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Different models of HPV vaccine decision making among adolescent girls, parents, and health care clinicians in New Mexico

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Abstract

Objective—HPV vaccination rates in the United States have been lower than anticipated since the vaccine became widely available globally in 2006. Of particular concern are data that suggest disparities in vaccine receipt among U.S. ethnic minority and health disparity populations such as Hispanics, who are disproportionately affected by cervical cancer. Given these trends, it is important to examine actual vaccination decision making processes among clinicians, parents, and adolescents to identify strategies to enhance uptake.

Design—We conducted a mixed-method study examining HPV vaccine decision making, utilizing both structured questionnaires of mothers and daughters and semi-structured interviews with mothers, daughters, and healthcare clinicians to more deeply investigate decision-making dynamics. Quantitative analysis was used for descriptive purposes, while qualitative analysis featured an iterative process to examine factors related to decision-making surrounding the HPV vaccine. The study was conducted in two primary care clinics serving predominantly Hispanic patients in an urban New Mexico setting through RIOS Net, a primary care practice-based research network.

Results—We conducted 22 questionnaires and 30 interviews. We identified three aspects of vaccine delivery that were similar across clinics: availability/supply of the vaccine, favorable clinician attitudes towards the vaccine, and clinicians' competing demands. We also identified three decision-making stages (pre-encounter, encounter, and post-encounter), though we found

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distinct differences in decision-making processes at the two sites. We describe the differences between an *encounter*-based and a *process*-based model of decision making, and the ways in which explanatory factors might influence the decision-making process.

Conclusion—Our findings suggest that factors other than race and ethnicity, such as education, socio-economic status, and health care access, play an important role in HPV vaccination decisions. Further research to elucidate the specific informational needs and communication strategies associated with these factors will be needed to enhance vaccine uptake.

Keywords

HPV; HPV vaccination; vaccine delivery; decision making; Latinos/Hispanics

Introduction

Available globally since 2006, the human papillomavirus (HPV) vaccine was heralded as a promising development in preventing cervical cancer. As the vaccine became widely available in the United States after the U.S. Food and Drug Administration approved it in June 2006, it was hoped that it would especially benefit the populations who stand to gain the most from it—namely, disadvantaged ethnic minority groups who experience restricted access to regular Pap screening, such as Hispanics. U.S. Hispanic females are disproportionately affected by cervical cancer (Downs *et al.* 2008; Kahn *et al.* 2007), particularly in the U.S.-Mexico border region (Giuliano *et al.* 2001). U.S. Hispanic women experience the highest cervical cancer incidence rate when compared to all other ethnic groups; from 2005–2009, the incidence rate among Hispanics was 11.8 per 100,000 compared to 7.1 among non-Hispanic whites (National Cancer Institute 2009).

Unfortunately, recent data have documented that vaccine uptake is lower than anticipated among these health disparity groups (Bach 2010). Further, vaccine receipt nationwide has also been much lower than expected; only 48.7% of 13–17 year olds initiated the 3-dose series while even fewer (32%) girls overall, and Hispanics (29.5%) in particular, received all 3 doses of the HPV vaccine in 2010 (Hitt 2010; Centers for Disease Control and Prevention 2011). The vaccine's low uptake has renewed attention to the dynamics of preventive health care decision making among adolescents, their parents, and the healthcare clinicians who are counseling them about the vaccine. The strong influence of a clinician's recommendation in promoting HPV vaccination has been well documented (Lechuga *et al.* 2011; Brewer and Fazekas 2007; Guerry *et al.* 2011; Reiter *et al.* 2009; Rosenthal *et al.* 2010).

Following the licensure and release of the HPV vaccine, an extensive literature has assessed general awareness of HPV and the vaccine and documented low levels of knowledge among adults, young adults, and adolescents. In a national survey examining parental HPV vaccine decision making, most parents reported that they had already vaccinated or made the decision to vaccinate their daughters, despite their limited knowledge about the vaccine (Allen *et al.*, 2010). Studies chronicling adolescent involvement in HPV vaccine decision making have found that nearly half of adolescent girls have taken an active role in decision making for vaccination, despite their lack of basic knowledge about it (Mathur *et al.*, 2010; McRee, Reiter, and Brewer, 2010). Collectively, this literature has informed the

development of conceptual models linking the influence of factors at multiple levels—individual, provider and health care systems, societal/health policy—in order to more accurately predict, and ultimately enhance, vaccine uptake (Bastani *et al.* 2011; Fernández *et al.* 2010). A critical gap in these models, however, is that the interactional processes between actors (e.g., clinicians, parents and adolescents) is not well understood (Mathur *et al.* 2010).

