Published in final edited form as:

Qual Health Res. 2016 May; 26(6): 842–850. doi:10.1177/1049732315575712.

Parents' Recall and Reflections on Experiences Related to HPV Vaccination for their Children

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Abstract

Human papillomavirus (HPV) vaccination coverage remains suboptimal in the United States. We conducted in-depth interviews with parents of adolescents from an urban primary care center serving a low-income minority population to describe their experiences. We identified the following themes: (a) parents of unvaccinated children generally had not discussed the vaccine with providers and had low awareness; (b) among unaware parents, provision of brief information generally resulted in positive comments about the vaccine; (c) vaccine was typically not requested by parents but rather offered by providers; (d) strength of the recommendations from providers varied, and vaccine was sometimes presented as optional or low-priority; (e) parents had low awareness of the 3-dose regimen and poor recall about completion; and (f) limited understanding of why boys should be vaccinated. More than seven years after introduction of HPV vaccine, there is substantial room for improving the way it is recommended and discussed by providers.

Keywords

human papillomavirus; immunization; health care; pediatrics; qualitative analysis; barriers

Human papillomavirus (HPV) is the most common sexually transmitted infection in the US and a substantial cause of morbidity. An estimated 79 million people are currently infected and 14 million new infections occur every year (Satterwhite et al, 2013). Up to 80% of sexually active individuals acquire an HPV infection at some point during their lifetime, including 50% from their first sex partner (Syrjänen, Hakama & Saarikoski, 1990; Winer, Lee, Hughes, Adam, Kiviat,& Koutsky, 2003). Many infections are asymptomatic and transient, but persistent infection can result in six different types of cancer. Infection with a

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Declaration of Conflicting Interests

Dr. Niccolai has received consulting fees from Merck.

high-risk type is a necessary cause of cervical cancer and HPV infections are further associated with anal, oropharyngeal, penile, vaginal, and vulvar cancers (Munoz et al, 2003; Jemal et al, 2013).

Prevention of HPV infections and related diseases is possible with two vaccines that are approved in the US and recommended for routine use in adolescents (Centers for Disease Control and Prevention, 2011; CDC, 2010). Despite proven high efficacy (Schiller, Castellsague, & Garland, 2012) and safety (CDC, 2013a), uptake remains suboptimal with only 38% of adolescent females and 14% adolescent males having completed the 3-dose series (CDC, 2014). Coverage is lower than for other vaccines recommended for adolescents to prevent tetanus, diphtheria, and pertussis (86%) or meningococcal disease (78%). Uptake also lags substantially behind that of other industrialized nations. Adolescent females in Australia, Denmark, and England, countries with national HPV immunization programs, have more than 70% coverage with all three doses (Gertig, Brotheron, & Saville, 2011; Baandrup, Blomberg, Dehlendorff, Sand, Anderson & Kjaer, 2013; Public Health England, 2014).

An extensive body of research has documented barriers to uptake of HPV vaccine. The results of these studies have been summarized in numerous review articles (Hendry, Lewis, Clements, Damery & Wilkinson, 2013; Holman, Benard, Roland, Watson, Liddon & Stokely, 2013), and several key issues have emerged (Zimet, Rosberger, Fisher, Perez & Stupiansky, 2013). First, parents' knowledge about HPV and HPV vaccine remains limited and often includes misinformation that creates barriers to vaccination. For example, not knowing about the vaccine, believing the vaccine is not needed, and having concerns about vaccine safety, efficacy, or impact on sexual behavior are cited as the most common reasons parents have not vaccinated their children (Kester, Zimet, Fortenberry, Kahn & Shew, 2013; Dorell, Yankey, Santibanez & Markowitz, 2011; Laz, Rahman & Berenson, 2012). Second, recommendations from health care providers are an important factor in HPV vaccine coverage. Results from both national surveys and targeted populations in high-risk areas revealed lack of health care provider recommendation as a major barrier (Dorell et al, 2011; Brewer, Gottlieb, Reiter, McRee, Liddon, Markowitz & Smith, 2011). This is important because in the US, immunizing adolescents is heavily reliant on physician visits in a health care setting. The US does not have a national immunization program, and use of alternate sites (e.g., schools) has been explored in only a relatively small number of local demonstration projects (CDC, 1996). Similar findings about the importance of health care provider recommendations have been reported from the majority of high-income countries that were studied in the regions of North America, Western Europe, and Australia. Finally, logistical obstacles to vaccination exist that reflect challenges with health care utilization more broadly including lack of a regular medical home or recent health care visits and not having health care insurance (Dorell et al., 2011; Moss, Gilkey, Reiter & Brewer, 2012; Perkins, Brogly, Adams & Freund, 2012).

