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Abstract

In 2009, Virginia became the first state in the United States to enact a school vaccine mandate for the human papillomavirus (HPV), putting it at the forefront of the national HPV vaccine mandate controversy. It is critical to explore the public response and sensemaking where the mandate has already been enacted. Thus, we conducted 8 focus group discussions among 33 Virginia parents to explore how they conceptualized the virus and vaccine and their responses to the mandate. Findings suggest that many parents are skeptical of and reluctant to follow a state-mandated vaccine requirement, choosing instead to opt out of the vaccine until they decide the time is right for their daughter and/or until they feel confident in their knowledge about the virus, vaccine, and the impetus for the mandate. Study results can inform future legislation among states considering HPV-related mandates and aid in the development of health-promotion materials within the context of a state mandate.

Keywords

cancer; communication; community and public health; decision making; families; immunization; parenting; relationships, parent-child; sexuality / sexual health; women's health

In 2006, the United States Food and Drug Administration (FDA) approved the use of Gardasil for young women, the first vaccine developed for the prevention of human papillomavirus (HPV), a sexually transmitted infection (STI) that is linked to cervical cancer (FDA, 2012b). The following year, the Commonwealth of Virginia passed a mandate that would require all girls entering the sixth grade to be vaccinated against HPV (Virginia Legislation Code ch. 2, § 32.1-46.01, 2010). The mandate went into effect in September 2009. Since then, parents of adolescent daughters have had to make a decision about whether to vaccinate their daughter or to select the informed opt-out provision (Virginia Legislation Code).

The Virginia mandate did not come without controversy. Despite a 2011 vote by the Virginia House of Delegates to repeal the mandate (Associated Press, 2011; Virginia House Bill 1419, 2011), the mandate was upheld by the Virginia State Senate; therefore, Virginia remains the first and only state to successfully enforce a vaccine mandate for a virus that is primarily transmitted through sexual contact (National Conference of State Legislatures [NCSL], 2011; Virginia Legislation Code, 2010). Although the mandate was praised by many health and legislative officials, it was a significant cause for concern among parents (St. John, Pitts, & Tufts, 2010).

HPV is a serious public health issue. The Centers for Disease Control and Prevention (CDC; 2012) estimated that each year in the United States there are about 12,000 new cases of cervical cancer—almost all of which are HPV related. There are more than 6,000 cases of other HPV-related cancers diagnosed annually among men and women (e.g., vulvar, vaginal, penile, and anal; CDC, 2012). The American Cancer Society (2012) estimates that there will be 4,200 deaths from cervical cancer in 2012. HPV is a significant health burden on families, communities, and the nation. It is also a significant financial burden. HPV is second only to HIV in terms of health care cost allocations for sexually transmitted infections (Luedtke, 2008).

Because the HPV vaccine is relatively new and under consideration for mandatory vaccination in other states (NCSL, 2011), and has recently become a topic of national debate (e.g., Grady, 2011), understanding how parents

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interpret and respond to issues surrounding the virus, vaccine, and mandate is valuable for informing future HPV-related policies, especially when health outcomes, such as cancer prevention, are at stake. Although previous research suggested that “a school-based immunisation programme is likely to meet with a favourable response” (Marlow, Waller, & Wardle, 2007, p. 1950), there has not yet been an opportunity to test this assumption. Thus, Virginia offers a unique case in which to explore the implications for parental vaccine acceptance within the context of a state mandate, and implications for other states considering similar action. The purpose of this investigation was to identify and describe the ways parents/guardians made sense of the virus and the HPV vaccine (within the context of a state mandate) and how they responded to the mandate.

Background

Human Papillomavirus and Vaccine

HPV is the name given to a group of viruses that includes more than 100 different types (CDC, 2010c). Of those, more than 40 types can infect the genital area (CDC, 2012). The International Agency for Research on Cancer (IARC, 2010) categorized these types as “low-risk” (genital warts) and “high-risk” (cervical and other cancers). HPV types 16 and 18 are carcinogenic to humans, with type 16 being the strongest carcinogen (IARC). At least 15 other types have demonstrated a “convincing association” with cervical cancer (IARC). Genital HPV is the most common sexually transmitted infection in the United States (CDC, 2010b). It is transmitted through sexual contact, infecting the skin and mucous membranes of the genital area in both men and women (CDC, 2012). The CDC (2012) estimated that in the United States about 20 million people are currently infected with HPV, an additional six million people become newly infected each year, and at least 50% of people who are sexually active will become infected at some point in their lifetime. HPV is also linked to other, less common but serious health outcomes, such as warts in the throat (recurrent respiratory papillomatosis), other genital cancers in women (i.e., vulva and vagina) and men (i.e., penis and anus), and oropharynx cancer (i.e., back of the throat, tongue, and tonsils; CDC, 2012).

Currently, there are two HPV vaccines available in the United States (FDA, 2012a, 2012b). Gardasil, approved by the FDA in 2006 for girls and women, provides protection against the two types of HPV that are most commonly linked to cervical cancer (16 and 18) and genital warts (6 and 11; FDA, 2012b). Cervarix, approved for girls and women by the FDA in 2009 (FDA, 2012a), prevents types 16 and 18. In 2009, Gardasil was also approved by the FDA for use among boys and men for the

prevention of types 6 and 11; protecting against most HPV-related genital warts and anal cancers (CDC, 2012; FDA 2012b). These new vaccines have the potential to prevent an estimated 70% of cervical cancer cases and 90% of genital warts cases (CDC, 2010a).