Now that the vaccine has been widely available in health care settings for as long as six years, it is important to examine actual HPV vaccination decision making processes—particularly among populations that stand to benefit from it the most, such as Hispanics. This is especially important in the U.S. context, given that the vaccine is still optional and not integrated into a national vaccination program, such as in Australia and the United Kingdom. In this manuscript, we present results of a study of HPV decision-making processes and experiences derived from a sample of primarily Hispanic mothers, their adolescent daughters, and primary health care clinicians in a New Mexico urban setting.

Methods

Overview and setting

We conducted a mixed-method study examining HPV vaccine decision making, utilizing both structured questionnaires of mothers and daughters and semi-structured interviews with mothers, daughters, and healthcare clinicians to more deeply investigate decision-making dynamics. Our research team consisted of two medical anthropologists (CMG and ALS), two sociologists (LB and EK), a health services researcher (DLH), and an adolescent medicine physician (ASK). Data collection took place with primary healthcare clinicians and mother-daughter dyads in two clinics from two different communities in the same New Mexico city between September 2009 and March 2010. The protocol for the study was approved by the University of New Mexico Human Research Protections Office.

The first clinic (Site 1) is located in a major safety net clinical system. The clinic is situated in a community where nearly 80% of all residents are Hispanic and over 50% of residents age five or over speak a language other than English at home. The household median income in the area is estimated to be \$30,000, with 22% of the population below the poverty level (United States Census Bureau 2010). The second clinic (Site 2), which was added to provide socio-demographic variation, is located in a different clinical system and based in a more socio-economically advantaged community where the proportion of Hispanic residents is approximately 28% with 20% of residents age five or older speaking a language other than English at home. The median income level in the Site 2 catchment area is higher, around \$38,000, with approximately 11% of the population below the poverty level (United States Census Bureau 2010).

Recruitment

Primary care clinicians who see adolescent patients at the two clinics were selected through their membership in Research Involving Outpatient Settings (RIOS Net), a practice-based research network (PBRN) of over 225 clinicians serving New Mexico's diverse populations.

We purposefully recruited clinicians who order the HPV vaccine as part of their provision of routine clinical services with adolescent patients. We did not recruit these clinicians on the basis that they directly provide care for the mother-daughter dyads also interviewed for the study.

Mother-daughter dyads (no fathers participated) were recruited through bilingual recruitment flyers placed in each clinic. Potential participants called a bilingual member of the research team (CMG), who screened them for eligibility and scheduled appointments. Participants were principally recruited via the flyers, though mothers from both sites referred members of their social circles (family members and friends) to the flyer as well. Recruitment at Site 1 took place during a 3-month period; there were two no-shows for appointments (one of which we were able to reschedule) and two potentially interested dyads that we were not able to schedule (due to inability to reach them). Recruitment at Site 2 took place during a 1-month period, with multiple interviews conveniently taking place over spring break. Four potential participant dyads, who received information about the study from a social contact, were deemed ineligible given that they did not receive care at the clinic. All eligible dyads at Site 2 showed up for their appointments. We recruited dyads with a range of HPV vaccine experiences—specifically those with daughters who had received, had not received, and had refused the HPV vaccine.

Interview guides and questionnaires

We tailored the semi-structured interviews for all three stakeholder groups (clinicians, mothers, and daughters) and according to the daughter's vaccination status (received vaccine, declined vaccine, or unvaccinated). Clinician interviews focused on topics such as adolescent health issues, prioritization of immunizations, perspectives on the HPV vaccine, circumstances under which the vaccine is discussed, framing of vaccine messaging, experiences in discussing the vaccine with parents and adolescents, communication/interactional dynamics, factors influencing vaccine acceptance, and perspectives on controversial aspects of the vaccine (e.g., vaccine mandates for school entry).

Mother/daughter interviews focused on family dynamics, family discussions about general health and sex, decision-making about daughter's general health, comfort with clinicians' recommendations, familiarity with HPV and the vaccine, HPV vaccine communication, HPV vaccine informational needs, and HPV vaccine decision-making experiences. As a part of the interview process with mothers and daughters, we reviewed an informational handout (adapted from the New Mexico Department of Health 2008), which was given to participants to take with them at the end of the interview. The handout details basic information about HPV and cervical cancer, transmission and prevention, the HPV vaccine, and factors to consider in making one's decision about getting the vaccine.