Unfortunately, after more than seven years of vaccine availability in the US, uptake has stagnated and new approaches are needed. We are not aware of any studies that have explored parents' recall of and reflections on their children's HPV vaccination experiences. A better understanding of these experiences including specific recommendations from

providers may shed light on salient or additional opportunities to increase coverage. The purpose of this qualitative study was to address this gap in knowledge by specifically eliciting recall of previous experiences (or lack thereof) to move beyond asking only about knowledge and attitudes. We used in-depth interviews to reveal how participants experience and interpret HPV vaccination visits with their children and the meanings that they attach to those experiences (Ulin, Robinson & Tolley, 2005). This primarily descriptive and exploratory qualitative approach, in contrast to other qualitative approaches (Patton, 2002; Guest, MacQueen & Namey, 2012), was chosen to establish observable and verifiable patterns in recalled experiences and subjective meanings in order to deepen our understanding of barriers to vaccination while allowing for new ideas about barriers to emerge.

Methods

This work was grounded in Ecological Systems Theory (Bronfenbrenner, 1979; US Department of Health and Human Services, 2005) that puts forth the idea that human development and health are affected by interactions across multiple levels of influence including individual, interpersonal, community, and social factors. We hypothesized that HPV vaccination would be influenced by factors at each level including, but not limited to, knowledge, awareness, and attitudes about HPV vaccine (individual level), interactions with health care providers (interpersonal level), access to health care (community level), and social norms and media messages (societal level). In particular, at the individual level, we relied on the Health Belief Model (Becker, 1974) to assess knowledge about susceptibility and severity of HPV infections and perceptions of the barriers to and benefits of HPV vaccination. We chose this model because it is widely used in public health and because of our interest in focusing on the role of personal beliefs in health behaviors.

For this study, we enrolled a sample of parents or caregivers (subsequently referred to as 'parents') of adolescents, regardless of HPV vaccination status, who receive primary care at an urban hospital-based outpatient clinic in the northeastern United States. This study was focused on low-income racial and ethnic minorities that are served by this clinic to address important health disparities in HPV-related disease. National prevalence studies show that HPV infections are most common in black and low-income women (Hariri, Unger, Sternberg, Dunne, Swan, Patel & Markowitz, 2011). Disparities also exist in precancerous cervical lesions caused by HPV and extend to the 'cancer disparities grid' in which racial/ ethnic minorities and women living in poverty bear a disproportionate burden of cervical cancer incidence and mortality (Newmann & Garner, 2005; Niccolai, Julian, Bilinski, Mehta, Meek, Zelterman, Hadler & Sosa, 2013). Previous analyses from this study revealed that this population has generally favorable attitudes to HPV vaccination and infrequent refusals (Niccolai, Hansen, Credle, Ryan & Shapiro, 2014).

An a priori sample size of 30–40 was selected based on recommendations for qualitative studies of this nature (Patton, 2002; Gorbach & Galea, 2007) and the anticipated complexity and desired level of depth for our research questions. Parents were eligible to participate if they had a child between the ages of 10 and 18 years (ages of children seen at this clinic that include those for whom the vaccine is approved). Purposive sampling was conducted to

ensure representation of a broad range of experiences and to examine possible differences by race/ethnicity (the vast majority of patients at this clinic are low-income). Specifically, we sought to ensure near equal participation by black and Hispanic parents by monitoring enrollment as recruitment progressed and subsequently targeting recruitment as needed. Participants were recruited by approaching parents in the clinic waiting area and provided with a brief verbal description of the study. If they were interested to participate, they provided written informed consent, and received a \$20 gift card upon completion of the interview. This amount was decided by the clinic's operations committee who deemed it comparable to other similar studies with no previous evidence of undue influence on patients' decisions to participate. Study procedures were approved by the university institutional review board and data were collected during May 2013 – January 2014.

