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Noninitiation and Noncompletion of HPV Vaccine Among English- and Spanish-Speaking Parents of Adolescent Girls: A Qualitative Study

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Abstract

Objective—The Advisory Committee on Immunization Practices recommends routine human papillomavirus (HPV) vaccination for female adolescents aged 11 to 12 years, yet vaccination rates remain low. We conducted a qualitative study to understand English- and Spanish-speaking parents' reasons for noninitiation or noncompletion of the HPV vaccine series for their daughters.

Methods—Parents of female adolescents aged 12 to 15 years who had not initiated or not completed the HPV vaccine series were identified through administrative data in 2 large urban safety net health care systems in Colorado. Focus groups and in-depth interviews were conducted with English-speaking parents and in-depth interviews were conducted with Spanish-speaking parents. All data were recorded, transcribed, and analyzed for thematic content by experienced analysts using established qualitative content analysis techniques.

Results—Forty-one parents participated in the study. Thirty parents participated in individual interviews and 11 parents participated in 1 of 2 focus groups. The most common reasons for noninitiation and noncompletion among English-speaking parents included a low perceived risk of HPV infection, vaccine safety concerns, and distrust of government and/or medicine. In contrast, Spanish-speaking parents most often reported that providers had either not encouraged initiation of the HPV vaccine series or had not explained the necessity of completing the series. Some noninitiating parents, particularly Spanish-speaking ones, also cited concerns that vaccination would encourage sexual activity.

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Conclusions—The reasons for noninitiation and noncompletion of the HPV vaccine series differed substantially between English- and Spanish-speaking parents. To maximize uptake of HPV vaccine, varying approaches might be needed to effectively target specific populations.

Keywords

HPV vaccination; noncompletion; noninitiation; qualitative research

Although almosta decade has passed since the Advisory Committee on Immunization Practices recommended routine human papillomavirus (HPV) vaccination for female adolescents aged 11 to 12 years, vaccination rates remain relatively low. Vaccination rates for HPV vaccine lag behind other recommended adolescent vaccines, such as those for tetanus, diphtheria, and acellular pertussis, and meningococcal conjugate. In 2014, 60.0% of adolescent girls had initiated HPV vaccination, and only 39.7% had completed the 3-dose series, representing only minimal increases in vaccination levels from previous years. Disparities in series completion have historically existed among minority populations, the very populations that are at highest risk of developing cervical cancer. However, recent data suggest a reversal of this trend, with initiation and completion rates for non-Hispanic white adolescents among the lowest of all female adolescents. By increasing 3-dose HPV vaccination coverage to 80%, an estimated additional 53,000 cases of cervical cancer could be prevented over the lifetimes of girls currently younger than 12 years old.

Previous research has suggested a number of barriers to HPV vaccine initiation and completion, including a lack of knowledge about HPV transmission and its relation to cervical cancer, 6-10 lack of knowledge about the HPV vaccine, 11 concerns about cost of the vaccine, 10,12 concerns about the safety of the vaccine, 13 low perceived need for the vaccine, ^{13–15} the perception of HPV vaccine as a potential cause of sexual disinhibition, ¹² and lack of provider recommendation. 16-18 One recent study reported that 84% of HPV-unvaccinated girls had a health care visit in which another vaccine was administered, suggesting that missed opportunities for vaccination exist. ¹⁹ Among ethnic minority populations, suboptimal HPV vaccine uptake has been linked to a lack of knowledge about HPV, 11,20-22 concerns about the safety of the vaccine, ^{21,23} low perceived risk of HPV infection, ^{15,24} concerns about adolescent sexual behavior, ²⁴ and lack of provider recommendation. ²¹ However, most studies investigating barriers to HPV vaccine uptake among ethnic minority populations do not consider how reasons for noninitiation or noncompletion might differ according to language. Although language preference (Spanish vs English) has previously been associated with a variety of health-related behaviors and receipt of health care services among Hispanic individuals in the United States, 25-27 most studies of HPV vaccinationrelated behaviors do not include language preference as a variable of interest and/or fail to disaggregate language preference and Hispanic ethnicity. ²⁸ Although 2 studies suggest that HPV vaccination rates do not differ according to Hispanic parents' preferred language, particularly when income and access are controlled for, ^{29,30} other studies have reported lower levels of awareness and information about the HPV vaccine among Spanish-speaking parents compared with English-speaking parents. 31,32 To our knowledge, only 1 study has examined language preference in relation to HPV vaccine uptake, and that study did not isolate language.³³ Instead, it used English language competence as one part of a composite