HPV Legislation Trends

School vaccination requirements are set by individual states. Virginia is the only state that has instituted a mandate requiring that girls entering the sixth grade receive the HPV vaccine. One unique aspect that distinguishes this vaccine mandate from other school-related vaccine requirements is the informed “opt out.” Specifically, Virginia Code Section 32.1-46(D) (3) recognizes that HPV is not communicable in a school setting and therefore allows parents to elect for their child not to receive the vaccine after reviewing materials approved by the State Board of Health that describe links between HPV and cervical cancer (Virginia Legislation Code, 2010).

At least 20 states and Washington, DC, have enacted HPV-related legislation, and 17 states currently have proposed legislation or resolutions regarding HPV and the HPV vaccine (NCSL, 2011). However, the majority of HPV legislation targets girls only; at the time of this writing there is no legislation proposing a mandated HPV vaccine for boys. Despite these attempts, legislation to mandate the HPV vaccine has failed or been delayed around the country, likely because of the debate surrounding the necessity of such a mandate and concerns about the vaccine (see Grady, 2011).

Many people and many state legislatures support the availability of and access to the vaccine, but do not support a school vaccine requirement (NCSL, 2011). Financing is one key concern, in terms of covering the cost of the vaccine as well as costs related to vaccine information dissemination. Currently, the HPV vaccine is available in all 50 states for children ages 9 to 18 who are on Medicaid, children who are Native Alaskan or Native American, and some uninsured and underinsured children through the Vaccines for Children (VFC) program (NCSL, 2011). Concerns other than costs center on issues regarding the safety of the vaccine, parents’ right to refuse, moral objections regarding mandating a vaccine against a sexually transmitted infection, and beliefs that vaccine-preventable diseases are rare (Olshen, Mahon, Wang, & Woods, 2007).

Literature Review

For preadolescent children, parental vaccine acceptance is the most important factor in whether or not a child will be vaccinated (Zimet, 2005). This is because, in most cases, the child will need parental consent to receive the vaccine (Zimet). In the following brief review of the literature we

outline influences and barriers to parental vaccine acceptance regarding the HPV vaccine outside of the context of a state mandate. Findings from these studies lay the groundwork for investigating how parents frame and respond to the vaccine within the context of a state mandate and the implications for parental vaccine acceptance.

Parental HPV Vaccine Acceptance

Early studies regarding parental acceptance of an HPV vaccine for preadolescent daughters demonstrated positive attitudes toward the vaccine and a substantial trend toward reported willingness to vaccinate (Brewer & Fazekas, 2007; Chan, Cheung, Lo, & Chung, 2007; Zimet, 2005)—up to 75% reported in one study (Marlow et al., 2007). However, parental acceptance of the HPV vaccine relies on several factors. For example, parental acceptance is positively associated with physician recommendation, positive beliefs about vaccines, and the belief that their child is at risk for an STI (Dempsey, Zimet, Davis, & Koutsky, 2006; Olshen, Woods, Austin, Luskin, & Bauchner, 2005). Olshen et al. (2005) demonstrated that parental acceptance is also influenced by perceptions of vaccine efficacy, cost, and HPV knowledge. Additionally, for parents, belief in the social benefits of HPV vaccines, peer group vaccination norms, personal experience with genital warts, and considering a daughter (compared to a son) were also positively associated with HPV vaccine acceptance (Dempsey et al.). Unlike Olshen and colleagues' (2005) earlier finding, Dempsey et al. did not find a significant relationship between increased HPV knowledge (prompted by HPV-related health information materials) and parental vaccine acceptance.

Barriers to Parental HPV Vaccine Acceptance

Barriers to parental HPV vaccine acceptance include concerns about vaccine safety, concerns that multiple vaccines might lead to a weakened immune system, and beliefs that children might experience significant discomfort or danger when receiving the immunization (Dempsey et al., 2006; Marlow et al., 2007). Lenselink et al. (2008) reported that among Dutch families, parents who opposed the vaccine were concerned about delayed side effects and wanted to wait several years after the release of the vaccine to immunize their children. Additionally, lack of HPV-related knowledge and misinformation about the virus and vaccine might be detrimental to vaccine acceptance (Gust et al., 2005). For example, parents who felt uninformed about the vaccine held negative attitudes toward immunizations, providers, and vaccine requirements, and held low levels of trust in people responsible for immunization policy (Gust et al.).

Knowledge pertaining to HPV and its relationship to cervical cancer is relatively low among parents and adolescents in the United States (Friedman & Sheppard, 2007; Gerend & Shepherd, 2007; Mosavel & El-Shaarawi, 2007; Vanslyke et al., 2008). Lack of HPV-related information and misinformation results in problems such as confusing HPV with HIV (human immunodeficiency virus), confusion about the severity of HPV and the ways in which the virus spreads, and not knowing what the cervix is or what cervical cancer is (Mosavel & El-Shaarawi; Olshen et al., 2005).

