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Strengthening HPV Vaccination Communication Between Caregivers and Providers in Georgia

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Strengthening HPV Vaccination Communication Between Caregivers and Providers in Georgia

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B.S. University of Florida 2016

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An abstract submitted to the
Faculty of the Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
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Abstract

Background: Despite the availability and recommendation of Human Papillomavirus (HPV) vaccination for adolescents in the United States since 2006, vaccination rates remain low. While many national studies have been conducted on the strength of recommendation quality and the communication strategies used to recommend HPV vaccination, there is little evidence on both provider and caregiver perceptions of communication. There is a need for local context in diverse socioeconomic communities, such as in the state of Georgia.

Methods: We conducted six focus group discussions (FGDs) with healthcare providers and eight FGDs with caregivers of adolescents in Georgia. We sought to identify parent and provider perceptions on communication around HPV vaccine recommendations and suggest improved strategies to tailor recommendations to local contexts. FGDs were recorded and verbatim transcribed. We conducted a thematic analysis to discover communication strategies used and identify major themes.

Results: We found three major themes: perceptions of communication identified by providers; perceptions of communication identified by caregivers; and communication strategies utilized by both caregivers and providers. Providers identified best practices for recommending HPV vaccination, including emphasizing cancer prevention and framing the vaccine as routine. Caregivers discussed how HPV was recommended but not required for school made them feel it was less important. They also identified the influence their peers, both in-person and online, had on their perceptions of HPV vaccination. Providers discussed how they liked using the announcement approach to recommend vaccination, but caregivers felt tricked and unable to say no. Providers used VIS and written information as tools to help recommend, but caregivers disliked the lack of explanation of the content of written materials. Caregivers felt more satisfied with the recommendation when providers took time to discuss written materials and answer questions.

Conclusions: There is a need for providers to be well-versed in strategies to promote HPV vaccination and be well-prepared for adapting their recommendation style to the needs of the caregiver/adolescent. Information sources, such as written material and peer influence, are important for caregiver perceptions. Although strategies such as the announcement approach are useful in increasing uptake, they may be damaging to provider/caregiver relationships and trust.

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Table of Contents

Chapter 1:Introduction

Problem Statement

Despite the availability and recommendation of Human Papillomavirus (HPV) vaccination for adolescents in the United States (U.S.) since 2006, vaccination rates remain low (Walker TY, 2019). In 2018, only 51.1 percent of U.S. adolescents were up to date for HPV vaccination (Walker TY, 2019). Provider recommendations were reported by 77.5% of parents for adolescent HPV vaccination. Nationally, one or more doses of HPV vaccination coverage was higher among adolescents whose parents reported receiving a provider recommendation (74.7%) than among those whose parents reported not receiving a provider recommendation (46.7%) (Walker TY, 2019).

Concerns about the HPV vaccine are varied, and one study found that long-term side effects were a key worry among parents (Gilkey et al., 2019). While there is evidence to suggest that strong provider recommendations and information influences parents and guardians to vaccinate their adolescents, and thereby prevent infection and disease related to HPV, recommendations are not always given (Walker, Elam-Evens, Yankey et al. 2019). There is a need to tailor recommendations to parents based on socio-demographics and economic diversity (King 2020, unpublished data) (Bairu 2020, unpublished data)(Dennison, King, Rutledge, & Bednarczyk, 2019). Strengthening communication strategies between parents and providers may increase HPV vaccination coverage and prevent future infection and related morbidity (King 2020, unpublished data).

Communication strategies must be tailored to specific questions and concerns raised by parents to providers during adolescent health visits (Gilkey et al., 2019). A communication

experiment conducted in 2019 found that communication regarding HPV vaccine may be more effective if providers include information about cancer prevention, that urgency is important when raising and recommending vaccination, and that providers should engage in longer discussions about HPV vaccination when parents express concerns (Shah et al., 2019). However, little is known about specific methods to tailor provider recommendations about HPV vaccination to parents of adolescents in the state of Georgia. Georgia has many diverse sociodemographic contexts, and tailored communication strategies to differing populations are needed to increase initiation of the vaccination series.

