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ORIGINAL PAPER

Caregivers of Adolescents' Motivators and Barriers to Vaccinating Children Against Human Papillomavirus

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Abstract

In the United States (US), acceptance of adolescent vaccines, as measured by vaccine uptake in adolescents, is high amongst caregivers. However, this does not routinely extend to Human Papillomavirus (HPV) vaccination. In the US state of Georgia, HPV vaccine coverage rates remain suboptimal, especially when compared to other adolescent vaccines. Our study aims to identify and examine caregivers' motivators and barriers towards vaccinating their adolescents against HPV. We conducted nine focus groups with caregivers ($n=75$) throughout the state. Using MAXQDA for thematic analysis, we identified common motivators and barriers related to adolescent HPV vaccine uptake amongst caregivers. Barriers reported include caregivers' inability to develop a trusting patient-provider relationship and HPV vaccine message framing issues. Motivators reported include caregivers' intrinsic need to protect their adolescents and trust their healthcare provider. Trust in healthcare providers was a key theme identified towards mitigating barriers and reinforcing motivators related to HPV vaccine acceptance and uptake. By improving patient-provider relationships throughout Georgia and streamlining digestible, representative vaccine information sharing across reputable sources, caregivers may become more receptive to vaccinating their adolescents.

Keywords HPV · HPV vaccination · Barriers · Motivators · Caregivers · Georgia

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Introduction

In the US state of Georgia, Human Papillomavirus (HPV) vaccine coverage remains subpar (73.1% initiate series of vaccines; 54.9% complete the series) and much lower than other adolescent vaccines' coverage (90.8% Tdap; 95.2% MenACWY) (Pingali et al., 2021). While HPV vaccine coverage in this US state is higher than the global estimate of 12.2% (Spayne & Hesketh, 2021), it still trails the US national averages of 75.1% for series initiation and 58.6% for series completion (Pingali et al., 2021). National and geographically-specific studies have identified common barriers towards uptake, including caregiver perceptions of risk, cost, and a general distrust in the healthcare system, perpetuated by a lack of public knowledge and understanding of HPV vaccination, none of which were Georgia-specific (Dennison et al., 2019; Newman et al., 2018). Similarly, findings on HPV vaccine hesitance in the US can help support global efforts to utilize this vaccine to prevent cervical and other HPV-related cancers. Georgia's growing diversity (i.e., 33% African-American; 10% foreign-born; 66.7% rural) requires state-specific research to improve contextual understanding and identify effective motivators and barriers to vaccination (U.S. Census Bureau, 2019). The aim of this study was to assess barriers and motivators to HPV vaccination in the US state of Georgia, to document these factors in a more granular fashion than is typically done at the national level. Conducting this type of geographically localized assessment can help identify local barriers and motivators, and should be considered in the global context, to ensure that locally and culturally appropriate vaccine outreach efforts can be developed and implemented.

Methods

Our study is part of a larger project examining influences on HPV vaccination uptake in the state of Georgia. We used a subset of data from the parent study to examine motivators and barriers to HPV vaccination among caregivers of adolescents across the state. We conducted nine focus groups (FGs) with 75 caregivers in Georgia between April and July 2018.

The study obtained Emory Institutional Review Board approval. We provided participants with printed informed consent forms to review, sign, and return before participation. We collected demographic information regarding age, rural or urban home location, race, and sex. All research documents were uploaded to and kept on a password-protected, HIPAA-compliant server that restricted access to our research team. Participants received a $30 gift card.

Data Collection

We collaborated with immunization and regional cancer coalitions throughout Georgia to recruit our respondents, supported by a staff member from each coalition. We provided a recruitment flyer template, eligibility criteria, and potential

FG dates to each assisting coalition. Recruiters from each coalition informed potential participants of the study and assessed participants' eligibility before inviting them to a FG. Eligible participants included caregivers of at least one adolescent (9–17 years old) who lived in Georgia and were at least 18 years old. For this study, we defined a caregiver as anyone responsible for the decision-making for one or more adolescents' health. Study participation required English fluency.

A moderator and a notetaker from our research team conducted all FGs in a private space convenient to participants. We used a moderator's guide containing open-ended questions to elicit participant perceptions on HPV and the HPV vaccine (see Appendix A). Our research investigators collected demographic information during the FGs, through the guide (i.e., age and residency) and observation (i.e., race, ethnicity, and sex). FGs took 1.5 h on average to complete and included between six and twelve caregivers.