variable for US acculturation, and reported that a higher level of US acculturation was associated with greater odds of HPV vaccine uptake.³³ No distinction was made in those models between initiation and completion of the vaccine.

The objective of this study was to understand how factors that influence parents' decisions about initiation and completion of the HPV vaccine series for their daughters might differ across English- and Spanish-speaking populations, potentially reflecting culturally-based differences in attitudes about the vaccine. Consistent with the recent focus on "patient-centered" approaches to health care, understanding the ways in which reasons for noninitiation and noncompletion might differ according to language preference will enable more effective design and tailoring of interventions to improve HPV vaccine uptake.

Methods

Study Design and Population

This investigation was part of a larger study with the purpose to develop, implement, and evaluate an adolescent vaccination program in public and private primary care practices. 34 For this portion of the study, English- and Spanish-speaking parents or guardians of adolescent girls who had not initiated or not completed the HPV vaccination series were recruited for participation in focus groups or interviews from July 2012 to January 2013. Eligible participants were parents of adolescent girls aged 12 to 15 years who had received well child care within the previous 2 years at 1 of 2 large safety net health care systems in the Denver, Colorado metropolitan area, had received childhood vaccinations, but had either not initiated or not completed the 3-dose HPV vaccination series. Noninitiators of the HPV vaccine series were defined as female adolescents who had been seen for well child care in the previous 2 years with no record of HPV vaccination. Non-completers were defined as female adolescents who were 6 months past the first HPV vaccination and had not yet received a second HPV vaccination, or who were at least 1 year past the second HPV vaccination and had not yet received the third HPV vaccination.

Administrative data from each health care system and the Colorado Immunization Information System were used to identify and contact potential study participants. Information about participants' language preference was included in the administrative data. Recruitment efforts were conducted in English and Spanish and included postcards mailed to eligible parents' homes and auto-dialer messages sent to eligible parents' primary phone numbers. Flyers were also placed in clinics advertising the opportunity to participate. Those interested in participating were asked to contact project staff via phone; these staff then explained the purpose of the study, confirmed language preference, scheduled dates and times for focus groups and interviews, and further screened parents for eligibility. Parents were selected for participation if they reported that, in addition to having daughters who met noninitiation or noncompletion criteria, they were familiar with the HPV vaccine, knew the HPV vaccination status of their daughters, were not generally opposed to childhood vaccinations, and had typically taken their daughters to health providers for preventive visits during their childhood. These additional eligibility criteria allowed for the exploration of barriers to initiation or completion among parents who were at least somewhat aware of HPV and engaged with the health care system (ie, avoided the recruitment of parents whose

daughters had not initiated or completed the HPV vaccine series simply because the parents were disengaged). After enrollment, reminder postcards and phone calls were provided to each participant. This study was approved by the Colorado Multiple Institutional Review Board.