Purpose statement

The purpose of this project is to identify provider and parent attitudes and perceptions regarding communication around HPV vaccine recommendations. To achieve the 80 percent coverage level goals specified in Health People 2020, new strategies must be implemented (ODPHP, 2014). Communication strategies by providers must be tailored and relevant to the communities they serve to effectively prevent HPV-related cancer and other health outcomes of HPV infection. Understanding the interplay between parent and provider communication will provide key insights on what information is most effective to increase vaccine uptake and the strength of recommendations.

Research Objective (Aims)

This project will analyze results from 16 focus group discussions consisting of parents of adolescents and healthcare providers conducted across the state of Georgia spanning peri-urban and rural communities. This project's main research questions are: "What are ways to

strengthen existing communication strategies between parents and providers?" and "How can we support development of better communication strategies to improve HPV vaccination coverage rates?".

This project has two aims:

1. Identify parent and provider perceptions on communication around HPV vaccine recommendations
2. Suggest new improved strategies to tailor provider recommendations to the needs of the local community, patients and their caregivers.

A thematic analysis of both caregiver and provider focus group discussions will be conducted, focusing on identifying communication strategies and perceptions of communication around HPV.

Significance Statement

While many national-level studies have been conducted on communication between parents and providers around vaccination, there is a need for Georgia- specific context (Dennison et al., 2019) (M. B. Gilkey & A.-L. McRee, 2016). In the state of Georgia, 68.1 percent of adolescents had initiated the HPV vaccine series in 2017, and only 49.6 percent were up to date (CDC, 2019d). Adolescents in rural compared to urban areas are less likely to be vaccinated against HPV, with the number of adolescents in rural areas who receive the first dose being 11 percentage points lower (CDC, 2018). This reemphasizes the need for an understanding of how tailored communication strategies support uptake of the HPV vaccination series among caregivers of adolescents, especially between rural and urban settings. Context is key in

understanding how different populations perceive risk, how providers give recommendations, and what leads to trust and initiation of vaccination.

By increasing uptake of HPV vaccination in Georgia, the state can begin to lower its HPV-related incidence. Cervical cancer was the 11th highest cause of cancer deaths among women in Georgia from 2007 to 2012. (Berzen et al. 2016) Cervical cancer incidence rate among non-Hispanic black women is 16 percent higher than among non-Hispanic white women in Georgia (Berzen et al. 2016). From 2011 to 2015, there were 1,090 new cases of HPV-attributed cancers yearly on average in Georgia (DPH, 2018). There were 357 average incident cases of cervical cancer, 394 cases of oropharyngeal cancer, and 208 cases of anal cancer over the same time period (DPH, 2018). Vulvar, vaginal and penile cancers made up the rest of the average yearly cases of HPV attributed cancers (DPH, 2018).

Given the stark income inequality and racial disparities that exist within the state, there is substantial need for increased prevention measures to prevent development of and mortality from cervical, vaginal and other HPV-related cancers. Therefore, understanding how to increase HPV vaccine coverage can help prevent these cancers. Through direct interactions with parents and patients, healthcare providers can incorporate improved communication strategies to vaccinate before adolescents are at risk.

Chapter 2: Literature Review

HPV Epidemiology

Human papillomavirus (HPV) is the most common epithelial viral infection in the United States (U.S.) and affects an estimated 79 million Americans (CDC, 2018). HPV is transmitted through close intimate contact with an infected person, mucous membranes or bodily fluids. It is commonly spread through oral or penetrative sexual intercourse (WHO, 2017). There are more than 120 strains of HPV, with negative health outcomes from infection including genital warts, cervical abnormalities and six HPV-associated cancers. There are several high-risk strains of HPV, specifically 16 and 18, which together account for about 70% of cervical cancers (CDC, 2018). An estimated 70 to 90 percent of all HPV infections are asymptomatic and resolve within 1-2 years.

Persistent infection, meaning it is untreated or not cleared on its own by the immune system, with high-risk HPV types are strongly associated with developing cervical or other HPV-associated cancers. The World Health Organization estimated that there were 570,000 new cases of HPV worldwide in 2018, and 16 percent were in developed countries (WHO, 2019). An estimated 311,000 women die yearly from HPV-associated cancers, accounting for 7.5 percent of all female cancer deaths in 2018 (WHO, 2017).