We designed a semi-structured interview guide with open-ended questions to elicit discussion about parents' recall of and reactions to their children's HPV vaccination. The guide was developed to address our conceptual frameworks of the Ecological Model and Health Belief Model. Topics related to each level (e.g., individual knowledge and awareness, interpersonal experiences with health care providers, ease or difficulty accessing health care at the clinic, and importance of social norms about vaccination) were presented at a scientific advisory board meeting consisting of local experts in pediatric and adolescent medicine, childhood immunizations, and community-based participatory research. Feedback was solicited and incorporated to the guide. The guide was subsequently pilot tested with parents during preliminary interviews and revised in an iterative manner. The interview began with general questions about parents' knowledge about HPV, HPV vaccine, and their children's HPV vaccination status. Those who reported having unvaccinated children were asked about the reasons. Those who reported having vaccinated children were asked to describe what they remembered about the experience and challenges they may have faced. The guide also included probing questions that could be used for follow-up of each question to allow collection of more detailed and informative responses. Interviewers included three of the authors who were trained in the use of the guide for this research project as well as how to build rapport, establish a conversational style, probe as needed, and remain neutral and non-judgmental. Materials were translated into Spanish for use with non-English speaking participants by a professional translator. Interviews with Spanish-speaking participants (n=8) were conducted with the assistance of confidential hospital interpreter services or a bilingual native Spanish speaker. Interviews were translated to English during the interview for audio-recording and transcripts were prepared in English. Interviews were conducted in dedicated research spaces at the hospital and lasted a median of 28 minutes. Refusals to participate were not systematically recorded but parents who declined the interview generally cited lack of time or interest.

Interviews were audio-recorded and transcribed verbatim for thematic content analysis using an established approach to identify themes, or patterns of implicit and explicit ideas, within the data (Guest, et al., 2012; Miles & Huberman, 1994). Our initial analysis involved multiple readings of the interview transcripts and discussions among members of the research team to review early impressions and identify emergent themes. Based on these discussions and questions in the interview guide, an initial codebook was developed and used to code all interviews using ATLAS.ti 7 software (ATLAS.ti Scientific Software

Development GmbH, Berlin). We discussed coded transcripts in an iterative manner to ensure general agreement about the meaning of codes and to continue identification of emergent patterns and themes. Data displays for relevant codes were generated through code reports that gathered all narratives on relevant codes to be reviewed both across and within transcripts. We reviewed these reports to confirm identified themes that described topics under study in a way that could be meaningfully categorized and defined. Interim analysis after approximately half the interviews had been coded and reviewed (n=22) revealed emergent themes that did not differ substantially from the final data set suggesting saturation had been approached.

Results

The sample (n=38) included 33 parents, 4 grandparents, and 1 step-parent. The sample was predominantly female (n=31) and black (n=18), Hispanic (n=13) or mixed race/ethnicity (n=4). Ages ranged from 31 to 63 years. Participants had a total of 61 children (28 girls, 33 boys) between the ages of 10 and 18 years with all ages represented in the sample.

The following themes emerged and each is discussed below: (a) parents of unvaccinated children generally had not discussed the vaccine with providers and had low levels of vaccine awareness; (b) among vaccine-unaware parents, provision of brief information generally resulted in increased enthusiasm about the vaccine; (c) when discussed, the vaccine was typically not requested by parents but rather offered by providers; (d) strength of the recommendations from providers varied, and vaccine was sometimes presented as optional or low-priority; (e) parents had low awareness of the 3-dose regimen and poor recall about completion; and (f) parents expressed limited understanding of why boys should be vaccinated. After identification of these six themes, transcripts were re-reviewed by race/ethnicity of participant to identify if there were patterns in divergent opinions; systematic variation between black and Hispanic participants, the two groups of primary interest, was not observed.

Lack of Provider Discussion with Parents of Unvaccinated Children

Most parents who reported their children had not been vaccinated had not discussed the vaccine with a provider and therefore had limited awareness. Common responses to a direct question about whether participants had ever heard of the HPV vaccine were "I never heard of it. Never heard of it." and "This [interview] is the first time I heard of that one." When prompted with the trade name of the vaccine, another parent responded, "No, that name [trade name], I never. That name I would've remembered." Some participants were also prompted with a direct question about whether their doctor had ever mentioned the HPV vaccine, one parent responded, "Not to my knowledge, no."