Data Collection

Data were collected from October 2012 through January 2013, after an initial focus group (n = 7) to pilot question wording. Data in this report do not include pilot data. Data collection was stratified according to parents' language of preference (English or Spanish) and daughters' HPV vaccination status (noninitiator or noncompleter). Data were collected through focus groups and in-depth, semi-structured interviews. Focus groups were conducted with English-speaking parents of noninitiators, but when recruitment and scheduling challenges prevented the organization of additional focus groups, data from the remaining strata were collected through in-depth interviews. Focus groups and interviews were conducted by project staff trained in qualitative data collection techniques and were conducted in parents' language of preference. The same guide was used for focus groups and interviews, and was organized around constructs of the health belief model,³⁵ using a combination of broad, open-ended questions and follow-up prompts designed to elicit parents' beliefs about HPV vaccination. All parents were informed of their rights as study participants; informed consent was collected from each participant through an institutional review board-approved verbal consent process before the initiation of each focus group or interview. All focus groups were held in public community sites located in close proximity to the health clinic locations available to the participants. All interviews were conducted via telephone. Focus groups lasted approximately 1.5 hours; individual interviews lasted approximately 45 minutes. All were digitally recorded and transcribed verbatim; transcripts in Spanish were subsequently translated to English. Participating parents received a \$50 gift card as compensation for their time.

Data Analysis

Analysis occurred in an iterative and team-based process involving established qualitative content methods and reflexive team analysis. ^{36–38} Focus group and interview transcripts were read independently and multiple times by 2 qualitative analysts (K.A., J.B.) to achieve immersion, and code categories were then independently developed and compared until code agreement was achieved. ³⁸ The qualitative analysts then applied the resulting codes to the transcripts, debriefed until consensus was reached, and met regularly with the study team to check new findings, discuss emergent codes and themes, and assess the preliminary results of the analysis process. ³⁹ Careful attention was given to the presence or absence of new and emerging themes throughout analysis, and thematic saturation was achieved. Throughout the analytic process, the qualitative data software program ATLAS.ti version 7.0 (Scientific Software Development GmbH, Berlin, Germany) was used for data organization and management.

Results

Twenty-one parents of noninitiators and 20 parents of noncompleters participated in the study. Among parents of noninitiators, 2 focus groups were conducted (Ns = 5, 6) with English-speaking participants and 10 interviews were conducted with Spanish-speaking participants. Among parents of noncompleters, 10 interviews were conducted with English-speaking participants and 10 interviews were conducted with Spanish-speaking participants. Demographic characteristics of study participants are presented in the Table.

Reasons for Noninitiation Among English-Speaking Parents

English- and Spanish-speaking parents gave substantially different reasons for failing to initiate the HPV vaccine series for their adolescent daughters. Several themes emerged among English-speaking parents that together indicated not only a lack of knowledge about HPV risk, infection, and the vaccination process, but also a distrust of sources that might provide that information. First, these parents described the risk of HPV infection as questionable. They supported their doubts about infection risk by noting that they themselves had had no problems with HPV infection; some also expressed the belief that infections are necessary to develop immunity. In the words of one parent, "I didn't need [HPV vaccination] and I don't know anyone who has." Second, these parents were concerned about the safety of the vaccine, because they considered the vaccine to still be new, especially compared with vaccines such as those for polio or tetanus. As one parent explained, referring to a perceived lack of data about the safety and effectiveness of the vaccine, "I wait awhile to see how the results are."

These parents also expressed a desire for more information about HPV infection and vaccination from a reliable source. Although they indicated that a trusted health care provider would likely be the most reliable source of information, they also indicated that even information from providers might not be sufficient for them to choose to initiate the HPV vaccine series for their daughters. As one parent put it, "Just on the information [from a provider alone]...I wouldn't do it. Because we are not the guinea pigs to just let them do things." Finally, a few parents also voiced concerns that vaccinating against HPV would encourage their daughters to have sex or engage in related adult-like behaviors. These parents believed that if they were to initiate the vaccination series, they would need to discuss with their daughters what HPV was, how the virus is transmitted, and why protection from HPV was a good idea. They believed that it was too soon to have these types of discussions: "It is awkward enough that they are growing up and developing and starting their period and then all of a sudden - Boom! 'You have to get this vaccine because you might be having sex soon.' You know? I mean you don't want to rush them into growing up."