Data Analysis

Our research team transcribed FG audio recordings verbatim and de-identified them (Lahijani et al., 2021). All transcripts were uploaded into MAXQDA 2018 (VERBI GmbH, Berlin, Germany) software and analyzed using thematic analysis. Our thematic analysis included code development, coder consistency, coding data, description of issues, and structured comparisons (Hennink et al., 2020).

Table 1 Characteristics of study participants by rurality, 2018

Characteristics	Overall	Urban[a]	Rural
Age in years, median (range)	40 (23–72)	38 (23–63)	41 (23–72)
Sex, *n* (%)			
Female	69 (92.0)	36 (90)	33 (94.3)
Male	6 (8.0)	4 (10)	2 (5.7)
Race, *n* (%)[b]			
Black or African American	62 (82.7)	40 (100)	22 (62.9)
Hispanic or Latino	2 (2.7)	0 (0)	2 (5.7)
White	11 (14.7)	0 (0)	11 (31.4)
Total, *n* (%)	75 (100)	40 (53.1)	35 (46.7)

Data collection occurred in Cobb-Douglass, Southwest, East Central, Northwest, and Coastal Georgia Public Health Districts

[a]Urban areas are defined by populations with 50,000 or more people (U.S. Census Bureau, 2021)

[b]Race is reported as an investigator observed variable collected during Focus Groups

Results

Participants

Demographics collected showed more African American and female participants, averaging 40 years old (see Table 1).

Introduction

Our study found motivators and barriers centralized around three key themes; healthcare provider-patient trust, inconsistent messaging, and an intrinsic need to protect adolescents. This section presents a summary of these themes and representative quotes.

Barriers

Inconsistent Messaging

Participants reported using social media, WebMD, and Google when seeking HPV and HPV vaccine information regarding their adolescents. A common issue they presented was difficulty deciphering which sources presented factual information, as different sites provided different information: "That's the problem though, you can keep on looking until you find the answer that you want, so how do you know what [is] real and what you want."

Caregivers perceived the HPV vaccine as a relatively new vaccine which caused uptake hesitancy. Caregivers were wary of potential adverse reactions, particularly for adolescents with pre-existing or underlying health conditions: "…the vaccine is not for everybody. Everybody can't tolerate it in their system, cause there has been problems with it (Centers for Disease Control & Prevention, 2020)."

All FGs referenced the MERCK© "Did You Know?" commercial when asked where they got information about HPV and the HPV vaccine. Some caregivers highlighted the inclusion of males as building an understanding of who is at risk and that these commercials remain an opportunity to expand media representation of other races and ethnicity: "The commercials are convincing though… I feel they don't resonate with my culture."

Most caregivers reported that they were unsure of the risks associated with HPV infection among male adolescents. The lack of messaging male adolescents received from their providers exacerbated this uncertainty: "…from what I saw on TV, it makes it seems so serious, and it is serious. Taking them to the doctor, they don't put an emphasis on it [HPV vaccination] for boys."

Inability to Develop a Trusting Provider-Patient Relationship

Many caregivers reported a distrust of healthcare providers and the medical system. Some speculated that a for-profit healthcare system might drive provider vaccine promotion rather than a patient-centric system: "Normally, [doctors] come down here to pay off their debts. I mean, they're good while they're here, but- you can't blame them for doing that."

Motivators

Protection for Adolescents

Some participants reported being motivated by concerns of unvaccinated adolescents infecting their adolescents. Some caregivers connected this to building herd immunity and social responsibility to vaccinate: "Like a lot of kids out there, a couple of kids who died because they were exposed to a child who didn't have it. I like to think [it's a] community concern."

Caregivers reported that they could not rely on abstinence for adolescents as a protective method and that HPV vaccination could help mitigate transmission. A few further elaborated that future marital sexual relations and nonconsensual sexual activities (e.g., rape) can bypass abstinence practices and transmit HPV.

Trust in Healthcare Provider

For many caregivers, trust in provider recommendations depended on the longevity of their patient-provider relationship and provider-community reputation: "All my daughters have had the same pediatrician for the last 24 years… So that way they know everything, the history, that they're familiar with my babies…".

Discussion

As reviewed, we found barriers and motivators to HPV vaccination in adolescents. Participants reported a lack of clear, uniform, and ethnicity-representative messaging, which challenged full HPV and HPV vaccine understanding. Caregivers found that an abundance of indecipherable and contradictory HPV vaccine information was accessible, amplifying the importance of a health proxy or trusted provider to help them navigate past misinformation and biased sources.