Other cancers, including anal, vaginal, vulvar, penile and oropharyngeal cancer have been associated with chronic HPV infection. From 2012-2016, the CDC reported 44,000 yearly cases of HPV-associated cancers on average (CDC, 2019b). Among women, 17.6% were of the anus, 16.2% of the vagina, 14% of the oropharynx, and 3.6% of the vagina. Among men, 81.3% of HPV-associated cancers were of the oropharynx, with the remaining found in the anus and

penis (CDC, 2019b). An estimated 34,800 cancers yearly were directly attributable to HPV. Of these, CDC estimated that 32,100 of these cancers could have been prevented by the nonvalent HPV vaccine(CDC, 2019b).

Before HPV vaccination was introduced in the mid-2000s, more than half of all sexually active American adults were infected with HPV at least once in their lives, with young women under 25 bearing the greatest rates of infection (Ault, 2006). One of the most highly associated risk factors for HPV infection is age (A. F. Dempsey). Younger age at sexual debut is associated with higher risk of acquiring cervical HPV infections. Risk peaks shortly after sexual initiation, and subsequently declines with age in women (Burger, Kim, Sy, & Castle, 2017). Modeling estimates showed that 50% and 75% of women acquired their causal HPV infection by ages 20.6 (20.1–21.1) and 30.6 (29.6–31.6) years, respectively (Burger, Kim et al. 2017). In a cohort of HPV-negative female university students followed before the vaccine was introduced, there was a cumulative incidence rate of 39 percent at 24-month follow-up (Winer et al., 2003). These findings underscore the need for comprehensive vaccination of adolescents before sexual initiation.

Prevention

Preventing infection with HPV can be at the point of sexual contact, or through primary prevention strategies such as vaccination. Physical barrier methods, such as condoms, can reduce the risk of transmission of HPV but not eliminate it entirely (CDC 2018). Delaying age of sexual onset and promotion of monogamous relationships with uninfected partners are most likely to prevent HPV infections (CDC, 2018; A. F. Dempsey).

A key secondary prevention strategy for HPV infection is cervical cancer screenings. Early cervical epithelial changes can be identified by a Pap smear test, which is the primary screening test for detection of precancerous changes that could become cervical cancer (Sachan, Singh, Patel, & Sachan, 2018). The United States Preventative Services Task Force (USPSTF) recommends screening for cervical cancer every 3 years with cervical cytology alone in women aged 21 to 29 years. For women aged 30 to 65 years, the USPSTF recommends screening every 3 years with cervical cytology alone, every 5 years with high-risk human papillomavirus (hrHPV) testing alone, or every 5 years with hrHPV testing in combination with cytology (Force, 2018). However, there is no regularly approved or practiced screening method for HPV infection in men.

Lastly, the recommended primary prevention strategy for HPV infection is the Bivalent (HPV2), Quadrivalent HPV (4vHPV) or Nonvalent (9vHPV) vaccine. The United States now solely uses the 9valent vaccine. These vaccines prevent against the most common high-risk HPV strains which are associated with developing HPV-related cancers. In two randomized placebo-controlled efficacy trials of the quadrivalent vaccine, prophylactic vaccination was found to be 95%–100% effective in reducing HPV16/18-related high-grade cervical, vulvar, and vaginal lesions and 97% effective in reducing HPV6/11-related genital warts (Muñoz et al., 2010). The nonvalent (9vHPV) vaccine is nearly 100% effective in preventing cervical, vulvar and vaginal cancers in women caused by the five additional strains it protects against (Chatterjee, 2014). Additionally, 9vHPV was shown to decrease diagnoses of anogenital warts by 67% and prevalence of precancerous lesions by 51% in girls aged 15-19 up to nine years after first dose (Drolet, Benard, Perez, & Brisson, 2019). Substantial decreases in anogenital warts and

precancerous lesions were also shown in women aged 20-24 (Drolet et al., 2019). Nonvalent vaccine can potentially prevent over 90% of cervical cancer worldwide by protecting against the nine highest risk strains (Huh et al., 2017).