Increased Enthusiasm about the Vaccine after Learning Brief Information

Approximately half of the sample had not heard or was not sure if they had heard of HPV vaccine previous to the interview. These participants were provided brief information that included statements that the vaccine is recommended for adolescents and that it prevents HPV which is a common sexually transmitted infection and an important cause of several

cancers and genital warts. After learning more about the vaccine, several parents had positive comments about the vaccine and described intentions or plans to learn more about the vaccine, discuss the vaccine with their children, and/or make appointments to vaccinate their children. "It's very important. I'm glad now that I know a little bit more about it." One mother described how the information she was provided at her child's health care visit was not helpful, but that she appreciated the knowledge gained during the course of the study interview.

So someone is just gonna come and pass you a pamphlet or tell you something about it. It's not like you're gonna pay it any attention. Most of the time when we get pamphlets we go, "Oh ok, yeah, alright.", and put it to the side, but see now you brought it to my knowledge, it's like my head is spinning, like, wow.

This increased enthusiasm about learning about HPV and the vaccine was not typically diminished by expressed concerns about impacts of vaccination on sexual behavior.

I would love that she be protected, so she wouldn't get it, you know.... I'll see what the doctor would say. Next appointment I'll actually talk, you know, when I go with her, tell her, "Make sure when I go with you to see the doctor, remind me to ask the question." ... And I'm going to talk to my wife today when I get home because she's the boss for her.

No, why would it [increase sexual behavior]? I wouldn't understand why it would change the way he behaves. I would let him know there are more deadly things out there that can't be prevented, so do not have unprotected sex, because you can't get a shot for some of that stuff to prevent it.

Reliance on Providers' Recommendations for Vaccination

Participants described a general reliance on recommendations from providers to vaccinate their children. Parents often described trusting their doctors and believing that they know best. A commonly expressed sentiment was that families should accept vaccinations that are offered by providers. Rarely was any additional information from other sources felt to be important, and vaccination was typically accepted with little questioning. For many parents, the discussion with providers was the first time they had heard of HPV vaccine. "No, I didn't [hear of HPV vaccine before], and I heard only when, um, I took him to the doctor the other week, and she was explaining to me, you know, what it is." Parents described that what they learned from the doctor was sufficient and they did not need additional sources of information. When children were vaccinated, providers typically initiated the discussion by offering the vaccine rather than it being actively requested by parents.

I didn't ask for it, or anything. I'd heard about it, but I didn't have that much information about it, and when I went in to the doctors, the doctor was like, they need, you know, they are going in for school, you know, shots they need for school. She was like, "Well, you know we can start this shot, have you heard about it?" Then she gave me a pamphlet that had more information on it, and I was like, ok, fine.

Variability in Strength of Provider Recommendation

The strength of the HPV vaccine recommendation parents reported receiving varied. Sometimes HPV vaccine was presented as optional, and sometimes it was presented as something that could wait until a later visit. "They explained to her, what the shot was for, and how it could prevent certain types of cancer, and that if she didn't want it she didn't have to get it." This led participants to consider vaccination a relatively low priority.

We were talking about that that shot, and then umm, something else came up and we got off the subject of it, but she said next time we come in we'll talk about it.... She said she would get back to me about it, but we've been so busy trying to get her everything for school that we haven't been able to talk again.

One parent expressed concern that she hadn't fully grasped the importance of the vaccine from her child's health care provider. "I don't have any concerns [about the vaccine]. It's just that maybe it should have been enforced a little stronger to the parents. To wake 'em up. To awareness of what's really going on."

Low Awareness of the Recommendation for Three Doses and Poor Recall of Whether Children Completed the Series

Several parents who knew about HPV vaccine and reported that their children had been vaccinated did not know about the recommendation for three doses. Some parents questioned if it was just a single shot or if it needed to be given annually. Parents also expressed uncertainty in knowing whether their children had received all three doses. "Umm, I'm, I'm not sure. I don't remember. I honestly don't remember. Like I said, he's getting some shots today so it might be what's going on now."

No, I don't remember that.... So, then she probably didn't have a HPV, because nobody said anything about a second dose. You know what I'm saying? She must not have gotten it, 'cause otherwise they would have said "You have to come back in two, make an appointment for two months later."

When parents were aware of the recommendation for three doses, they expressed support for this regimen and strong desires for their children to complete the series. The commitment to completing the series was based on strong feelings about protecting their children from the possible harmful effects of infection. "I don't play when it comes to my kids' health. That's one thing I am always on top of." However, parents also expressed varying degrees of difficulty in making additional health care visits and cited several specific challenges. Some challenges were related to difficulties with health care utilization in general, such as parents not wanting children to miss school to attend medical appointments. One challenge that was mentioned that was more directly related to subsequent doses of HPV vaccine was described as difficulty scheduling due to confusion about the nature of the visit. Because HPV vaccination is the only 3-dose series for adolescents, it requires additional within 6 months of the first dose that are not routine for this age group.