Though the Food and Drug Administration approved and monitored the HPV vaccine, another barrier we found was that participants believed not enough post-market research had been conducted to understand how the vaccine interacts with different sub-populations (i.e., race, ethnicity, sex, and immunocompromised) (2018). Considering Georgia's growing population and diversity, health promotion tactics will need to improve the inclusion of sub-populations in research, marketing,

and information presentation to match demographics and empower caregivers to make informed decisions (U.S. Census Bureau, 2019). The high provider turnover rates in rural areas where continuity of care remains limited may have exacerbated caregiver distrust in the healthcare system (Spleen et al., 2014).

The inconsistent messaging targeting male adolescents was a barrier. While the inclusion of male adolescents in HPV commercials promoted awareness of HPV and HPV vaccination in males, it was not heavily communicated by providers, leaving the urgency of HPV vaccination for male adolescents in question. Although HPV is untestable in males, Georgia's high STI rates (Gonorrhea in 202 and Chlamydia in 644 per 100,000 tested) raised concern that these high transmission rates may infer high HPV prevalence (Centers for Disease Control & Prevention, 2019). Males are more commonly at risk for oropharyngeal cancer, making up 82% of HPV-related male cancer cases nationally (Centers for Disease Control & Prevention, 2018). The FDA recently approved HPV vaccination to prevent oropharyngeal cancers, presenting a considerable need for further development of marketing and communications to this population (Versaci, 2020).

Protecting their adolescent was seen as a motivator of getting the HPV vaccination. This intrinsic parental need seemed to underly all decision-making. For some, this meant vaccinating, although they may not have had all the information desired, preferring to be safe rather than sorry. Although a motivator, Gust et al. (2005) stressed that caregivers vaccinating without complete information might be prone to vacillating on this decision as vaccine safety concerns arise.

Despite Georgia's conservative religio-political climate, caregivers acknowledged that faith in abstinence would not protect their adolescents and had limited control as HPV transmission is not exclusive to specific groups of people or forms of relationships. HPV vaccine campaigns may utilize this dialogue to provide relatable perceptions that de-stigmatize HPV vaccination.

Generational trust was a recurring marker for overall trust, influencing current beliefs about providers and the healthcare system. Considering Georgia's highly rural nature, developing programs or policies to improve recruitment and retention of providers practicing in rural communities would be beneficial to building community-provider trust. Trust in healthcare providers persisted as a critical factor in HPV-vaccine acceptance and general vaccine confidence, permitting caregivers to believe their adolescent's holistic well-being in mind while recommending the HPV vaccine. Jones et al. (2012) reported that the *rural-background effect* was successful in international contexts, providing grounds to support research or programs supporting Georgia's rural provider retention efforts.

Limitations

Participants were primarily female and African American. For future research, increased diversity in sex and ethnicity in study participants may increase the generalizability of results within Georgia. Conducting future research in other relevant languages (e.g., Spanish and Korean) may improve representation of Georgia's growing ethnic diversity. Due to the nature of qualitative research, our

findings are not generalizable; however, they do provide sound footing for future research projects.

Public Health Implications

These findings suggest that building a trusting and communicative patient-provider relationship is likely to mitigate many of the barriers identified, allowing caregivers to place more value in provider recommendations, thus improving uptake of HPV vaccination. However, clear, uniform, and relatable information must be available to ensure caregivers' buy-in to make a well-informed decision for their adolescents. The growing diversity in Georgia will require additional outreach and adaptation of health promotion campaigns to resonate with sub-populations, increase HPV vaccination message inclusivity, and improve perceived risk–benefit.

Appendix A: Moderator's Guide

Parents of Adolescents (Age 9-17)

Key:
Red Italics – Do not read aloud.

Materials:
2 Copies of FGDG (1 Moderator, 1 Note Takers)
Markers (2 Red, 2 Green, 2 Black)
Flip Chart Paper (1 Stack)
Post-it Notes (Red and Green)
Snacks and Refreshments
Bathroom Sign

(Read the following introduction after all participants have joined the room for the discussion group. Ensure that all participants are comfortable in their place and offer any refreshments (drinks, snacks, fruit, etc.). Ensure that all participants know where the closest restroom is (set up a sign if necessary).)

Introduction:
Welcome and thank you very much for agreeing to participate in this focus group today. My name is _____ and my role is to guide the discussion today. This is _____ and they are here to take notes during our discussion to ensure that we capture each of your thoughts and views. I am working with the Winship Cancer Institute at Emory University, and Dr. Robert Bednarczyk on this project. The focus of this project is on Human Papillomavirus and HPV vaccine. Today I'd like for us to discuss topics related to HPV. Please include any of your own experiences, opinions, and perceptions of the topic. The discussion should last between 1 ½ - 2 hours.