Demographic characteristics, such as ethnicity and religiosity, have been linked to lower rates of vaccine acceptance also. For example, Constatine and Jerman (2007) found that African American and Asian American families showed less willingness than Latino or White families to immunize their daughters. Vanslyke et al. (2008) reported that Hispanic women in their investigation had significant concerns about and negative attitudes toward the possibility of a school HPV vaccine requirement. Marlow et al. (2007) reported that compared to low religiosity families, families who scored high on religiosity were less likely to accept the vaccine, or more likely to delay the vaccine until their daughter was older.

An additional inhibiting factor for parental vaccine acceptance is some parents' concern that by vaccinating their daughters against HPV they would be condoning sexual promiscuity or that the vaccine might lead to a false sense of security and promote unsafe sexual behavior (Chan et al., 2007; Mays, Strum, & Zimet, 2004; Olshen et al., 2005). Concerns about raising the risk of unsafe sexual practices following the vaccine might stem from vaccine-related media reports. For example, Forster, Wardle, Stephenson, and Waller's review of articles published between 2003 and 2008 in the United Kingdom demonstrated that although news reports provided parents with "broadly positive descriptive norms about vaccination" (2010, p. 205), the media reports also included significant and regular discussion about adolescents engaging in risky sexual behavior following an HPV vaccination.

Previous research has demonstrated that parental attitudes toward and knowledge about HPV and the HPV vaccine influences their willingness to accept the vaccine for their preadolescent daughter (Dempsey et al., 2006; Lenselink et al., 2008; Olshen et al., 2005). Moreover, despite Marlow et al.'s (2007) suggestion that a school-based vaccination program could be positively received, and research indicating that parents generally hold positive attitudes about the HPV vaccine (Constatine & Jerman, 2007), parents' attitudes toward the vaccine within the context of a state mandate are unknown. In light of national debate and increased trends toward HPV legislation, it is critical to understand how parents make sense of and respond to the virus, vaccine, and mandate.

Therefore, we posed two exploratory research questions: How do parents/guardians make sense of the HPV virus and vaccine? How do parents/guardians respond to the HPV vaccine school mandate?

Methods

We used focus group discussions to tap into parental perceptions about the virus, vaccine, and mandate. We then engaged in thematic analysis (Coffey & Atkinson, 1996; Strauss & Corbin, 1998) to uncover patterns among parents' expressed concerns, perceptions, thoughts, and so forth regarding the virus, vaccine, and mandate. Focus group discussions offer insight into the shared impressions of specifically targeted groups of people (Rubin & Rubin, 1995)—in this case parents/guardians of preadolescent daughters. Focus groups have been employed successfully to identify public opinions and knowledge regarding a host of health- and community-related issues such as HIV/AIDS (Tufts, Wessell, & Kearney, 2010), cancer (Marks, Reed, Colby, & Ibrahim, 2004), and the HPV vaccine (Mosavel & El-Shaarawi, 2007; Olshen et al., 2005; Vanslyke et al., 2008), and in community-based participatory research (Daley et al., 2010). This method of data collection has the potential to yield positive effects beyond strengthening our knowledge of how parents frame the HPV vaccine and respond to the mandate. Focus group interactions can also enhance community members' knowledge about the topic, influence community members to participate in public dialogues regarding the issue, and heighten participants' communicative self-efficacy (Zorn, Roper, Broadfoot, & Weaver, 2006).

Procedures

The Old Dominion University Institutional Review Board approved this study, which took place in the Hampton Roads region of Virginia. The Hampton Roads metropolitan area is the 35th most populous in the United States. It includes Virginia's largest city, Virginia Beach (population 433,746), and has a diverse population of more than 1.6 million people (U.S. Census Bureau, 2012). Participants completed the informed consent process, including discussion about voluntary participation, the right to withdraw, confidentiality, benefits, and risks of the investigation. Each participant gave informed consent and received a \$25 grocery store gift card as a token of appreciation.

Participants and recruitment

We used purposive and convenience sampling to screen and recruit participants. We recruited through the public school system, newspaper advertisements, by posting recruitment flyers in community centers and public

spaces, distributing fliers at softball games and summer camps, and through electronic list serves. Eligible participants were parents and guardians ("parents" hereafter) of girls entering the fourth through seventh grades (ages approximately 9 to 13) in the Hampton Roads region. Thirty-three people (28 women, 5 men) participated in the discussions. Thirty participants were birth parents; additionally, 1 aunt and 2 grandmothers participated. Eighteen participants were White, 12 were African American, 2 were Asian, and 1 was Latino. The average age of the daughter for whom participants were considering the vaccine was 12 years.

Focus groups

We facilitated eight focus group discussions. The research team facilitating the interviews was comprised of women (the authors and two assistants). All but one focus group included an African American and a White facilitator. Our research team also spanned four age cohorts. Given our diverse sample, diversity in our ages and races as facilitators likely helped increase many participants' level of comfort and perceptions of trustworthiness (Barbour, 2007). Four focus groups were mixed-gender; the remaining four were all comprised of women. One focus group was held at a Boys and Girls Club, one was held at a community-based dance school, and the remaining six were held on a university campus. Focus group discussions lasted approximately 2 hours each and were held either on a weekend afternoon or a weekday evening.

We posed questions in a funnel-type pattern (see Figure 1). The session started with broad questions designed to orient participants to each other. We then asked questions designed to elicit general knowledge about the vaccine and the virus. Finally, we asked questions designed to elicit opinions about the mandate. We concluded each focus group with a brief information session about HPV, the vaccine, and the state mandate.