Well, I tried to set it up but she said, the lady said she put it down for follow-up. So I don't know if she wants to talk to us to see how everything is going after. I thought it was just the nurses, you know, where they just go in and see the nurses

and get the shots and we leave. But the lady, the doctor put on there 'follow-up'. So it's another appointment basically.... No [haven't made he appointment yet], because she said they didn't have the schedule. I have to call within a week. That is another inconvenient thing because what if I forget?

Limited Understanding of Rationale for Boys and Different Experiences than with Girls

Several parents of boys reported not knowing about the routine recommendation for HPV vaccine for boys. Some parents who were aware of the recommendation for boys were unclear as to why boys should receive HPV vaccine as it was typically thought to be for the prevention of cervical cancer. Parents discussed knowing that boys should get it because they were aging into adolescence, but not knowing a more specific reason. There was poor knowledge of HPV-related diseases in boys; for example, one mother of a son thought it was related to prostate cancer.

The one [vaccine] you're telling me about, is that the one just for girls or does it affect boys too? ... See then, I don't know about that one. I know about that one about the girls, that prevent them from getting, there is a shot that they give them to prevent them from getting cancer when they get older.

So I was kind of surprised, with my grandson, I was like "He's a boy!" [laugh]. I was like, "Why is he? He is a boy." You know, I heard something on television but it was solely related to girls, and everything, it was about was the girls, and like you were saying about the cervical cancer, but I didn't hear anything about the boys, nothing about the boys.

Despite general agreement with the recommendation for boys, some parents reported different levels of motivation to vaccinate their sons. "No [son hasn't been vaccinated], because he don't go to the doctor as regular as I do with my girls. I am going to take him to his appointment for his yearly check-up because it is time for him." Some parents described stronger feelings about protecting daughters compared with sons. For some parents, this was related to more general reproductive health concerns, for example, believing that girls are more susceptible to sexually transmitted infections. Others talked about being more proactive about the health of daughters in general.

I think I ask more questions, much more than I did with the boys.... Yeah, yeah. I'm like getting everything done for her. Making sure ... And I wanted to get it done more fast. I don't know why. Probably because they can't get pregnant and all that stuff.

Discussion

This study deepens our knowledge about parental knowledge, attitudes, and intentions toward HPV vaccination by examining parents' recall of vaccination recommendations and reflections on their actual experiences in a low-income and predominantly racial/ethnic minority population. Results indicate that for many parents, HPV vaccine was not actively sought out or requested for their children but rather accepted when offered by providers with high levels of trust. However, recommendations from providers varied in strength, and they

sometimes presented the vaccine as optional or low-priority. Many parents who reported their children had not been vaccinated had not actively refused the vaccine but rather were not aware of it or had not discussed it with a provider. Furthermore, many of these parents expressed a desire to learn more about the vaccine or to have their children vaccinated without expressing concern about possible impacts on sexual behavior. These findings suggest that there continues to be room for improvement in how providers recommend the HPV vaccine in this setting.

Though parents' reliance on recommendations from providers may occur similarly for other vaccines, HPV vaccine could present a special challenge. Tdap vaccine is required in most states and meningococcal vaccine in many states for enrollment in school, but HPV vaccine is rarely required and school mandates for HPV vaccine may not be effective (Pitts & Adams Tufts, 2013). However, the strength of recommendation from American Academy of Pediatrics and Advisory Committee on Immunization Practices is the same (routine and universal). Presenting HPV vaccine as different or optional may enable parents or children to opt-out more easily. Several studies have shown that strength of provider recommendation is an important predictor of uptake (Holman et al, 2013). Results from our study show that many parents hear about HPV vaccine from their doctors first, and that they trust these recommendations. These results indicate that improving the consistency and strength of recommendations from providers at all visits with age-eligible children who have not completed the 3-dose series may help to increase uptake. A small number of interventions that have included a component of provider training to increase HPV vaccination rates have had promising results (Fiks et al., 2013; Moss, Reiter, Dayton & Brewer, 2012) and these efforts should be considered in health care settings with similar characteristics to this study.