Vaccine Development

The Food and Drug Administration (FDA) approved the first quadrivalent HPV vaccine for use in the U.S. in 2006 to protect against HPV16 and HPV18, which can cause cervical cancer and HPV6 and HPV11, which can cause genital warts. A bivalent vaccine was made available in 2010 that protected only against HPV16 and HPV18 (Castle & Maza, 2016). Approvals for these vaccinations were based on incredibly high efficacy of over 90 percent in preventing HPV infection, cervical abnormalities and pre-cancerous lesions caused by high-risk HPV strains. It is important to note that pre-cancerous lesions were used as the outcome of interest in clinical trials used to demonstrate the effectiveness and efficacy of these vaccinations. This is for two reasons: (1) cancer outcomes are rare in young adult populations and would require a longer time observing these populations and (2) it would have been unethical to not treat pre-cancerous lesions and observe the participants to see if they progressed to HPV-derived cancers (Castle & Maza, 2016). In December of 2014, the FDA approved a second-generation nonvalent (9vHPV) vaccine. This vaccine protects against HPV6, HPV11, HPV16 and HPV18 as well as five more genotypes: HPV31, HPV33, HPV45, HPV52 and HPV58 (Emiko Petrosky, 2015). Compared to 4vHPV, the 9vHPV vaccine showed a 97 percent reduction in the incidence of cervical, vulvar and vaginal disease. Additionally, the 9vHPV vaccine showed non-inferior seroconversion for HPV6, HPV11, HPV16 and HPV18 when compared to 4vHPV. However, there were more reports

of injection site reactions (Castle & Maza, 2016). The additional strains the 9vHPV vaccine protects against have been attributed to other HPV-associated cancers, which is why the 9vHPV vaccine is now the only recommended vaccine in the United States (Petrosky et al., 2015).

Adverse events for all three of the FDA-approved HPV vaccines have been minimal. A report from the Centers for Disease Control and Prevention analyzed vaccine safety data on 56 million doses of 4vHPV. The Vaccine Adverse Event Reporting System (VAERS) received 21,194 adverse event reports on HPV vaccination from 2006 to 2013, and 8 percent were classified as serious(CDC, 2013). The most common serious events were headache, nausea, vomiting and generalized weakness. The most commonly reported event overall was injection-site pain (CDC, 2013). Over 800,000 9vHPV doses were monitored over 2 years for a surveillance study, and no new safety concerns were identified (Donahue et al., 2019). All unexpected safety signals were not confirmed after further investigation and evaluation or were determined to be false positives. Both the 4vHPV and 9vHPV vaccines have a favorable safety profile (Donahue et al., 2019).

The HPV vaccine is fully endorsed by the WHO for use in preventing HPV infection and associated cancers" (WHO, 2017). Studies have shown that vaccination with any of the three FDA approved vaccines results in immune responses with antibody titres significantly above those resulting from natural infection and will prevent incident infection for at least 8–9 years (Castle & Maza, 2016). The vaccine is efficacious and prevents HPV infection and related cancers (WHO, 2017). Additionally, there is new evidence that just one dose of the vaccination can provide similar protection against HPV infection compared receiving 2-3 doses (Sonawane et al., 2019). As the rates of adolescents beginning the vaccine series are higher than those who

have completed, the potential to have the vaccination be given once is promising increase coverage and protect adolescents against the impacts of HPV infection (CDC, 2019d; Sonawane et al., 2019).

Vaccine Recommendations

The CDC Advisory Committee for Immunization Practice (ACIP) published their first recommendations for HPV vaccination of adolescent girls and young women in 2007. They recommended "routine vaccination of females age 11-12 years with 3 doses of quadrivalent HPV vaccine" (Markowitz LE, 2007). The vaccine was recommended for ages as young as 9 and as old as 26 years. Catch-up vaccination of females aged 13 to 26 was recommended to be administered before sexual initiation, but was approved for those already exposed to HPV, to protect against any high-risk genotypes that they may not have been infected with (Markowitz LE, 2007). Vaccination of males aged 9-26 years with the quadrivalent vaccine was not approved by the FDA until October of 2009. The ACIP began recommending vaccination of males in 2011 (Castle & Maza, 2016).