We audio recorded the focus group discussions and one or two note takers were present during each session. We instructed note takers to take detailed notes of participants' talk and nonverbal cues for use in transcription and data analysis. To reduce challenges with transcribing multiple voices (see Kidd & Parshall, 2000) and ensure accuracy of the transcript, one member of the research team who was present at a specific focus group prepared that transcript alongside the detailed set of notes from that session. Then, we compared the typed transcripts to audiotapes to ensure accuracy.

Coding and Data Analysis

We used thematic analytic procedures described by Coffey and Atkinson (1996) and Strauss and Corbin

1. Please introduce yourself. Tell us your first name, the name and age of your daughter, and tell us about something you and your daughter enjoy doing together.
2. How many of you have heard about HPV (the human papillomavirus)?
3. What do you know about HPV?
4. How many of you have heard about the new HPV vaccine, Gardasil?
5. What do you know about the new HPV vaccine?
6. How do you feel about the new the HPV vaccine?
7. What are your thoughts about the 2009 state mandate to vaccinate 6th-grade girls against HPV?
8. What decisions have you made about vaccinating your daughter?
9. How did you go about making your vaccination decisions?
10. How did you become informed about the HPV vaccine?
11. What messages have you heard about the HPV vaccine?
12. What messages are the most influential to you as you make the vaccination decision?
13. What messages are the least influential to you as you make the decision to vaccinate or not?
14. What issues are the most important for you to consider while making this decision?
15. What issues were the least important for you to consider while making this decision?
16. Please take 2 minutes to jot down a summary of your perspective on the HPV vaccine for your daughter. We would like to give each parent one minute to summarize his or her final thoughts.
17. Have we missed anything?

Figure 1. Focus group discussion questions.

(1998) to collaboratively organize data by inductively deriving categories from the themes evident in parents' responses to focus group questions and ensuing discussions. We coded responses at both the individual and group levels by using single-participant utterances, as well as interparticipant linked turns at talk, as the units for analysis. We coded the transcripts and notes by focusing broadly on parental framing and narrowly on responses to the new state mandate. This system of coding allowed us to identify core concepts and develop provisional themes. Themes, as defined by DeSantis and Ugarriza represent "an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole" (2000, p. 362). As thematic categories emerged, we discussed responses that did not fit the coding scheme, and when necessary, we revised the coding scheme to accommodate new data. We engaged in each stage of coding and analysis collaboratively, simultaneously reading and coding each transcript, and negotiating each analytic decision.

To meet the "trustworthiness" criteria of qualitative research, we used Lincoln and Guba's (1985) dependability, credibility, transferability, and confirmability benchmarks. We met the dependability criterion by achieving theoretical saturation in the final focus groups. Theoretical saturation occurs when no new themes emerge from additional data and there is significant overlap and repetition of themes across a diverse data set. Theoretical saturation is the signpost in qualitative data analysis that indicates to the researchers that they are nearing completion of data collection because no new information is surfacing from

additional data (Schwandt, 1997). For example, themes that emerged from the last two focus groups were similar to earlier groups and did not generate new insight, but rather reinforced ideas expressed in earlier groups. We achieved credibility by using in-vivo codes when possible and demonstrated participants' voices through vivid extracts of the discussion. To ensure transferability, we provided sufficient detail about the HPV mandate case and parental responses to increase likelihood of transferability to other similar cases (see the rationale section above regarding the many other states considering a similar mandate, and the description of the Virginia mandate). Finally, we addressed confirmability of findings by linking interpretations to data and linking data to previous research (see discussion).

Results

How Parents Made Sense of HPV and the Vaccine

Age and maturity. Parents considered their (respective) daughter's age and level of maturity in their discussions about HPV and the vaccine. Parents were concerned that the sixth grade is "a young age to expose my daughter to those risks on something I hope she [does not] even think about." This mother was concerned about potential risks related to unknown negative health implications of the vaccine. Although parents expressed hope that their daughter was not yet sexually active, they demonstrated an awareness of sexual activity among children in that age group (9 to 13 years). One parent acknowledged, "They're having sex at a lot earlier age now, so that's why

they're targeting earlier age groups [for the vaccine]. They want to get them before they start becoming active." Other parents questioned why the mandate is for preadolescent girls: "Is it because they think that girls in middle school will start their [menstrual] cycles?" Parents acknowledged difficulty in considering "a vaccination for a sexually transmitted disease for my baby." At least one parent voiced the concern that her daughter might engage in risky sexual behaviors if she felt the vaccine protected her from STIs: "Sometimes when you use preventative measures with adolescents who're not really informed, sometimes they feel like they have a safety net, and they may go farther than they would without that safety net."

After discussion of the vaccine's effectiveness before sexual activity, parents generally accepted the rationale that sixth grade was an appropriate time to start implementing the vaccine mandate. One father explained to another,

I think [sixth grade] is a good time to stick 'em with a shot if you're going to have to do it. . . . They are usually not sexually active yet. You're pretty darn positive your daughter's not, you know? But, I guarantee you when she's fifteen or sixteen, you might say that, but you might be surprised.

However, parental acceptance of the sixth grade as a starting point (i.e., "I don't have a problem with that; you [have] got to start somewhere") did not indicate their willingness to have their own daughter vaccinated: "I think it is a good way to have a mass level of vaccination so that you can gather more data, and to know that it is effective, but not on my child."