Reasons for Noninitiation Among Spanish-Speaking Parents

Among Spanish-speaking parents whose daughters had not started the HPV series, the concern that vaccinating against HPV would encourage sex or adult-like behaviors was a much more prominent theme. At least in part because of their religious and spiritual beliefs, these parents expected their daughters to abstain from sex until marriage, and they did not

want to give their daughters the message that sexual activity was permissible or give them a false sense of protection:

"Maybe she will hear from a nurse or a doctor or somebody else that she won't be exposed to anything if she gets that [HPV] vaccine. So... she will think that if she gets the vaccine, she can sleep with as many men as she wants."

"I have a little doubt [that my daughter is at risk for HPV infection]... I think that I don't really understand why they need [the vaccine]. To me it is just like for girls who are very liberal [sexually] ... so there is a different risk of getting the disease. We don't raise our kids... to be with one and another and another [sexual partners]."

In addition to fearing that the vaccine would encourage undesirable behavior among their daughters, Spanish-speaking parents indicated very little understanding of HPV or the risks and benefits of HPV vaccination. This lack of understanding was linked to the reported failure of their health care provider to effectively communicate information about HPV or the HPV vaccine. Indeed, no Spanish-speaking parent in this study reported that they had received encouragement from their providers about vaccinating their daughters against HPV. Instead, they reported that the messages they received from their provider were neutral about the vaccine or the issue was simply not mentioned by their provider at all. In the words of one parent:

"I think they gave her a pamphlet but I don't really remember... I would like to get this [information about HPV directly] from the doctor, because sometimes they give you pamphlets but you never read them."

Reasons for Noncompletion Among English-Speaking Parents

The reasons for noncompletion of the HPV vaccine series also varied according to language preference. Among English-speaking parents whose daughters had started but not completed the series, the themes that emerged were similar to those that had emerged among English-speaking parents of noninitiators. These parents described the HPV vaccine as seeming unnecessary or irrelevant to them, because cervical cancer was rare and their daughters did not have a genetic predisposition to it:

"That type of cancer doesn't run in my family and we feel if it ain't broken, we're not fussing with that right now then. Why go through something for nothing, basically. I do know that there's always 1% chance that we can catch something or spread something but... that type of thing doesn't run in our family."

These parents also expressed concerns about the safety of the vaccine series and desired information containing definitive proof and conclusions about its safety and effectiveness. As one parent put it, "What I've read so far [about the HPV vaccine] is really vague." Interestingly, many reported that their concerns about HPV vaccine did not start until after their daughters had received the first dose, when they began to read or hear things that encouraged doubt. Several of these parents also reported a general distrust in government and health care providers that contributed to their doubts about the safety of the vaccine:

"See, I don't even know who [the government and health system are] offering [the HPV vaccine] to. You know what I'm saying? ... There has been some things where race influenced [what the government/health system did]. But I don't know whether I can say that I believe that now or not 'cause, like I said, I don't know enough about it... but I don't give you any leeway."

Finally, a few of these parents reported that they were simply not aware of the importance of getting all 3 shots. These parents believed that reminders from their providers would be helpful in raising their awareness about the 3-shot series and the necessity of completing the series for the vaccine to be effective.

Reasons for Noncompletion Among Spanish-Speaking Parents

In contrast to the English-speaking parents of noncompleters, the Spanish-speaking parents whose daughters had started but not finished the series reported overwhelming trust in the health care system and health care providers, and expressed the desire to take advantage of any services offered, including HPV vaccination. As one parent explained, "There are a lot of diseases now and I think it is better to get [my children] vaccinated." However, these parents reported that they were simply unaware of the need to complete the series. According to them, their providers had not explained that 3 shots were necessary for completion of the series and/or there had been no logistical follow-up from their provider to facilitate completion of the series. As one parent complained, "They were not clear on when to get the next one... as long as you let me know [about the follow-up appointment] then we should be fine, because we are responsible." In contrast to the Spanish-speaking parents of noninitiators, these Spanish-speaking parents of noncompleters did not indicate that spirituality and/or religion had any connection to their decisions about HPV vaccination.