When the FDA licensed use of the Cervarix bivalent vaccine in 2009, they provided updated recommendations on the use of either 2vHPV or 4vHPV for routine immunization of adolescents (ACIP, 2010). At this time, both versions of the vaccination were administered on a three-dose schedule. The second dose was suggested to be administered one to two months after the first dose, and the third, six months after the first dose (ACIP, 2010). Following licensure of the 9valent HPV vaccine in 2014, ACIP published updated recommendations. 9vHPV and 4vHPV are licensed for use in females and males. 2vHPV was still recommended only for

use in females (Petrosky et al., 2015) as it only protects against HPV infection associated with cervical, vaginal, and vulvar cancers. Since 2015, review of existing and new immunogenicity data has led to the ACIP revising recommendations and approving a new two-dose schedule for adolescents who start the vaccine series before their 15th birthday. The new two-dose recommendation was based on non-inferiority studies which showed the immune response was as high when vaccinated as young adolescents compared with efficacy of three-dose schedules for young adolescents (Castle & Maza, 2016). As of late 2016, only 9vHPV is being produced and used in the United States (Meites E, 2016).

Recommendations on the vaccination schedule for adolescent HPV are to vaccinate with two doses with a six-month interval between doses if the individual is below 15 years old at the time of vaccination initiation (Petrosky et al., 2015; WHO, 2017). The second vaccine should not be given less than five months after the first dose, or three doses may be required. Additionally, the WHO recommends a three-dose schedule for all those vaccinated at greater than 15 years, immunocompromised persons and those infected with HIV. For all conditions and ages at vaccination, there is no need to screen for previously acquired HPV infection or co-infection with HIV (WHO, 2017).

Parental Reactions and Barriers to Vaccination

When 9valent HPV vaccine was licensed, a commercially available option for HPV prophylactic vaccination had been available for more than eight years. However, a study utilizing online focus groups found low and variable knowledge about HPV, related cancers and vaccinations among parents of female adolescents (Fontenot, Domush, & Zimet, 2015). In fact,

a 2019 study found that most college-aged men and women in their sample were aware of HPV and the vaccine, but had very lowed perceived and measured knowledge on how HPV is transmitted, what diseases result from HPV infection, and how to prevent infection (Preston & Darrow, 2019). Vaccination against HPV has been recommended since 2006, yet parents, adolescents and young adults exhibit low understanding of the importance of HPV vaccination, even as educational resources and provider recommendations are given (Leung, Akinwunmi, Elias, & Feldman, 2019; Patel & Berenson, 2013; Preston & Darrow, 2019).

While other childhood and adolescent vaccinations have high uptake of over 85 to 90 percent, uptake and completion of the HPV vaccine series across the U.S. consistently lags behind intended targets (CDC, 2019d). Several myths in particular limit healthcare practitioners in educating and recommending parents of adolescents to initiate the vaccination series. Common myths about the vaccine include: HPV vaccination is not effective at preventing cancer, pap smears are sufficient to prevent cervical cancer, HPV vaccination is not safe, HPV vaccination is not needed since most infections are naturally cleared by the immune system, and 11-12 years of age is too young to vaccinate (Bednarczyk, 2019). Beliefs in each of these myths is pervasive across the United States, as propagation of myths and misinformation is fueled by social media, anecdotal influence and alarmist blogs and websites (Pluviano, Watt, & Della Sala, 2017).

Sources of vaccine hesitancy in parents are surprisingly, not motivated highly by the virus being sexually transmitted. National survey samples have found parental attitudes around HPV vaccination are more reflective of parents' attitudes towards vaccines in general, and not

sexual stigma or conservative values (Patel & Berenson, 2013). Vaccine hesitancy, especially for HPV, is still a significant issue, as low coverage rates reflect.

A nationally representative sample of parents of adolescents aged 11-17 found that 28 percent of parents reported having refused HPV vaccine (Gilkey, Calo, Marciniak, & Brewer, 2017). Parents who refused, rather than delayed, vaccination more often reported their reasons were believing their child was not sexually active, concern about lasting health problems, or believing their child did not need the vaccine. Additional barriers to adolescent HPV vaccination, identified by other research groups, are financial concern with HPV vaccination's cost, social influences, and irregular access to or use of preventative care (Gilkey et al., 2017). Parents across several different studies reported needing more information before vaccinating their children (Holman et al., 2014).