Comparison to other childhood vaccines. Parents compared HPV to common childhood illnesses and the HPV vaccine to other mandated or recommended vaccines. Most notably, parents compared HPV and the HPV vaccine to meningitis, polio, varicella (chickenpox), the MMR (measles, mumps, and rubella), rotavirus, and T-DaP (tetanus, diphtheria, and pertussis [whooping cough]) vaccines. One mother gave an account of her pediatrician offering the vaccine at her daughter's well-child visit: "You're thinking it's a 'regular shot' like with chicken pox, measles, mumps, [and] MMR. They don't really tell you the background of the shot." She drew a distinction between the HPV vaccine and what she considered "regular" vaccinations. The HPV vaccine is, in this sense, out of the ordinary. When compared to chicken pox, for example, parents (fathers in particular) remarked that they lacked information about and familiarity with HPV. The chicken pox vaccine was easier for parents to accept because they had familiarity with the virus and they understood how easily it is transmitted and how widespread infections are. One parent commented, "I think more information was out and we've all had the chicken pox, you know. We know

what to expect from that." Another expressed feeling more positive about a vaccine for chicken pox than for HPV, "Because one thing I know about HPV is that there's not a large [amount] of people that get cancer from it . . . relative to the number of infections that there are."

Why are we just hearing about HPV now? Another theme that was prominent within focus group discussions was a general concern about why HPV was only just then emerging as an important health topic: "People are just now really seeing [and] hearing [about] HPV." The consensus among parents was that they felt uninformed about the virus. The only exceptions were among those who had personal experience with HPV. Parents only became aware of the virus in light of the recently approved vaccine. In fact, for most parents, their first sources of information concerning the virus came from the Gardasil campaign and news reports about adverse effects of the vaccine. One parent posed a rhetorical question that captured a sense of skepticism about why HPV had only become a concern in light of the availability of a vaccine: "How many of us have heard about [HPV] before, you know, it hit the news? I don't know." She later followed with, "Is [HPV] something I worried about for my daughter before this vaccine came into light? Um, of all the things we are bombarded with [pause], it goes back to the plastic bottle or AIDS, um, I don't know." Before the vaccine, very few parents were aware of HPV. They questioned why they were only then hearing about such a major health concern:

Why haven't we heard of it before the advertisement on TV? [pause] I mean, an article in the paper or anything! I mean, like she said, the pediatricians who should have told us about it. That it's a concern to the CDC [Centers for Disease Control and Prevention]. Why?

Necessity. Parents questioned the necessity of the vaccine in light of the prevalence of the virus, as well as modes and ease of transmission. One parent asked, "Is the human papillomavirus infectious? Is it a huge epidemic for our country?" Another asked,

Are you gonna take this chance of getting a vaccination and it basically addresses a few diseases that one out of 7,000 people might come in contact with? Or . . . something that one out of five come in contact with? . . . What exactly are we preventing?

Parents also questioned the necessity of the HPV vaccine in light of other global social and health concerns:

There [are] so many other illnesses that are just as important, and other cancers that are so important,

and I just don't understand what the jump on [HPV] is all of the sudden. I'm not putting those down, like, "Oh, cervical cancer and genital warts, oh those are nothing." I'm not saying that. I'm just saying you don't hear a lot about them, first of all. I mean, AIDS, you hear of AIDS, you know, and all the other STDs [sexually transmitted diseases], and cancers, and heart attacks, and childhood obesity, and there's nothing [about HPV].

Prevention and protection. Parental discussions also centered on potential prevention and protection aspects of the vaccine. Uniformly, parents emphasized the potential good of the vaccine, agreeing that, "if you can help prevent something and there's something that will help prevent it, then you should do it. It's just a question of when you're going to do it." One message ran through the prevention/protection theme across focus groups: daughters need protection. Beyond a sentiment that the vaccine is a preventive measure because "who knows what life holds" was a more concrete message: "I don't know what decision she's going to make and there's always going to be that moment when, if there's that little bit extra that's going to help protect her from something, then I'm all for that." Parents were especially concerned about their daughter becoming a victim: "I'd rather protect my child than have one of you little nasty boys pass something on to her." Despite parental acknowledgment that the vaccine had potential benefits, they were skeptical about the protective benefits of the vaccine in light of the perceived risks.

Do we protect our daughter from the virus or the vaccine? Several parents felt the vaccination decision was a "Catch-22," referring to Joseph Heller's (1961) World War II novel in which the protagonist uses the term to describe a situation in which it is impossible to resolve a problem because the solution inherently leads to another problem and likely continues until the person is back at the original problem. Today, the term *Catch-22* is often loosely used to suggest that it is impossible to make a decision because the available solutions are problematic.

One mother asked, "Are we crucifying our kids for getting [the vaccine], or are we crucifying them for not?" Discussing implications of the vaccine requirement for school, one mother presented the issue as choosing "their education" or "possibly damaging their lives." Parents' uncertainty about possible negative future health implications of the vaccine left them with the perception that "you're playing with your kid's health." Many parents speculated about unintended consequences: "Does it have long-term effects? Is there something else that it's going to do? Maybe it protects [against] these four strands, but maybe it causes another strand, or it causes some kind of other cervical cancer, later on." Finally, parents gave significant consideration to consequences of what they perceived were possible short-term side effects (e.g., Bell's

Palsy, fainting, pain, weakness), and speculated at length about possible unknown long-term outcomes (e.g., infertility, autism, other types of cancer).