We also completed brief questionnaires with the mother-daughter dyads prior to the interviews. The parent questionnaire elicited patient demographics, queried HPV and cervical cancer knowledge, and administered the perceived efficacy in patient-physician interactions (PEPPI) (Maly *et al.* 1998) and decisional conflict (O'Connor 1995) scales. The parent questionnaire also included an established health literacy measure (Chew, Bradley

and Boyko 2004). The daughter questionnaire was adapted to include demographics, HPV and cervical cancer knowledge, and decisional conflict.

Data collection

Clinician interviews were conducted by ALS and CMG in advance of the mother-daughter dyad interviews and held in clinicians' offices or other available spaces at the clinic; clinicians received a \$50 gift card for their participation. Clinician interviews lasted between 45–75 minutes. Mother-daughter dyads were met at the clinic by the researchers (CMG and EK), consented together, and then interviewed separately (CMG with mothers and EK with daughters) in exam rooms or other private available spaces at the clinic. Questionnaires and interview guides were translated into Spanish ahead of time by CMG, the Spanish-speaking member of the research team, and offered to participants in their language of choice. Participants each received a \$30 gift card at the end of the session. Interviews with the mothers lasted between 30–50 minutes, while interviews with the daughters lasted between 15–30 minutes. All clinician, mother, and daughter interviews were digitally recorded, transcribed verbatim, and translated (as necessary). We first completed data collection at Site 1, reaching saturation on thematic responses quickly, and then began data collection at Site 2.

Data analysis

Questionnaire data were entered into the statistical program Statistical Package for the Social Sciences (SPSS). Given the small sample, we used these data for descriptive purposes only, summarizing sample demographics and assessing knowledge of HPV and the HPV vaccine at the time of the interview. The descriptive data were also used to identify trends that helped to guide our interpretation of the interview data.

Qualitative analysis of the interviews followed the principles of grounded theory (Strauss and Corbin 1990) and featured an iterative process to examine factors related to decision-making surrounding the HPV vaccine. First, research team members independently identified key themes in an initial set of transcripts and then met to compare emergent themes and develop initial coding structures. We conducted data collection and analysis concurrently, reviewing sets of two to three dyads until no additional themes were identified. We achieved data saturation with a total of 30 interviews across the sampling categories. Two separate coding structures were set up; one for the clinicians and one for the mothers and daughters. After the larger team agreed on the basic coding structures, the two medical anthropologists (CMG and ALS) coded a set of subsequent interviews from each participant category independently and then reviewed them together. Discrepancies between codes were discussed and resolved by reaching clear agreement about their application. Once the two coding structures had been finalized, transcripts were then imported into QSR International NVivo8 and coded by CMG and ALS.

We developed seven major provider coding categories: context of adolescent care, immunization delivery, general views of the HPV vaccine, dissemination of the HPV vaccine, parent/daughter responses to the vaccine, ideas about when to give the vaccine, and perspectives on the HPV vaccine debate. We developed 12 major mother/daughter coding

categories: family context/relationships with family members, influences of life experiences, peer relationships, adolescent sexual activity, discussions about health, daughter's medical care, health care decisions (general), general clinician communication, HPV vaccine communication, HPV vaccine perceptions, HPV vaccine experiences, and HPV vaccine decision making.

As another step in the iterative analytic process, coding reports were periodically generated for the entire team in order to clarify core themes and generate collective interpretations from the data. At this stage, we integrated findings from the questionnaires into the analytic process by comparing/contrasting summaries of each domain with the qualitative themes from each of the categories listed above. Lastly, we also compared our summary findings to conceptual and logic models of factors influencing HPV vaccination (Fernández *et al.* 2010) to further refine the interrelationships of each component both within and across levels. These reports led us to discuss the differences between the sites, and ultimately develop the models of decision-making presented in this article.

Results

Demographics

Overall, we conducted 30 interviews (eight with clinicians, 10 with mothers and 12 with girls between the ages of 12 and 17). Five clinicians at Site 1 participated—two family physicians, two pediatricians, and one physician's assistant. Three were female; three were Hispanic and two were non-Hispanic white. At Site 2, three clinicians participated—a family physician, nurse practitioner, and a physician's assistant. All were female; two were non-Hispanic white and one was Hispanic. There were six mother-adolescent daughter dyads at Site 1, while at Site 2, we interviewed four mothers (including one stepmother) and six girls (two sets of whom were sisters). (See Table 1 for dyad participant demographics.)

