11} along with the use of presumptive language¹² is persuasive and critical for HPV vaccine uptake among adolescents. The Centers for Disease Control and Prevention has recognized this fact and has developed resources for providers to help strengthen their communication regarding this vaccine.¹³ In order to enhance efforts to foster effective communication between providers and families, it is useful to understand how parents and their adolescents who received the HPV vaccine viewed the decision-making process. Previous research shows that adolescents and parents view their individual role in HPV vaccine decision-making differently.^{14–16} Respecting both parental authority and adolescent autonomy could make it challenging for a provider to make a strong recommendation to both at the same time.

Thus, we sought to examine how adolescents and their parents describe decision-making regarding initiation of the HPV vaccine series. We specifically analyzed these descriptions with regards to who they viewed as making the final decision.

Materials and Methods

Settings and participants

As part of a larger study, participants were approached in the adolescent medicine clinics of two large urban medical centers and through snowball sampling (in which an individual is referred to the study by a current study participant). Adolescents 14–17 years of age and one of their parents or legal guardians were eligible to participate if they spoke English or Spanish and both agreed to participate. The study was approved by the Institutional Review Boards of Columbia University Medical Center and Weill Cornell Medical College and all participants provided written informed consent/assent. The primary purpose of the parent study from which this data was drawn was to evaluate willingness to participate in a hypothetical clinical trial examining the safety of a topical microbicide for sexually transmitted infections/human immunodeficiency virus (STI/HIV) prevention.^{17–19} For the present study, we focused on the questions related to decision-making regarding the HPV vaccine.

Procedures

At baseline, simultaneous interviews were conducted with each adolescent and his/her parent separately. Adolescents and parents were interviewed in either English or Spanish by trained research assistants. Dyad members were individually asked: “*The HPV vaccine series is now offered starting at 11 years of age for both males and females. Have you ever been offered the HPV vaccine series?*” If the individual responded “yes”, they were asked if they started the series and then asked: “*How did you make a decision about whether or not to receive the HPV vaccine series?*” Responses that were given in Spanish were translated into English. For the purposes of the qualitative analysis, we only included those dyads who agreed that they were offered and started the HPV vaccine series.

Analysis

Descriptive characteristics included adolescent and parent demographics, adolescent sexual histories and the parent’s perceptions of the adolescent’s sexual experience. We then

determined the degree of concordance in adolescent-parent dyads about whether or not the adolescent had been offered the HPV vaccine series and then if offered, if they decided to start the series. In the results, we provide representative quotes and identify adolescent subjects by age in years (y) and gender, denoted as “M” for male and “F” for female. Parent quotes are identified as the adolescent’s mother or father.

Qualitative Coding

The responses to the question, *“How did you make a decision about whether or not to receive the HPV vaccine series?”* were coded for each individual member of the dyad, in those dyads in which both agreed the series had been started. This allowed for comparison between adolescent and parent responses. All answers were coded independently by two coders and disagreements were resolved through consensus.

Adolescents’ and parents’ answers were coded individually for the final decision-maker. The final decision-maker was coded as adolescent or parent (*“I made the decision. Doctor spoke to me about the vaccine.”*), or joint decision-making (*“The doctor explained the dangers to us and we [my daughter and I] both agreed to get the vaccine for prevention.”*). Dyads were also coded for the similarity of the account or “story” irrespective of the coding of the final decision-maker. Finally, the spontaneous mention of a health care provider was coded in order to explore the salience of the health care providers in decision-making.

Results

Participants

There were 262 adolescent-parent dyads from unique families who were asked questions about the HPV vaccine. The demographic characteristics of the sample are presented in Table 1.

Forty-six percent of adolescents reported they were offered and started the HPV vaccine series. Seventy-eight percent of parents reported they were offered and started the HPV vaccines series for their adolescent. Forty-two percent (n=109) of adolescent-parent dyads agreed that they were offered and started the HPV vaccine series. There are no demographic or sexual behavior differences between the 109 dyads compared to the larger group of 262 dyads. In six dyads, either the adolescent or the parent gave a response that was not able to be coded, for example, stating *“I don’t remember.”* Since we were interested in dyadic analysis, in those cases, we excluded these dyads from analysis. Thus, for purposes of qualitative analysis, we analyzed 103 dyads.

Vaccine decision-making

In four of the dyads, either the adolescent (n = 3) or both adolescent and parent (n = 1) reported that the decision was made by the doctor and did not mention the involvement of the adolescent or parent. In the most extreme case, both reported vaccination despite vaccine refusal. The adolescent (17 y, F) said, *“When they offered it, my mom and I both said no but they gave it to me anyway.”* Her mother said, *“...I said we would discuss it. However, they*

just gave her the shots without my decision.” It is certainly hoped that this is not what actually happened; however, it is concerning that this is the family’s perception of the event.