How Parents Responded to the Mandate

Parental rights. Several parents responded to the mandate by emphasizing that it was their parental right to make a vaccination decision about a sexually transmitted infection; that is, the decision to vaccinate should be a parental choice, not a governmental mandate. One mother stated that the mandate was particularly bothersome because of the nature of HPV transmission:

Even though I got my daughter vaccinated, I think it should be a parent's choice. . . . I don't want you telling me that I have to get my daughter vaccinated for something that is sexually transmitted. Are you next going to tell me that I have to put my daughter on birth control? And, I think that needs to be a parent's decision.

Another mother remarked that the mandate itself was a barrier to parental decision making. She emphasized that "[parents] should be able to make the decision," and argued that the mandate "is definitely a barrier . . . to making a decision about the vaccine. The mandate really takes away your decision."

There is not enough research to mandate the vaccine. During discussions, parents frequently stated that research on the vaccine was far too insufficient to justify a mandate. Some parents emphasized the lack of time and research between the FDA approval and the state mandate: "If they don't have complete research, I don't think it should be mandated in this short period of time." Others clearly stated that there was not enough research: "I just think that there should have been more study before the state mandated that we had to [vaccinate]." Some parents compared it to other mandated vaccines, stating that unlike other vaccines, the long-term efficacy of the HPV vaccine against cervical cancer had not been established. One father argued,

I just have a big problem with it being mandated right now. We're going down the road towards mandating a vaccine where there's just an association between this long-term effect, or this condition, that may or may not have been caused by this certain papillomavirus that's in this vaccine, and we're not going to see the results of the efficacy of the vaccine for, you know, years.

"I didn't even know about the mandate." Parents' lack of knowledge about the mandate frequently emerged during focus group discussions. Several parents indicated

they were unaware of the mandate before they were recruited to be a part of the focus groups (e.g., “I didn’t even know the state mandated it until I heard about this study”). Although some parents had heard about the mandate, they stated that they did not know specific details; particularly that they were unsure of implementation dates and were unaware of the opt-out option. Parents indicated that their lack of knowledge about the mandate was in part attributed to their overall lack of knowledge about the HPV virus and vaccine.

The mandate must come with parental education. Parents raised the issue of the need for education about the mandate: “If they’re going to mandate it, they need to start educating people about it.” One mother pleaded, “To be totally real with it, right? If we have to do it, then you have to give us information on it. Educate us.” Parents expressed shock that “I’ve never even heard about . . . Gardasil until recently, and now [I am] finding out it’s going to be mandated and there’s still not any education going on?” Another mother expressed her concern that the lack of education would result in parents being “tricked” into following the mandate:

They haven’t given us any information. I mean, if he was a single dad and he goes to the check-up to get his daughter’s shots and you say, “All right, you need to give her the HPV shot,” he doesn’t know anything about it. . . . What’s he supposed to say? I think people are going to be tricked into receiving a mandatory vaccination that they don’t know about yet. Because if they’re going to mandate it, that’s what’s going to happen.

Finally, parents asked for comprehensive education from multiple sources. Parents wanted to be “flooded with the information to the point where you go, ‘Oh my God, I’ve read this five times.’” They acknowledged the importance of delivering the information through multiple channels, not just using flyers placed in children’s backpacks, but also using other outlets such as the media and parental group meetings: “I mean we definitely need to be more informed, and the papers in the backpack are not gonna get it like this. It’s gonna have to be highly informed. We need newspaper, we need groups, we need meetings.”

“We could opt out, you know.” Parents’ responses to the vaccine mandate most often centered on their right to opt out: “They can’t just say you have to do something. I mean, they can, but . . . [we] don’t have to do it, we could opt out, you know.” Parents were positive about the opt-out option because it allowed daughters to make their own decisions later on: “Yes, they may still get lots of side effects or something, but then it was their choice, you know? That would be the good part of the opt-out to me.”

Some parents felt the right to opt out gave them time for their daughter to mature and be able to actively

participate in an informed decision. One father explicitly stated that he planned to opt out until his daughter was old enough to participate in a discussion about the potential benefits and consequences of the vaccine: “My daughter will have it when she is fifteen or sixteen, and at that time we can sit down and talk about it—discuss benefits and information that at that time will be available to us.” For others, the informed opt-out provision was necessary because of the lack of information available to parents. The option gave parents time to make an informed decision rather than take uninformed action: “I’d definitely opt out at this point. There’s not enough information out there. I’ve gotta study up on everything. I mean, I do a lot of studying and research. On this I’ve done none. So, opt out, I guess.”

Discussion

To our knowledge, this investigation was the first of its kind to explore implications of an HPV vaccine mandate for parental vaccine acceptance where the vaccine mandate has been enacted. Specifically, we investigated how parents made sense of the virus and vaccine within the context of the school vaccine requirement, and how they responded to the mandate. The findings presented here suggest many implications for vaccine acceptance or opting out within the context of a state mandate and can be taken into consideration in future HPV-related legislation. To increase positive health outcomes from similar mandates, the Virginia case points to several areas in need of improvement.