Each of you has been invited to join our discussion as you are all parents of adolescents and your opinions and perceptions are vital in health research. The information that you provide on this topic will likely influence future health related programs, health messaging, and will further health research programs not only in Georgia, but around the U.S. Please answer questions to the best of your ability pulling from your own experiences, beliefs, and opinions. There are no right or wrong answers to any of these questions and you are allowed to not answer any question you are not comfortable with. Agreement is not required and differing opinions or views are encouraged. While it is not necessary to reach consensus on topics, I do request that everyone respects one another's views and opinions. Information that you all share may be used in developing future HPV related interventions and/or research programs across Georgia; this may include the development of an online platform focused on providing various forms of HPV related information, educational tools, and the creation of written materials. For your involvement, you will be compensated with a $30 gift card.

Before we get started today, I'd like to make each of you aware that our discussion today will be audio recorded to ensure the collection of all shared data. Each of you brings valuable information and opinions with you today and our research will benefit greatly from everything that each of you shares. After completion of the focus group the audio recording will be transcribed for further analysis and the audio recording will be deleted. No names or identifying

factors will be included in the transcript to protect each of your confidentiality. This study is entirely voluntary. Is everyone okay with the discussion being recorded today?

Wait for all focus group members to respond. Pass out individual consent forms to all participants. Allow time for participants to read the form and answer any questions, when necessary. After all members have signed the consent form continue with the ground rules. Write ground rules on a piece of flip chart paper.

Ground Rules:
Now, I'd like to set a couple ground rules that each of us should follow during our discussion. Please read through the list of rules on the flip chart and let me know if you all agree with these rules. If there are any rules you believe should be added to this list please let me know.

- Respect each member of the discussion group as well as their views and/or opinions.
- There are no right or wrong answers and everyone's opinion/view is important.
- Avoid side conversations during the conversation.
- Turn off all cell phones. If you need to take a call during the discussion please leave the room and return when the call has finished.
- Whatever is said in the discussion group is said in confidence and no one should discuss things shared during the discussion outside of this group.
- It is okay to disagree but this should not be an argument.

Ask participants if there are any other rules that they believe should be added to this list. Add suggested rules that the group agrees on. After all ground rules have been agreed upon tape the sheet with ground rules in the front of the room for all participants to see.

Are there any other questions or concerns before we begin? If anyone needs to use the restroom, now is a good time to do so before we begin the discussion.

If everyone is ready we will go ahead and begin our conversation

(Let participants know that you are turning on the audio recorder. Turn on audio recording device)

Warm Up:

- Please tell us a little bit about yourself (name, age, occupation, etc).
- What brought you to live in _____ *state name of town*?
- How many children do you have?
    - Age and Sex of each child.

Section 1: General Health

1. What are some health-related behaviors that we do in order to maintain our own, and our families' health and wellness?
    a. Are there somethings that we do regularly in order to protect our health? (Examples: Using sunscreen, wearing seat belts, etc.)

   b. What are some specifically health-related activities that we do to maintain health?
      i. Probe: Regular visits to the doctor (How often)
      ii. Probe: Dentist visits
      iii. Visits to OBGYN (for female participants)
      iv. Etc.
   c. What about immunizations/vaccinations? (E.g., flu shots, tetanus, etc)
   d. How do you all feel about the flu shot?
   e. Has your opinion about the flu shot changed due to this year's flu season? (Probe: How, why?)
2. What health related habits are children taught in efforts to promote long term healthy behavior?
3. What are the factors that affect health decision making? (Probe: Cost, distance, time, etc)
   a. How do these factors differ when making decisions for your children?
4. Where do you typically seek health related information? (Probe: Internet, doctor's office, hospital, etc.)
   a. How do you feel about any health-related advice you may receive from community or religious leaders?
      i. Do you typically follow this advice?
5. Where are some places that you have sought healthcare in the last year?
   a. How do you decide where to seek healthcare for yourself?
   b. How do you decide where to seek healthcare for your children?
6. What are some specific issues that make it difficult when seeking healthcare in the community that you live?
   a. What are some ways to address these issues?

Probe: Has anyone else experienced things like this?

7. Has the topic of adolescent immunizations come up when talking with your children? (probe for: context, who brought it up, comfort level)

Section 2: Human Papillomavirus

8. What do you all know about Human Papillomavirus or HPV?
   a. What can you tell me about how HPV is spread?
   b. Who is at risk for HPV infection and other HPV-related cancers?
   c. Where have you gotten information about HPV?
   d. Do you trust this source of information? Why?