Similarities across clinic sites

Prior to presenting the observed models of HPV vaccine decision making, we first describe three key contextual aspects in both of the clinical settings that relate to vaccine delivery. First, the overall availability and supply of the HPV vaccine was comparable across sites; both provide the vaccine as a part of the Vaccines for Children (VFC) program, which assures universal vaccination coverage for minors. However, both clinics reported difficulties in successful vaccine implementation beyond the first dose since they lacked fully-functional tracking systems and reminder capabilities; as a female family physician at Site 1 described, "Right now we depend on prior providers or ourselves having filled in this cover sheet in the paper chart that says what vaccine they got and when and the parents are supposed to bring the card. But it doesn't always come and...it doesn't always match what's in the chart."

Even though Site 2 had an electronic medical record system, a female nurse practitioner characterized it as "a double-edged sword...because if the immunizations haven't been put in, in a timely fashion, you've got a stack of hundreds of papers that someone has to key in, in order for that to come up." Clinicians also identified the lack of reminder capabilities as a

contributor to missed opportunities for getting adolescent girls to return for the second and third doses in the series. As a male pediatrician at Site 1 noted, “The burden’s on [the patients]. To be honest I don’t have the personnel to be calling the patients.”

Second, despite the delivery system challenges, clinician attitudes towards the vaccine were also similar across sites—all eight held favorable views of the vaccine. A male family physician at the Site 1 described his approach to discussing the vaccine with parents, stating “I always use the, ‘I’d give it to my daughters, that’s how much I believe in it.’ And then they’re okay...if [he] will do it for his daughters, why would he want to hurt his daughters?” A female nurse practitioner at Site 2 echoed this positive predisposition to the vaccine, stating “I’m like the super vaccinator...I make sure they get that done.”

Lastly, clinicians all described the competing demands that influenced vaccine receipt, including limited time in the clinical encounter. Further, they noted that the target population is generally a healthy one, limiting their chances to opportunistically offer the vaccine while patients are there for another reason. A male pediatrician at Site 1 noted, “It’s a complicated population...because they don’t get seen very often, they rarely come to the clinic...but the rest of the time they’re healthy people so really what we have to do is to try to use those few visits to do the most that we can.”

Different models of HPV vaccine decision making

Despite similarities in vaccine access and level of clinician endorsement, we found key differences in the decision-making processes described at each site (see Table 2). Table 2 outlines three phases of the decision-making process. Phase 1, the pre-encounter phase, refers to the time period before the clinical encounter in which the HPV vaccine was discussed with the clinician and/or administered. The encounter phase, Phase 2, represents the actual clinician-patient encounter and the dynamics of clinician-mother-daughter communication that takes place during the actual visit. Finally, Phase 3, the post-encounter reflection, refers to activities following the encounter with the clinician—specifically, whether the dyads continued to reflect on their decision making about the vaccine by conducting additional research and/or engaging in further discussion with friends or family members. We highlight the three phases at each site to elaborate the differences between an *encounter*-based (Site 1) and a *process*-based (Site 2) model of decision making.

Site 1: An encounter-based model

Phase I: Pre-encounter—Prior to the clinician visit, both mothers and daughters at the first clinic site reported not knowing much about the HPV vaccine. In some cases, when arranging the interviews, mothers were uncertain of the daughter’s vaccination status. One mother of five, whose daughter received the vaccine at school, commented, “I don’t know if they gave her the vaccine. I don’t think they gave it to her. But they were saying that she needed it.” Even if they had heard about the vaccine, the details were fuzzy, such as in this example of a mother who stated, “I heard that it prevents...I don’t know...but it does help with different cancers and stuff. I mean, I just heard little bits and pieces about it.” Similarly, the daughters’ responses indicated that they also were not clear about the specifics of the vaccine. When asked if she had heard of the HPV vaccine, a 14-year-old stated, “I think so,

but I don't remember." The daughters also reported that they had largely not discussed the vaccine with anyone before receiving it—either their parents or peers.

Questionnaire data also suggest that dyads from this clinic had limited knowledge of HPV and the HPV vaccine. We asked participants eight basic yes/no questions about HPV and the vaccine and gave respondents one point for each correct answer. Out of a perfect score of 8, we grouped knowledge scores into two categories: low (0–4 correct responses) and high (5–8 correct responses). Half of the mothers (3 out of 6) exhibited low knowledge of HPV and the vaccine, while the daughters (4 out of 6) exhibited lower knowledge.