Providers themselves, especially pediatricians, may not treat older patients with downstream HPV-related conditions. These providers may not see the effects of HPV, and therefore do not recognize the importance of HPV vaccination. This can reduce the strength and confidence of a recommendation given to a parent weighing decision on whether or not to vaccinate their child. It has been well-documented in past research that emphasizing cancer prevention is one of the best tools to recommend HPV vaccination. However, a majority of a national sample of providers (59%) reported taking a risk-based approach to recommending vaccination of adolescents (Gilkey, Malo, Shah, Hall, & Brewer, 2015). Recommendation quality was lower for those providers who were uncomfortable discussing HPV vaccination or believed caregivers did not value the vaccine (Gilkey et al., 2015). When physicians do not convey strong recommendations, it can convey ambivalence to parents (Gilkey et al., 2016) However, when

parents report satisfaction with provider recommendations, it increases uptake of vaccination and completion of the series (Kornides, Fontenot, McRee, Panozzo, & Gilkey, 2018).

HPV Vaccination in Georgia

The National Immunization Survey-Teen (NIS-Teen) estimated that 68.1 percent of 13 to 17-year old teenagers in the United States had initiated the HPV vaccination by 2018 (Walker TY, 2019). However, the state of Georgia falls behind the national average at only 64.3 CI:[57.5, 70.6] percent coverage with one or more doses of the vaccine. While Georgia has the second highest coverage in its region, HHS region 4, the state falls short of the national average and Healthy People 2020 targets (Walker TY, 2019).

Many studies have been completed, focused on HPV in national contexts to identify barriers, motivations, uptake of and communication surrounding HPV vaccination with parents, providers and community members. Until recently none were solely focused on the state of Georgia, resulting in a gap in knowledge of specific population contexts critical to increase uptake and knowledge of HPV vaccination (Dennison et al., 2019).

Georgia has an increasingly diverse composition. Racial minorities make up 38.7 percent of the state's population (U.S. Census Bureau, 2019). In 2017, 9.3 percent of Georgia residents were of Hispanic or Latino ethnicity (U.S. Census Bureau, 2019). About 10 percent of Georgia residents were foreign-born in 2017 and over 13 percent had no health insurance coverage. For those under 18, 21 percent live under the federal poverty line. Additionally, 14 percent of the state's population in 2017 were between the ages of 10 and 19- the ideal, and recommended, ages to receive HPV vaccination before sexual activity (U.S. Census Bureau, 2019).

A recent systematic review presented key findings relating to HPV vaccination in the state of Georgia (Dennison et al., 2019): The 2014–2019 Georgia Comprehensive Cancer Control Plan identifies HPV as an issue of importance; HPV vaccination needs and promotion of cervical cancer prevention are both lacking significantly in Georgia hospital community needs assessments; and barriers for HPV vaccination vary throughout Georgia based largely on demographic characteristics; these barriers to HPV vaccination have been shown to be particularly difficult to overcome in rural areas and among minority populations (Dennison et al., 2019).

Within the Georgia Cancer Control Consortium (GC3) exists an HPV-specific work group, however a series of points for improvements in programming and capacity building which could lead to more effective results and vaccination promotion were recently identified (King et. Al) GC3 HPV working group members described how a set mission, purpose and set of goals, more specific and measurable outcomes, expanded networks of members, and better outreach could improve the organization's ability to fulfill its cancer prevention and vaccination aims (King, Moon, Agnew, & Bednarczyk, 2019).

These findings are critical in understanding the importance of context-specific data to inform local and state immunization programs, physician recommendations, and parental outreach and education. Increasing vaccine coverage in the state would reduce HPV-related cancer burdens. There is considerable state-level variation among HPV vaccination rates nationwide (CDC, 2019d). While some states have reached or are close to targets of 80% coverage, states in the Southeast (HHS Region 4) reported only half (54.2%) of adolescents completing the series in 2018 (CDC, 2019d). Additionally, understanding how to address

complex barriers underscored by the diversity in the state could lead to the development and implementation of new initiatives to address a spectrum of health concerns related to HPV. Georgia-specific research has identified that trust in healthcare providers is low, and caregivers value relationship longevity with their providers (Vu 2020, manuscript submitted for publication) (Bairu 2020, unpublished data). Specific demographics such as faith-based communities can be utilized in the state to present health messages in a trusted, familiar setting to the community (Lahjiani 2020, manuscript submitted for publication). Understanding provider and caregiver perceptions of vaccination and the approaches used within Georgia is essential to addressing the barriers that are limiting practices from reaching adolescent vaccination targets.