Probe: Billboards, radio advertisements, TV commercials, Pamphlets, Webpages, medical professionals, etc.

   e. What has your doctor told you, or your child, about HPV?
9. What do you know about the link between HPV and HPV-related cancers?
   a. What are some HPV-related cancers that you know of?
   b. Who do you think is most at-risk for HPV-related cancers?
   c. Where did you receive information about HPV-Related cancers?

Parents of Adolescents (Age 9-17)

10. What do you know about the HPV vaccine?
    a. Where do you get information about the HPV vaccine?
    b. What resources do you, or have you, used to gather more information about the HPV vaccine?
    c. Why do you use these resources?
11. How do you feel about the HPV vaccine?
    a. Is what you think about the HPV vaccine different from how you feel about it?
        i. Why/Why not?
    b. Have others given you information that changes the way you think or feel about the HPV vaccine?
        i. What did they tell you?
        ii. Why did this change your perception?
    c. Who has affected your opinion of the vaccine most?

Probe: Health Care Provider, community leader, religious leader, other, etc.

Activity: Ranking HPV Vaccine Barriers and Motivators

Now, we are going to do an activity as a group. I'd like for everyone to think about having their child (between 9-17 years old) vaccinated against HPV. I want you to think of the reasons that you would (Motivators) and the reasons that you would not (Barriers) have your child vaccinated. On the post-its provided I'd like for you to list the reasons that you all come up with. Please write Motivators on green post-its and Barriers on red post-its (5 minutes).

Now that you've all listed your reasons for or against vaccination, I'd like you to place your reasons on the sheet provided. Please rank the reasons that you've all come up with and place your post-its on the line in order of least to most influential (i.e. 0= least influential, 10 = most influential). (5 minutes)

****See the below depiction to ensure participants correctly label flip chart paper****

Now, let's discuss our reasons for ranking some of the items the ways that we did.

12. Would someone please read off the top three Motivators you've all ranked for having your child vaccinated against HPV?

a. Why were these ranked as the top reasons?
b. Why do you all believe that #1 is a stronger influence than # 2?
c. Why do you all believe that #1 and #2 are stronger influences than #3?
d. Did anyone not agree with this ranking at first? Please explain.
e. What can be done to make these even stronger motivators for vaccination?

13. Would someone please read off the top three Barriers you've all ranked for having your child vaccinated with the HPV vaccine?
    a. Why were these ranked as the top reasons?
    b. Why do you all believe that #1 is a stronger influence than #2?
    c. Why do you all believe that #2 is a stronger influence than #3?
    d. What can be done to address any issues we've come across so that they may not be barriers in the future?
    e. Did anyone not agree with this ranking at first? Please explain.

Section 3: Web Portal Development

Now, I'd like to discuss using a website as a resource for HPV related information. (Loop back to answers participants provided to question 4 when preparing for the next set of questions. Use the specific information that participants provided when answering question 4)

14. You stated above that you use _____ as a common resource for health related information; (Either: 1) Do you think that an online website could also be beneficial to you? Or, 2) What makes the website(s) you use beneficial for you?)
    a. Please explain
15. What information would you most want to see on an online website containing information on HPV, HPV vaccine, and HPV-related cancers?
    a. What would be the best ways to present information? (Videos, infographics, pictures, graphs, text, etc.)
16. What type of interactive aspects of a website would you like to see on a website about HPV, HPV Vaccine, and HPV-Related Cancers?
    a. How would interactive aspects of a website would you find the most useful?
17. Would you use an online website devoted to HPV-related information if it was available to you?
    a. Why/why not?
    b. Would/have you shared this source with your social networks?
18. Would you find this information more or less useful if it was available in an interactive mobile app?
19. Are there any other questions or comments you'd like to add before we end our discussion?

Closing:

This is the last of my questions. I want to thank you all again very much for your time and participation today. You've all shared very helpful information that will surely help with this research. If you all have any other questions or concerns please feel free to contact myself or Dr. Robert Bednarczyk at _____. If there are no other questions or concerns at this time you are all free to leave as you please. Thank you all again very much for your involvement!

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Declarations

Conflict of Interest The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Approval This study obtained approval from the Emory Institutional Review Board (eIRB).

Informed Consent Participants were provided informed consent forms (ICF) to review, which included permissions for audio recording. Written informed consent was required from all participants prior to participation.

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