Of the 99 remaining dyads where both adolescent and parent responses indicated at least one of their involvement, 43 dyads (43%) agreed on who made the decision (adolescent, parent, or jointly); 56 dyads (57%) did not agree on who made the decision (see Table 2).

Among the 56 dyads who did not agree, there were 13 dyads in which the parent described a joint decision, but the adolescent stated it was the parent’s decision. For example, in one dyad, the mother said, *“Just talked about it and doctor told me more about it and we decided to go for it. We made the decision together,”* but the adolescent (17 y, F) said, *“My mom just told me you gotta go to the doctor and I found out then. Pretty much it was my mom telling me.”*

In 10 dyads, the parents reported making the decision yet the adolescent viewed him/herself as having made the decision alone. For example, one mother said, *“... I thought yes since he had started having sex. I explained it to my son but it was my decision,”* and the adolescent (17 y, M) said, *“... they asked me if I wanted to get it and I said yes.”*

There were 20 dyads where the parent stated he/she was the one who made the decision but the adolescent described it as a joint decision. For example, one parent said, *“I made the decision. Doctor spoke to me about the vaccine and it was for my son’s protection,”* and her son (16 y, M) said, *“The doctor said it was to protect against something. I forgot but I took it just in case. My mom was there with me. We both agreed.”*

There were 11 dyads where the parent described a joint decision, but the adolescent felt it was he/she who made the decision. For example, one parent said, *“I thought about it future-wise, whenever she does become sexually active, and god forbid the condom breaks or whatever, at least she’s protected in some way... it’s kind of scary. It was a joint decision.”* Her daughter (16 y, F) said, *“Well I was a little undecided because I don’t like shots but I know HPV is a big deal now and everyone has it so I talked to my mom about it and she let me decide...I had the final say.”*

Similarity of the adolescent’s and parent’s “story”

Many adolescent-parent dyads were consistent in the description of the “story” of decision-making and the decision maker ($n = 44$). For the remaining dyads, most described the same story with a different decision-maker ($n = 47$). For example, an adolescent (17 y, M) said, *“The doctor bring it up and I decided to get it.”* His mother said, *“The pediatrician told me and we talked about it. The doctor discussed it with me and him and they were offering it to boys and felt it was a good thing to take it.”* For a minority of dyads, the adolescent and parent appeared to be describing very different scenarios ($n = 12$). For example, an adolescent (17 y, F) said *“I got it in school. I had to do it. I didn’t discuss it with my parent.”* Her father said, *“I discussed it with her doctor, and then briefly discussed with my daughter. She agreed to it.”* Stories also varied based on very different descriptions of who was involved in the discussion or present when a decision was made. For example, an adolescent (16 y, M) said, *“Me and my mom discussed it together and we decided that I should get it.”*

His mother said, “*It wasn’t discussed with me; it was a discussion between him and his pediatrician. Generally the pediatrician asks me to leave and they talk amongst themselves so his decision.*” These differences often related to the inclusion by one member of the dyad of an additional source of information such as an extended family member or outside health care professional.

Mention of the health care provider in description of the decision-making

Of the 103 dyads, 56 (54%) adolescents and 59 (57%) parents mentioned the provider in their description of the HPV vaccine decision-making process. In 49 dyads (48%), both adolescent and parent mentioned the provider. In 22 dyads (21%), neither mentioned the provider.

Among those who mentioned the provider, not all made it clear that the provider had made a recommendation such as when an adolescent (15 y, M) said, “*The doctor asked if I’d had it yet and explained what it was. She asked me if I wanted it and I said yes.*” In other cases, the provider was described as making a clear recommendation that was followed such as the adolescent (16 y, M) who said, “*I was at the doctor for something else and the doctor said you should get it.*”

In dyads in which only one member mentioned the provider, it seems likely that the provider’s recommendation may have had a direct impact for that individual. For example, in one instance, a mother indicated that the doctor’s recommendation was key to her decision-making and the adolescent was following the mother’s lead. The mother said, “*Listening to the doctor, that it was good for her health or something like that, to avoid future diseases. The decision was mine.*” Her daughter (15 y, F) said, “*It was actually up to my mom. We didn’t discuss it. She had the final say.*” In another dyad, the adolescent mentioned the provider and the parent did not. The adolescent (16 y, M) said, “*The doctor said I needed it so I got it,*” and his mother said, “*We talked about it amongst ourselves, his father and I. We weighed the pros and cons and we discussed it with him.*”

Discussion

The findings of the current study add to our understanding regarding the decision-making process of adolescents and their parents around the decision to start the HPV vaccine series. Among those adolescents and parents who agreed the vaccine series had been offered and started, most described the same story of the decision-making experience though the interpretation of the event was often slightly different. One of the ways their interpretation slightly varied was that over half (57%) of the dyads did not agree on who made the decision to start the vaccine series. Most of the time, these differences reflected understandable variations in interpretation of the event. They may have reflected a lack of communication from the parent to the adolescent regarding his/her process of coming to a decision (such as the role of the provider in the decision-making), other times it may have reflected either an adolescent wishing to assert his/her autonomy, or a parent granting autonomy to the adolescent. These differences in parent and adolescent interpretation of events were not related to vaccination outcome as all of these adolescents were immunized, but may be

helpful to providers in promoting decision-making and engaging both adolescents and parents in the process.