Discussion

The results from this study suggest several similarities in participants' reasons for noninitiation and noncompletion of the HPV vaccine series for their adolescent daughters. English-as well as Spanish-speaking participants indicated a notable lack of information or understanding about HPV infection and the HPV vaccine series. Parents who had failed to initiate the HPV series also shared a concern that HPV immunization might promote sexual behavior, although this concern was particularly pronounced among Spanish-speaking parents. However, the results indicate important differences in the reasons for noninitiation and noncompletion of the HPV vaccine series among English- and Spanish-speaking parents. These differences are particularly pronounced according to language preference. English-speaking parents indicated much more doubt about the risk of HPV infection, uncertainty about the safety of the vaccine, and distrust of sources of information about it relative to Spanish-speaking parents. In contrast, the noninitiation and noncompletion of the series among Spanish-speaking participants appeared to be primarily linked to a lack of effective communication from their health care providers about the risks and benefits of HPV vaccination and the need to complete the 3-dose series for full protection from HPV. Although previous research has not examined how reasons for noninitiation and noncompletion might differ according to language, these patterns are consonant with other studies that identified different barriers to HPV vaccination intention, with English-speaking

parents more likely to be concerned about vaccine safety and side effects, ³⁰ and Spanish-speaking parents less likely to have sufficient information or a provider recommendation to vaccinate. ^{30–32} Whereas female adolescents of Hispanic ethnicity have a higher overall completion rate for the HPV series than do their non-Hispanic counterparts, ⁴⁰ this pattern of results suggests that language preference might be a particularly relevant factor in HPV vaccination uptake patterns, even among the Hispanic population.

These findings have a number of implications. Perhaps most importantly, they suggest that health care providers need to improve their communication with parents of adolescents about the risks of HPV infection, the safety of the HPV vaccine, and the time course of the 3-dose series. Such communication efforts should include explaining the ubiquitous nature of HPV infection, so that parents understand the importance of vaccinating their children even if abstinence is the expectation. Providers should also make their recommendation of the HPV vaccine clear to patients and parents, and their offices should improve efforts to coordinate and schedule follow-up appointments for the second and third doses to facilitate series completion.

Beyond these broad recommendations for improved communication, however, these results also suggest that maximizing the uptake of HPV vaccine might call for varying approaches among different populations. The Spanish-speaking parents in this study did not evidence the same level of distrust and doubt about HPV vaccination as did the English-speaking parents. Many Spanish-speaking parents appeared very willing to initiate and, especially, complete the HPV vaccine series if they received encouragement to do so by their provider and received help in facilitating the second and third doses. This suggests that providers should not only make a conscious effort to talk about the importance of HPV vaccination with parents, but that they should develop effective reminder methods regarding the need to schedule subsequent doses of the series. In addition to talking directly with patients and parents, providing Spanish-language materials explaining HPV and the risks and benefits of vaccination might also be helpful. Such a targeted, HPV-specific approach has been previously reported to be effective in promoting HPV vaccination among US Hispanic individuals. 41 However, because our data indicate that at least some parents "never read" informational pamphlets and instead desired direct communication with providers, this recommendation should be undertaken thoughtfully. The most effective approach is likely to be one in which written materials are used as a supplement to conversations with providers, rather than a replacement for them.

For providers serving English-speaking noninitiators and noncompleters, an effective approach might look somewhat different. Because this population perceived the risks of HPV infection to be low and the safety of the HPV vaccine to be uncertain, frank conversations describing the nature of the HPV infection and the evidence regarding vaccine safety might improve the knowledge base among this population. However, because this population also indicated distrust toward certain sources of information about the HPV vaccine, and claimed to want more "reliable" sources from which to learn, providers might supplement their conversations with these parents by providing them with multiple links to Web sites containing trustworthy medical information and/or links to research articles showing the benefits and safety of HPV vaccination. If possible, these links might also