Despite limited knowledge about HPV transmission and prevention, mothers perceived a high sense of sexual risk for their daughters that heightened their receptivity to the HPV vaccine. Their concern about their daughters' sexual health was raised because of behaviors of their older siblings, such as drug use and teenage pregnancy, as well as their own experiences with sexually transmitted infections, childhood sexual abuse, early pregnancy, and marital infidelity. As one mother put it, "[The vaccine] came out and they said that it was to prevent the HPV. And I said, 'Oh, this is something that my daughter needs.'... Personally I've had trouble with my Paps in the past. It's something that you just don't want to go through." Not surprisingly, the daughters did not perceive as great a sense of risk for themselves when asked about it or mention the same types of concerns that their mothers did.

Phase 2: Encounter with clinicians—We explored parental and adolescent girls' perceptions about their interactions with clinicians, both in a general context and more specifically in relation to the HPV vaccine. Questionnaire data reflect that mothers at Site 1 generally felt comfortable in their interactions with clinicians. When asked how confident (on a scale of 1 to 5 with 1 being "not at all confident" and 5 being "very confident") they felt that they could get doctors to answer their questions about their daughter's health care, half of the mothers responded with a 5 and half responded with a 4, indicating a high level of confidence. Likewise, half of the mothers responded with a 5 and half responded with a 4 when asked how confident they felt that they could get their doctors to take their main health concerns about their daughter seriously. However, questionnaire data also suggest that mothers from Site 1 had greater health literacy challenges, including filling out medical forms (2 of 6 mothers reported they were only "a little sure" they could fill out forms by themselves) and learning about health problems (3 out of 6 mothers reported that they "often" had problems learning about a health problem because it is hard to understand written information).

These challenges may provide insight into vaccine discussions and interaction that we detected between the dyads and clinicians. Mothers and daughters at Site 1 generally portrayed the interaction with the clinician as being minimal, such as this mother of a 12-year-old who said, "Jeez, I don't remember anymore. The doctor said that it was good, but she doesn't talk a lot. All she said was, 'Yes, it's good. Let's give it to her.'" The girls also reported minimal interaction with the clinician about the vaccine, such as this 14-year-old who remembered, "All they told us was, like, that something bad would happen if you didn't get it. They didn't tell me if you did get it what the risks were." This daughter's comments

are reflective of the general lack of participation in the decision-making process. Another girl, aged 13, reflected, “I don’t really ask questions to the doctors. Like, I don’t know what the shots are about that I took.”

The dyads at Site 1 also described relatively passive relationships with their clinicians, a sentiment echoed by a female physician’s assistant who explained, “A lot of parents just have a lot of trust in doctors. If the doctor recommends it, then you need to have it. You get very few people who say, ‘You know what, let me read about it.’” Indeed, those who were either unvaccinated or partially vaccinated stated that the reason they did not get the vaccine (or subsequent doses) was simply because the clinician had not raised the topic. For dyads at Site 1, decision making primarily occurred during the clinician encounter and in response to the clinician’s recommendation of the vaccine.

Phase 3: Post-encounter—Lastly, we inquired about how mothers and daughters later felt about the decision to get the vaccine or not. The dyads who had made the decision to get the vaccine expressed unanimous satisfaction with their decision. As one 14-year-old stated, “I feel better...because I know that if something were to happen to me, like sexually, that I know I’d be protected...with the shot.” Despite her affirmative feelings about the vaccine, though, this girl was still not clear about the purpose of the vaccine. Indeed, our questionnaire data suggest a disconnect between vaccination and awareness of risk, despite indicating satisfaction during interviews. For example, only one of the four mothers and none of the daughters from the group receiving the vaccine “strongly agreed” that they knew the vaccine risks on the questionnaire.

Some of the mothers’ positive feelings about their decision to get their daughters vaccinated may have been related to the heightened sense of sexual risk they felt for them. A mother whose eldest daughter had gotten pregnant at age 15 shared, “Now at least I know that she’s protected from that. There are so many illnesses because of sex that you don’t even know how to protect them.” Though not entirely clear on which sexually transmitted infections the vaccine targeted, this mother nonetheless felt that any degree of additional protection was worthwhile, a feeling shared by the mothers at Site 1.

Site 2: A process-based model

Phase 1: Pre-encounter—At Site 2, by contrast, mothers and daughters described a different pattern in the pre-encounter phase. They were already more knowledgeable about HPV and the vaccine prior to the clinic visit. All four of the mothers at this site scored in the high knowledge category as did four of the six adolescent girls. One 13-year-old shared, “I remember in 7th grade they asked me if I wanted the shot and...I was confused about what it was and then I went to researching it.” Some of the adolescents at Site 2 had already discussed it with peers, such as this 13-year old who stated, “I just told some of my closer friends about it. I was like, ‘I’m going to do this’ and they’re like, ‘Oh, my God. Isn’t that the one where they put the needle down your back?’ They made it sound like an epidural. I’m like, ‘Are you kidding me? No. That’s not the way it is.’ I’ve heard a lot of rumors about it so I talked to the girls.”