However, it was also true that among adolescent-parent dyads, there were cases of disagreement in their recall as to whether or not the HPV vaccine was initiated. This finding highlights the importance of patient immunization registries²⁰ to avoid duplication of vaccination, as many adolescents and parents do not agree in their recall of whether or not they received the vaccine. Another important finding is the potential for dramatic differences in adolescent and parent descriptions of the encounter, despite agreement that the vaccination occurred, as in the case of the dyad who disagreed as to where the vaccination had taken place (school vs. clinic).

Patient-centered care is associated with positive health outcomes including treatment adherence and satisfaction with care.^{21–23} In order to deliver effective patient-centered care to adolescents, providers should have a clear understanding of both adolescent and parent desires and expectations. Britto and colleagues²⁴ found that adolescents' priorities in the health care setting include honest provider communication and the ability to participate in their own care and have their viewpoints and concerns taken seriously. Adolescent-centered care models^{25–26} would support that both adolescents and parents should perceive themselves as dynamic participants in the vaccine decision-making process.

We know that health care provider recommendation and attitude play a key role in HPV vaccination.^{7–11} Rahman and colleagues⁹ found that health care provider recommendation independently predicted HPV vaccine initiation and completion. In our dyads, only a very few suggested that the provider had made the decision without their involvement. On the other hand, in only 22% of the dyads was there no mention of the provider in the adolescent or parent response despite it not being queried. It is possible that if we had specifically asked about the role of provider, we would have a greater number who described the provider as making a clear recommendation given that the participants were recruited from adolescent medicine clinics.

The range of adolescent and parent descriptions found in our study illustrates the complicated and dynamic process of decision-making in health care settings. Additional mixed-methods research is needed to further understand vaccine decision-making and address the high-risk group of under-immunized children and adolescents. For instance, research methodology that assesses not only the strength of the provider recommendation, but also the adolescent and parental perception of this process would advance our understanding.

Interventions are needed to engage adolescents in the decision-making process and to encourage adolescent-parent communication regarding this decision. Understanding the range of descriptions of these dyads is helpful to guide interventions to promote vaccine uptake in a manner that balances provider expertise, adolescent autonomy, and parental involvement.

This study is not without limitations. Since study participants were recruited from adolescent medicine clinics with trained adolescent medicine providers, vaccine rates may be higher

than the national average. In addition, the timing between the interviews and when the adolescent received the vaccine varied. There may have been difficulty with recall of the event in some cases. We chose to focus on those dyads who agreed they started the HPV vaccine series; dyads who disagreed and adolescents who did not start the series may have had different perspectives on decision-making roles. Finally, the adolescent-parent dyads were recruited together into a larger study therefore the dyads comprising our sample may have some degree of communication and cohesion that may differ from other adolescent-parent dyads. It is reasonable therefore to consider that our findings are potentially biased toward agreement and yet, less than half of the dyads agreed that they started the HPV vaccine series. Even lower rates of concordance may be found among dyads recruited more broadly.

Despite limitations, these findings can help providers develop ways to talk to adolescents and parents and ensure that vaccine decision-making is a positive experience for both. Future research should further investigate dyadic descriptions of adolescents' and parents' decisions surrounding HPV vaccination and specifically inquire about the relative influence of various factors, including the provider's recommendation on decisions to initiate or not initiate the series.

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Table 1

Sample Characteristics of 262 Adolescent-Parent Dyads

Characteristic	% (n) or Mean (SD)
<i>Adolescent</i>	
Age	15.5 (1.1)
Gender (female)	61 (160)
Ethnicity (Hispanic)	68 (179)
Lack of sexual experience (no experience beyond kissing)	65 (170)
<i>Parent</i>	
Gender (female)	92 (241)
Ethnicity (Hispanic)	71 (185)
Perceived level of adolescent sexual experience:	
No experience beyond kissing	47 (123)
Sexual contact beyond kissing	25 (66)
Don't know	28 (73)

Table 2

The Final HPV Vaccine Decision-Maker

		Adolescent Report			
	Who made the decision?	Adolescent	Parent	Joint	Provider
Parent Report	Adolescent	1	-	2	-
	Parent	10	21	20	2*
	Joint	11	13	21	1*
	Provider	-	-	-	1*

* adolescent and/or parent stated the provider made the decision, without involvement of the adolescent or parent