include several that lead to sites that explicitly refute privately-circulated claims that vaccines, including the HPV vaccine series, are unsafe and/or used for nefarious purposes. Although providing such information is unlikely to change the minds of all parents with these concerns, it could be helpful in educating at least some within this population. Providing links to multiple sources that provide reliable information about HPV vaccination (ie, not solely Web sites run by government agencies) might be particularly effective in reducing some of the distrust expressed toward single sources by participants in this study. Web sites of provider organizations (eg, the American Academy of Pediatrics) might be especially useful, because one study reported that parents consider such Web sites to be the most trusted information medium for vaccine safety information. ⁴² Providers might also consider providing or reinforcing such information at multiple time points during the 3-dose series, because some English-speaking parents reported that their concerns began after their daughters' receipt of the first dose.

There are several limitations to this study. Data were collected only from parents in 1 large metropolitan area and thus might not be generalizable nationally to parents. The criterion for at least some baseline awareness of the HPV vaccine among participating parents potentially restricts the full range of reasons for noninitiation (although not noncompletion); however, this criterion was necessary to recruit parents who were not simply disengaged from the system but who were making decisions about their daughters' health care and had at least enough familiarity with HPV to discuss it. The fact that data from English-speaking noninitiator parents were collected via focus groups whereas the data from the remaining 3 categorical types were collected through interviews is also a potential limitation, although this potential is mitigated because the same guide was used in both approaches and thematic saturation was achieved in each category. Finally, as with most qualitative work, the sample size of this study was relatively small. Thus, it is impossible to determine the representativeness of the data reported because of the limited number of participants. However, the qualitative design of this study allowed for a richer and more nuanced exploration of themes not generally possible with surveys or other data collection techniques, and our analysis suggests several novel aspects to HPV vaccine decision-making that warrant further study.

To our knowledge, this is the first study to specifically explore reasons for noninitiation and noncompletion of HPV vaccine and to compare responses between English- and Spanish-speaking parents. Future research should further investigate the insights generated from these data to examine whether reasons for noninitiation and noncompletion of HPV vaccination are similarly different according to language among larger samples, and whether/how these results might be applicable to male adolescents. Future intervention efforts should take into account the different perspectives that emerged in these data and consider varying approaches to effectively target specific populations to improve HPV vaccine uptake.

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What's New

To our knowledge, this is the first study to explore reasons for noninitiation and noncompletion of the human papillomavirus vaccine series among English- and Spanish-speaking parents of adolescent girls. Substantial differences emerged according to language preference, suggesting that varying approaches might be necessary to maximize uptake.

Table

Participant Demographic Characteristics

	Noninitiate	Noninitiators (n = 21)	Noncomple	Noncompleters (n = 20)	
Characteristic	English-Speaking (n = 11)	Spanish-Speaking (n = 10)	English-Speaking (n = 10)	Spanish-Speaking (n = 10)	Total $(N = 41)$
Gender					
Male	1 (9.1)	1 (10)	1 (10)	0 (0)	3 (7.3)
Female	10 (90.9)	(06) 6	(06) 6	10 (10)	38 (92.7)
Race and ethnicity					
White, non-Hispanic	4 (36.4)	0 (0)	1 (10)	0 (0)	5 (12.2)
Hispanic	1 (9.1)	10 (100)	4 (40)	10 (100)	25 (61.0)
African-American, non-Hispanic	3 (27.3)	0 (0)	4 (40)	0 (0)	7 (17.1)
Mixed race	0 (0)	0 (0)	1 (10)	0 (0)	1 (2.4)
Unknown/not reported	3 (27.3)	0 (0)	0 (0)	0 (0)	3 (7.3)
Age					
18 to 29 years	8 (72.7)	1 (10)	0 (0)	0 (0)	9 (22.0)
30 to 49 years	3 (27.3)	(09) 9	(06) 6	(09) 9	24 (58.5)
50 years or older	0 (0)	1 (10)	1 (10)	1 (10)	3 (7.3)
Unknown/not reported	0 (0)	2 (20)	0 (0)	3 (30)	5 (12.2)

Data are presented as n (%).