Communication Between Parents and Providers

Several studies have found that recommendations from physicians are key facilitators for increasing uptake of HPV vaccination (Fontenot et al., 2015; Holman et al., 2014). However, not all recommendations from providers are equal. Parents are more likely to choose to vaccinate their children if they are satisfied with the provider's communication; often determined by the provider's ability to address their concerns, ability to answer questions and use of easy to understand language (Kornides et al., 2018). In Georgia, providers have identified the cirtical need to recognize views and opinions of caregivers (King 2020, unpublished data). A study focused on caregivers in Georgia also identified trust and longevity of relationship as key drivers of positive HPV vaccination appointments (Bairu 2020, unpublished data).

Some national surveys report less than half of parents received no provider recommendations, and of that half which did receive a recommendation, only 36 percent received high-quality recommendations (Gilkey et al., 2016). This study defined “high quality recommendations” as a combination of three indicators- strength of endorsement, prevention message, and urgency (Gilkey et al., 2016). When high-quality recommendations are made, it is associated with nine times the odds of vaccine series initiation (Gilkey et al., 2016).

There are several different strategies that have been tested regarding communication around uptake of vaccination, including presumptive approaches, written informational material, and conversational approaches (Malo, Hall, Brewer, Lathren, & Gilkey, 2018). Vaccine information sheets (VIS), which are required to be distributed before vaccination by law, have been perceived as helpful by parents and healthcare providers on presenting information about HPV (Gilkey et al., 2017; Lockhart, Dempsey, Pyrzanowski, O'Leary, & Barnard, 2018). Several studies have found parental preference for discussing HPV vaccination with physicians as opposed to nurses and other clinical staff, as they perceive them to be more knowledgeable about the vaccine and the patient’s history (Gilkey et al., 2017; M. B. Gilkey & A. L. McRee, 2016). In one study, only 19 percent of parents perceived talking to a nurse as being helpful (Gilkey et al., 2017).

Another common approach that has been promoted in recent years, the “announcement approach” for HPV vaccination, involves providers announcing the child is due for the vaccination at that appointment, rather than following a conversation or question and answer based discussion around the vaccine to ease concerns (Malo et al., 2018). The CDC website on HPV vaccines for healthcare professionals’ states that providers should recommend

HPV vaccination in the same way and on the same day they recommend other vaccines for adolescents (CDC,2019). They provide a short script example for how to do so: You can say, *"Now that your son is 11, he is due for vaccinations today to help protect him from meningitis, HPV cancers, and whooping cough. Do you have any questions?"* (CDC, 2019). Presumptive or announcement approaches have been associated with higher rates of HPV vaccine series uptake (Brewer et al., 2017). Providers also view announcement-based approaches as easier to use and more effective than conversational approaches (Malo et al., 2018). This presumptive approach has been identified as a "best practice" that providers in Georgia perceive as increasing initiation of vaccination in their practices (King 2019, unpublished data).

Conversely, parents are likely to want to discuss HPV vaccination with their children's physicians. Safety and side effects, age to begin the series, and prevention of diseases are topics parents reported wanting to discuss (Attia, Wolf, & Nunez, 2018; Gerend, Shepherd, & Lustria, 2013; Holman et al., 2014; Shah et al., 2019). Barriers identified by caregivers in Georgia include trust in providers, cost of vaccination and side effects (Vu 2019, manuscript submitted for publication). Communication around cancer prevention ranked high on increasing confidence among parents and motivating them to initiate vaccination (Shah et al., 2019). This disconnect between providers preferring the quicker announcement approach and parents preferring an information-based approach to discuss concerns about vaccination is likely to contribute to parents perceiving the recommendation quality as less than favorable (M. B. Gilkey & A. L. McRee, 2016).