Parents generally supported the recommendation for three doses of HPV vaccine and expressed strong desires for their children to complete the series. However, they also cited challenges related to additional health care visits (e.g., children missing school, scheduling difficulties, and remembering). Though these challenges may reflect issues about access to care more broadly, it could be particularly problematic for HPV vaccine due to the number of additional health care visits (at least 2) needed in a relatively short period of time (6 months). Other studies have shown that low-income and minority populations are more likely to need additional health care visits to complete the series because of fewer health care visits overall during which vaccine could be given (Rand, Szilagyi, Albertin & Auinger, 2007). The cost of vaccines for low-income populations is covered by the federal Vaccines For Children program, but it is important to note that additional health care visits may incur other costs such as transportation or time off work that do present additional barriers. The use of schools to administer doses of vaccine on a voluntary basis (for example, through school-based health centers) might help to mitigate some of the difficulties faced by families and should be explored. Countries with high completion rates of HPV vaccine for adolescents, such as Australia, have managed to achieve this largely through widespread school-based vaccination programs (Brotheton et al, 2013). In the United States, several school-based interventions have had demonstrated successes (Caskey, Macario, Johnson, Hamlish & Alexander, 2013; Daley et al, 2014; Kempe et al, 2012; Stubbs, Panozzo, Moss, Reiter, Whitesell & Brewer, 2014). These promising approaches have reduced some identified barriers and their use should be considered when possible.

Given the noted importance of provider recommendations, our finding that approximately half of the sample was not aware of HPV vaccine is of concern. Though not the intention of this study, it is possible that the brief information we provided served as an educational intervention. The generally positive response from parents should be reassuring to providers that brief and directed statements are often sufficient for parents and that long conversations may not be necessary to promote uptake.

There are additional challenges for HPV vaccination of boys, including a general lack of awareness of reasons why boys should be vaccinated. Parents who had knowledge of HPV-related diseases primarily cited cervical cancer and were not aware of HPV-related cancers that affect boys (e.g., anal, oropharyngeal) or genital warts. This could be due to early marketing of HPV vaccines in the US that was focused on cervical cancer and vaccination for girls. Additional challenges are related to stronger feelings about protecting daughters compared with sons. These challenges could be overcome by more directed recommendations from providers to clarify the importance of HPV vaccine for all adolescent children at the recommended ages. The development of alternative methods to communicate more effectively with parents about HPV vaccination (in addition to vaccine information sheets) such as the development and dissemination of talking points may be helpful and should be evaluated (Brady, 2014; CDC, 2014). Social marketing campaigns for parents have been conducted for HPV vaccination with some success (Cates, Shafer, Diehl & Deal, 2011), and their utility for continuing to raise awareness about the vaccine should be explored in other areas.

This study has some limitations to note. First, findings from this select population at a hospital-based urban clinic may not hold for other groups. Though many low-income urban populations receive care at similar settings, this was a sample from single clinic and we did not seek to include other populations (e.g., white, middle- or upper-income families). Though we recruited a sample that included male and female parents, grandparents and stepparents of both sons and daughters, we may not have captured the full range of experiences. However, many of the key themes were expressed by several participants, suggesting we have captured most salient ideas. Another limitation was that our sample size did not permit more detailed stratification of results. While we did examine possible differences by race and ethnicity, we were not able to examine if other differences (e.g., by sex of child within racial/ethnic groups) were present.

In conclusion, these findings reveal the need for renewed efforts that strive to strengthen HPV vaccine recommendations given by providers where they may be inconsistent or inadequate. Though our recommendations are based on results from an urban, low-income, predominantly minority population, similar issues may be salient for different populations (e.g., non-urban and/or middle to high income) and this should be explored in future research. Programs that facilitate completion of the 3-dose series and efforts to raise awareness of HPV-related diseases in males are also needed to increase uptake so that we may realize the full potential impact of currently available HPV vaccines. Future program development, evaluation, and research should focus on interventions at the provider, clinic, and/or community level that make it easy for parents to adhere to vaccine recommendations.

Acknowledgments

This work was supported by National Institutes of Health grants R21 CA163160, P30 MH062294, T32 AI00721, and CTSA grants UL1 TR000142 and KL2 TR000140 from the National Center for Research Resources (NCRR) and the National Center for Advancing Translational Science (NCATS), components of the National Institutes of Health (NIH), and NIH Roadmap for Medical Research. Funders had no role in design, implementation, or interpretation of this work. Its contents are solely the responsibility of the authors and do not necessarily represent the official view of NIH.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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