Beyond just having more knowledge about the vaccine and discussing it with peers, several of the dyads had discussed the vaccine with each other prior to being offered the vaccine by a clinician. Referring to her daughter, one mother shared, “She brought it up. She said, ‘You know, maybe I should get that vaccine.’ And I’m like, ‘Why? Why are you thinking about that now? Are you giving me subtext of other information?’ She’s like, ‘No, but if it’s something that can protect me from cancer I think it would be a good vaccine.’” Consistent with these findings, several of the dyads reported in the interviews that they had discussed the vaccine with other friends and family members. The same mother reported, “The group I usually discuss it with is my book club. It’s all women and we all have kids and so it’s just kind of like a normal subject.”

Mothers at this site did not express a heightened concern about their daughters’ sexual risk or mention their own experiences with irregular Paps or anything else as influencing their views of the vaccine. As the mother of a 13- and 15-year old stated, “...my girls are good girls and they hang out with good girls...so far I’m not real concerned.” The daughters also minimized their own sense of personal risk, with some making a clear link between risk and sexual activity. One 13-year-old stated, “I don’t think I’m at risk for HPV. At this point, no, because I’m not sexually active. But once I start having sex, probably.”

Phase 2: Encounter with clinicians—In contrast to the pattern observed at Site 1, the decision to vaccinate was an evolving and multi-step process for dyads at Site 2 with a more multifaceted pattern of interacting with the clinician. Questionnaire data reflect that mothers at Site 1 felt extremely comfortable in their interactions with clinicians. When asked how confident (on a scale of 1 to 5 with 1 being “not at all confident” and 5 being “very confident”) they felt that they could get doctors to answer their questions about their daughter’s health care, all four mothers responded that they were “very confident.” All four mothers similarly felt “very confident” that they could get their doctors to take their main health concerns about their daughter seriously. Questionnaire data also suggest that these mothers felt confident in their ability to read and understand medical information; all 4 mothers reported that they “never” had problems learning about a health problem because it was hard for them to understand written information given to them by clinicians.

The dyads shared their experiences evaluating the risks and benefits of the vaccine, in addition to considering clinicians’ endorsement of it. As one mother reflected, “I had to decide if I was going to give it to her or not. And I went through that, hmmm, do I want my kid to have a vaccine? Are vaccines good?” One of the female family physicians estimated that half of the patients she offered the vaccine to agreed to take it on the spot, while the other half ultimately took more time to reflect on it.

The dyads generally indicated an active relationship with clinicians (all daughters at this site reported having a regular clinician compared to only half at Site 1) and both mothers and daughters came into the clinic interaction with more knowledge of HPV and the vaccine. Consistent with this overall pattern, the mothers at Site 2 afforded a higher degree of autonomy to their daughters. As a mother of a 14-year-old stated, “I think [she’s] fairly well-informed. If the doctor can share her perspective I would be glad to hear what her feeling was. I think she would probably have a good concept of when it’s time to get that. She has a

pretty good head on her shoulders, for the most part, good common sense.” The daughters’ description of this extended decision-making process demonstrated a higher degree of involvement with the parent. Interestingly, one female clinician felt that the children were *too* involved in the process, stating: “[The decision] really rests on the parent but a lot of modern parents are very permissive and if their child says no, they don’t want something, that’s the end of the discussion.” In this multistep decision-making process, then, the clinician played an important, though less influential, role.

Phase 3: Post-encounter—The dyads at Site 2 were also satisfied with their decisions regardless of whether or not vaccine receipt was the final outcome. As one 13-year old stated, “I’m happy that I got it whether it hurts or not because I’m pretty sure cervical cancer hurts a lot more than that.” Questionnaire data revealed that the mothers at this site expressed no decisional regret. In addition, all of the mothers (4 out of 4) “strongly agreed” or “agreed” with statements stating that they knew the benefits and the risks of the vaccine. All of the dyads agreed that they would make the same decision to get—or not get—the vaccine again. A 15-year-old who decided against receiving the vaccine shared that she would make the same decision again, “because I feel like it was thoroughly researched...my research was done so I feel like I know well enough about it to make that decision.” Though they were knowledgeable about HPV and the vaccine, mothers at Site 2 also found that the information we presented (whether new or not) reinforced their decisions. As the mother of the aforementioned 15-year old reflected, “I feel better actually about it. And now that I know a lot more about it...it’s going to help... make decisions for the future for them. It will help them make decisions.”