Although parents addressed potential benefits of the HPV vaccine (i.e., prevention of certain types of HPV and protection against cervical cancer), their discussion of the virus, vaccine, and mandate was marked more by their concerns about the vaccine and mandate than their support. Parents explored concerns about whether a school vaccine mandate for a sexually transmitted disease was appropriate for preadolescent girls, and concerns about the safety and efficacy of the vaccine. They also questioned how the vaccine/virus compared to other common childhood vaccines/viruses, the necessity of such a mandate in light of other national health issues, and why HPV had not been widely known as an important health concern before the vaccine was mandated.

Considering the mandate explicitly, even parents who indicated an intention to vaccinate their daughter expressed concerns about the government making a decision about their daughter’s sexual health. Moreover, many parents were concerned that the vaccine had not undergone enough testing to be considered for a mandate. Several parents heard about the mandate for the first time during focus group discussions and were frustrated by their lack of awareness about the mandate and the lack of credible HPV-related information. As a result,

and perhaps in response to their perceptions that the government was taking away their right to make a family health decision, the majority of parents responded to the mandate by emphasizing their right to opt out.

For the parents in this study, the opt-out provision served an important mitigating factor in their attitudes toward the mandate and also emphasized the importance of the decision. The mandate also served an important function of bringing to parents' attention the importance of HPV as a public health concern that could affect their daughter. For example, one mother noted,

To me . . . [the mandate is] just saying, well, they feel that it's pretty important. . . . It will still be up to the family's decision, but I don't know. I think [the mandate] is just a sign going off to me that if they feel . . . they need to mandate it, then, that's telling me something.

The opt-out provision within the mandate gave parents the choice to vaccinate or not, but also made certain that a vaccination decision would be made, at least in the short term. In Virginia, parents are allowed to opt out after reading educational materials about HPV (Virginia Legislation Code, 2010); however, the majority of parents in this study were unaware of the opt-out provision. Of the parents who did know about it, they did not know the conditions under which they would be eligible to choose it. Many parents were relieved to learn about the provision, indicating that if they were asked to make a vaccination decision "today," they "would just opt out, because you always can do it later." Thus, the opt-out provision offered parents a necessary sense of authority over their daughter's health care while at the same time bringing salience to the health concern.

In addition to providing an educated opt-out option, other states considering an HPV vaccine mandate must make evident the necessity for such a vaccine in light of parents' lack of HPV knowledge and awareness. In this study, parents were skeptical about the sense of urgency surrounding a vaccine mandate for a virus with which they had little to no familiarity. Parents' concerns about why they were hearing about HPV for the first time point to what Friedman and Sheppard called "concerns of secrecy"; namely, "Why haven't I heard of this?" "How long have they known about this?" (2007, p. 478). As Luedtke (2008) pointed out, historically, information about the presence, transmission, and morbidity associated with HPV has not been well publicized. Therefore, many people are still largely unaware of the virus.

Complicating the issue, media coverage about HPV increased in the months surrounding the FDA approval of the vaccine (Kelly, Leader, Mittermaier, Hornik, & Cappella, 2009). Public knowledge about HPV sharply

increased at the time of the FDA announcement, remained high, and continued to grow over the months that followed (Kelly et al., 2009). The sudden rise in public awareness about the virus partially accounts for parents' skepticism regarding the necessity of a mandate for a virus they had only recently heard about, but which was apparently prevalent enough and risky enough to warrant such a mandate. Moreover, significant gaps between what journalists reported in mainstream newspapers about HPV and the mandate and what parents wanted to know frustrated the situation (St. John et al., 2010). Prior to enforcing a vaccine mandate, a foundation of knowledge must be laid and parents must become familiar with the virus/vaccine.

Consistent with earlier research (e.g., Friedman & Sheppard, 2007), our findings make evident the lack of knowledge held in the general public about the virus and vaccine, and point to the importance of increasing parental HPV knowledge, especially when a vaccine mandate is under consideration. Previous research highlighted the need for HPV-specific information such as symptoms, transmission, links to cancer, and other health consequences (Friedman & Sheppard). The findings from this investigation amplify that need by adding to it a need for information about the vaccine and about the school requirement. Owing to the lack of knowledge surrounding all issues related to HPV, the focus group discussions demonstrated remarkable consistency with regard to parents' reported need for HPV information and transparency regarding the decision to mandate the vaccine.

Specifically, parents wanted to know (a) why that age group (11 to 12 years) was targeted for the mandate; (b) how HPV compared to other common childhood viruses in terms of transmission, severity, and prevalence; (c) why HPV suddenly emerged as a public health issue; (d) why there is an HPV vaccination mandate in light of numerous national health concerns, such as childhood obesity, that appear to be more prevalent; (e) what the possible long-term consequences of the vaccine are; (f) why the HPV vaccine is mandated as a school requirement when HPV is not contagious in a school setting; (g) why the vaccine mandate was enforced so soon after FDA approval rather than waiting for research on long-term effects; and (h) why parents were so uninformed about HPV and the mandate, and who was responsible for disseminating information.

Recommendations

The study results suggest that under a state-mandated school HPV vaccine requirement, certain conditions must be met before parents feel confident enough to make a vaccine decision. The findings reported here highlight parental need for factual and current information about the HPV virus, vaccine, and the particulars of the state

mandate if they are going to make informed vaccination decisions. Several of the suggestions for increasing public health information about HPV offered by Friedman and Sheppard (2007) were punctuated by this study: educate the public about the natural history, transmission, and prevention of HPV; provide HPV information that causes neither undue anxiety nor complacency regarding health decisions; and be transparent about current limitations and gaps in HPV science. Moreover, despite parents' stated desires for more HPV-related information, it is not evident that increased HPV knowledge will help parents to make the decision, nor is it evident that increased knowledge is related to parental vaccine acceptance (e.g., Dempsey et al., 2006).