Discussion

Findings from this study contribute to an expanding literature on actual decision-making processes for the HPV vaccine in the post-licensure period (Mathur *et al.* 2010; Allen *et al.* 2010; McRee *et al.* 2010), highlighting the need to examine different decision-making pathways for the HPV vaccine. We encountered distinctly different decision-making processes in our examination of two clinic sites from different healthcare systems in an urban setting in New Mexico. At Site 1, we identified an *encounter*-based model of decision making. There was little or no prior awareness of the vaccine but a general predisposition of the mothers towards perceiving higher risk in their daughter’s (potential) sexual behaviors. Clinicians generally initiated the conversation about the vaccine, and the dyads deferred the decision to the clinician. While participants expressed no overt decisional regret, the mothers and daughters were not entirely confident in the choice and did not feel like they had enough information.

Dyads at Site 2 shared a pattern of decision making that we characterized as a *process*-based model in which the clinical encounter was only one step and decision making was more equally distributed among actors and across phases. Mothers and daughters were more knowledgeable about the vaccine going into the clinical encounter and many had already discussed the vaccine with each other or with others. The dyads at Site 2 also saw the clinician’s recommendation as one piece of the decision-making puzzle. Some dyads delayed their decision after the clinical encounter, taking more time to evaluate it; some then

reengaged in discussions about the vaccine with members of their social and family networks. The adolescent girls at Site 2 also took a much more active role in deciding about the vaccine—both in decisions to get it and not to get it. Our questionnaire data suggest that the dyads at Site 2 were more confident that they had enough information to make an informed decision.

Comparisons with existing literature and implications

Much of the literature has framed vaccine acceptance and decision making in reference to ethnicity, to the extent that they have examined ethno-cultural differences in decision-making patterns (McRee *et al.* 2010; Cates *et al.* 2009; Constantine and Jerman 2007; Scarinci *et al.* 2007). Despite the samples from both study sites being predominantly Hispanic, we found key differences between them, suggesting that ethnicity alone does not fully explain HPV vaccine decision making differences. Variations in other factors including education, socio-economic status, and health care access likely play a role in vaccination decisions. This perspective is consistent with findings from a recently published study examining parental attitudes toward school-located administration of adolescent vaccines. The authors found that parents who were unmarried and had children who attended schools with the highest percent eligibility for free/reduced lunch were the most willing to consent for vaccines at school (Kelminson *et al.* 2012).

While this mixed-method study cannot specifically identify the source of these differences, our findings offer support for this type of interpretation, especially in light of the similar vaccine delivery conditions in each of the clinic settings. Despite dyads being primarily Hispanic at both sites, Site 2 is located in a more socially advantaged neighborhood, these mothers had a more comfortable command of English, and the mothers and daughters interacted in an environment in which they received knowledge and information about HPV and the vaccine outside of the health care setting.

Consistent with other studies, we found that clinicians' recommendations were influential (Lechuga *et al.* 2011; Brewer and Fazekas 2007; Guerry *et al.* 2011; Reiter *et al.* 2009; Rosenthal *et al.* 2010). However, our findings suggest a more nuanced role of clinician recommendations in actual vaccine receipt. In Site 1, clinician recommendations were cited as an essential component in HPV vaccine decision making, whereas in Site 2, the clinician's input was highly valued though not seen to be determinative. In both clinic sites, not surprisingly, and consistent with other studies, competing clinical demands likely undermine opportunities to foster informed decision making about the HPV vaccine (Nordin *et al.* 2010). Lastly, these clinicians are unable to actively track and remind patients about their vaccination status, leading to missed opportunities, not only in seeing patients but in providing relevant information to adolescents and their parents.

This study highlights the importance of identifying specific informational needs and communication strategies among adolescent patients and their mothers about the HPV vaccine. We found that those who participated in the more passive, encounter-based decision-making model (Site 1) were just as satisfied with the decisions they made as those who more actively engaged in the process-based decision-making model (Site 2). A key difference was that dyads from Site 2 preferred to engage in discussions with clinicians as an

additional source of information, while mothers from the former group expressed their preference for a strong directive from the clinician.

While previous studies suggest that Hispanics are more likely than non-Hispanic Whites to prefer such a directive from the clinician (Levinson *et al.* 2005), our findings suggest that neither race nor ethnicity alone sufficiently explain differences in decision making. Given that education and socioeconomic status are often identified with less-than-optimal utilization of health interventions, the challenge for health practitioners is to identify and utilize innovative approaches to optimize vaccine use (and other preventive health behaviors) in these populations. The results of this study and others should inform the development and testing of tailored strategies to overcome barriers created by education, socioeconomic status, health care access, and other related factors.

Limitations

This study focused on predominantly Hispanic mother-daughter dyads and the clinicians who serve them in two clinics located in urban New Mexico. The transferability of these findings, therefore, to Hispanic populations located elsewhere in the United States and to other clinical settings nationwide may be limited. The generalizability of these findings might also be limited by the small sample size, rendering the decision-making models presented here as preliminary. However, given that we found distinct decision-making pathways *within* the Hispanic population, we believe it is not appropriate to generalize these findings to the extremely diverse U.S. Hispanic population on the basis of ethnicity alone. Instead, further research is needed to clarify how education, socioeconomic status, and clinician/system contextual factors influence decision making across diverse populations and settings.

Another potential limitation of the study is that there may have been differences in vaccine delivery across the two clinic sites that influenced experiences in vaccine decision making that we did not detect. However, we identified consistency in key structural elements of the practice setting, including vaccine availability, dissemination challenges, and of clinician endorsement, therefore supporting our findings that factors external to the clinical setting more likely explain these decision-making differences.

Conclusion

Given sub-optimal levels of HPV vaccine dissemination, the more pressing inquiry now should be assessing the full range of factors influencing vaccine receipt, including the ways in which parents and daughters—in concert with their primary care clinicians—are making vaccination decisions. Our findings demonstrate variability and complexity in decision-making processes related to ethnicity and socioeconomic status. Further research is needed to understand these interrelationships as a way to guide our efforts in establishing interventions to enhance patient-clinician communication, develop/disseminate materials that address both cultural and socioeconomic factors, and are feasible for primary care clinicians in the context of their health care systems.

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Key Messages

This study highlights the importance of identifying specific informational needs and communication strategies among adolescent patients and their mothers about the HPV vaccine. Attributing HPV vaccine decision making differences to race and ethnicity may be an overly simplistic explanation. Variations in other factors including education, socio-economic status, and health care access likely play a role in vaccination decisions. Given that education and socioeconomic status are often identified with less-than-optimal utilization of health interventions, the challenge for health practitioners is to identify and utilize innovative approaches to optimize vaccine use in these populations.

Table 1**Dyad Participant Demographics**

	Site 1 mothers (n=6)	Site 1 daughters (n=6)	Site 2 mothers (n=4)	Site 2 daughters (n=6)
Mean age	40	13.3	45.7	14
Ethnicity	Hispanic (6)	Hispanic (6)	Hispanic (2) Non-Hispanic white (2)	Hispanic (5) Non-Hispanic white (1)
Birthplace	Mexico (4) U.S. (2)	U.S. (5) Mexico (1)	U.S. (3) England (1)	U.S. (6)
Language preference	Spanish (3) Both (3)	English (5) Spanish (1)	English (4)	Both (3) English (3)
Educational background	Less than HS (2) HS (2) Some college (1) Bachelor's (1)	6 th (1) 7 th (2) 8 th (2) 11 th (1)	Some college (1) Bachelor's (1) Post-graduate (2)	7 th (1) 8 th (3) 9 th (1) 10 th (1)
Vaccination status	n/a	Fully vaccinated (3) Partially vaccinated (1) Unvaccinated (2)	n/a	Fully vaccinated (3) Unvaccinated (1) Refused (2)
Access to a Regular Provider (Care Continuity)	n/a	Yes (3) No (3)	n/a	Yes (6)

Table 2

Models of HPV Vaccine Decision Making

	Phase 1: Pre-Encounter	Phase 2: Encounter	Phase 3: Post-encounter reflection
Encounter-based (Site 1)	<ul style="list-style-type: none"> Little or no prior awareness/discussion of HPV vaccine Difficult life circumstances – heightened sense of risk 	<ul style="list-style-type: none"> General acceptance of clinician recommendation 	<ul style="list-style-type: none"> Little additional thought about or discussion of HPV vaccine Little to no decisional regret
Process-based (Site 2)	<ul style="list-style-type: none"> Greater exposure to information and discussion in social network 	<ul style="list-style-type: none"> Evolving decision – may postpone to assess 	<ul style="list-style-type: none"> Vaccine receipt decision may still be pending Re-engagement with social networks Little to no decisional regret