The concerns voiced by parents during focus group discussions offer insight into the ways similar mandates might be announced and enforced in the future. Effective mandate information will include a rationale for why sixth grade is targeted for implementation. Parents might respond more positively to messages that emphasize the protective benefits of the vaccine in the future than to messages that focus on the sexual nature of virus transmission. For example, emphasis should be placed on the importance of receiving the vaccine series well before children are sexually active to ensure the full protective benefits of the vaccine later in life. Such a focus would alleviate some of the uncertainties and discomfort associated with vaccinating a child against a sexually transmitted disease.

Effective messages will also include transparency in the decision-making process that led to the state mandate. Messages must be strategically developed for parents that debunk misconceptions about the virus and the perceived negative consequences of the vaccine. Effective messages will document credible research and support for the vaccine. Strategies for information dissemination must also be considered, including the use of already-existing social and community networks and the development of norms for informed decision making among peers (Mosavel & El-Shaarawi, 2007). Finally, the availability of an HPV vaccine cannot diminish the importance of sexual health education and cancer screenings. Informational materials for parents should emphasize the importance of well-child visits and annual exams. They should also emphasize the importance of parent-child discussions about sex, sexual health, and norms and expectations for sexual behaviors.

Limitations and Future Research

The transferability and applicability of focus group findings reported here are somewhat limited. Participants were drawn from the Hampton Roads area of Virginia and therefore represent a geographically homogeneous group. Similar results might not be evident among parents in other regions or demographic strata. However, we believe that the unique context in which focus groups were conducted

(under the direction of a new state mandate) and the timeliness of the issue supersedes this limitation.

It is also possible that this investigation was subject to a selection threat. Parents who participated in this study might have been highly motivated to learn about HPV and the state mandate, or might have been passionate vaccine advocates/opponents. However, given the variance in attitudes toward and knowledge about HPV, this is only a minor limitation. Finally, we collected data for this investigation after the mandate was signed but before it was enacted. The next logical step is to examine any changes in parents' knowledge, attitudes, and behaviors regarding the HPV vaccine since the mandate went into effect. Follow-up studies on parental decision making and the resulting vaccination decision in the context of a school vaccine requirement would provide an even better understanding of the implications of such a mandate for vaccine acceptance.

Future researchers should also consider gender bias evident in the vaccine mandate and parental framing of the virus/vaccine. That is, although Gardasil was approved for use among boys and men, there has been little discussion about an HPV vaccine mandate for boys. Before the release of Gardasil for young men, Luedtke wrote, "It appears that HPV vaccination would remain a gender-specific requirement for immunization, despite potential advantages (nonfinancial) to women if men were also immunized. The likelihood of similar mandates in males is unlikely" (2008, p. 2151).

Gender discrimination in reproductive health is evident and might influence policies regarding HPV mandates as well as parental decision making. That is, gender might have an undue influence on parental decision making regarding their daughters. Results from this investigation show some evidence of this because parents tended to cast their daughters as victims needing protection against HPV, but also protection against sexual violence. As one mother noted, "[Our daughters] can be in a situation at any given moment where they can't defend themselves." Parents in this study were asked only to respond about their daughters, because at the time of the investigation the FDA had not yet approved the vaccine for use among boys. Therefore, until future research can explore gender bias in HPV-related legislation and health promotion, these implications are largely conjectured, but certainly important.

Conclusion

The findings reported here suggest that parental knowledge and attitudes about the virus, vaccine, and mandate, as well as their concerns about transparency in health policy decisions concerning the sexual health of their pre-adolescent daughters, influence parental vaccine acceptance within the context of a state mandate. Specifically, the majority of parents in this study indicated they would

choose to opt out of the vaccine until the timing was right for them and their daughter. Two of the themes uncovered in the focus groups, parental rights and the recognition that they could opt out, featured prominently in parents' decisions not to follow the mandate. Moreover, parents indicated that although they wanted to protect their daughters and prevent health complications for them in the future, they had strong concerns about whether they should protect their daughter from the virus or the vaccine, about the necessity of the vaccine within a school context, and about whether the timing of the vaccine was appropriate for the age and maturity of their respective daughter.

Parents felt uninformed about the virus and vaccine. They questioned why they were just hearing about HPV at the time, and tried to make sense of the virus and vaccine by making comparisons to other childhood vaccines. Finally, these concerns, coupled with parents' lack of (and desire for) knowledge about the mandate and their perceptions that there had not been enough research to mandate the vaccine, resulted in their decision to opt out—thereby diminishing the likely intended result of the mandate. In fact, an Associated Press article in the Hampton Roads newspaper, the *Virginian-Pilot*, reported, "State health officials say fewer than one in five incoming sixth-grade girls received the vaccine last fall" (2011, p. B3). The findings from this study can help inform legislation and generate a more positive response from the community, with greater likelihood of compliance. Moreover, understanding how parents make sense of and respond to such a mandate is critical to the development of health-promotion materials that will be used to help parents make an informed vaccination decision.

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