Tailoring HPV vaccination messaging to specific populations concerns and perceived barriers has been shown to increase intention to vaccinate and knowledge of HPV (Gerend et al., 2013) When recommending vaccination to diverse audiences, such as uninsured, non-English speaking, or marginalized groups, providers were less likely to engage in discussion and recommendation quality suffered as a result (Getrich et al., 2014). Parents from minority backgrounds in these cases were dissatisfied with the communication they received from providers (M. B. Gilkey & A. L. McRee, 2016). It is important for providers to tailor recommendations to diverse groups to improve intent and knowledge to vaccinate, especially in contexts with highly variable knowledge on HPV, health literacy and socioeconomic background.

Successful communication in clinical settings around human papillomavirus and HPV vaccination depends on strong provider recommendation, messaging emphasizing cancer prevention, and the perceived strength of the recommendation by parents who may be hesitant (M. B. Gilkey & A. L. McRee, 2016). Evidence is needed on targeted, tailored messaging and relevant communication strategies that caregivers respond well to in the state of Georgia. An understanding of the strategies and style of communication between parents and providers will help strengthen recommendation quality and perceptions of vaccination.

Chapter 3: Methodology

Introduction

This project is part of a larger cross-sectional environmental scan in the state of Georgia around attitudes, beliefs and barriers to HPV vaccination. Semi-structured focus groups (n=23) were conducted between March 2018 to July 2018. Focus Group Discussions (FGDs) involved six target groups however, this analysis and paper will focus on two target groups: healthcare providers and parents and caregivers of adolescents. This thesis project is an analysis of the parents or guardians (n=8 FGDs) and healthcare providers' focus group (n=6 FGDs) data, analyzing communication strategies between parents of adolescents and healthcare providers and how the use of different strategies can improve HPV vaccination series uptake and completion. The research team will also present suggestions on how to tailor strategies to diverse contexts within the state.

Population and Sample

FGDs were conducted throughout the state of Georgia to capture sociodemographic diversity in the sample. Participants were recruited by staff members at regional cancer coalitions and other community and health-focused organizations. Each organization designated a point-person to assist with recruitment. All recruiters were provided with eligibility criteria for the study. Caregivers were defined as parents and guardians who were included only if they were the responsible caregiver for at least one adolescent between the age of 9-17 years old.

Recruitment processes included flyers and newsletter announcements. Additionally, partner organizations employed direct recruitment tactics, such as calling or emailing eligible individuals. Eligible participants were invited to a central location for the focus group discussion on a pre-determined day and time.

This project focuses on six healthcare provider focus group discussions with a total of 55 participants and eight parents or caregivers of adolescents focus group discussions with a total of 65 participants. The total number of focus groups included in this analysis is 14, with 120 participants. Recruitment was completed using a convenience sample based on efforts by the study recruiter. The recruiter was supplied with eligibility criteria and then reached out to applicable professional or community organizations for potential FGD participants.

Procedures and Instruments

All FGDs were conducted in-person in a private location. A trained qualitative researcher facilitated the focus group while a note-taker assisted to capture participant responses and reactions (verbal and non-verbal). Different focus group guides were developed and used for healthcare providers and parent focus groups. Examples of questions asked during discussions are detailed in Table 1. Guides were reviewed by the Winship Cancer Institute's Intervention Development and Dissemination and Implementation (IDDI) shared resource to ensure appropriate tailoring for each specific population, clarity of the questions, and relevance. All FGD guides were reviewed and approved by the Emory University Institutional Review Board (EIRB).

All focus group discussions were audio recorded and manually transcribed verbatim. Transcriptions were verified through a three-step review process. An initial transcription was

completed followed by a second research team member review and edit. A third, and final, team member reviewed all proposed edits and finalized the transcription .

Table 1: Focus Group Discussion Questions from Healthcare Provider and Caregiver Guides

Question Topic Area	**Focus Group**	**Discussion Questions**
General Health	Parents and Guardians of Adolescents	What are the factors that affect health decision making? (Cost, distance, time, etc). How do these factors differ when making decisions for your children?
HPV Knowledge		What do you all know about Human Papillomavirus or HPV? • What can you tell me about how HPV is spread? • Who is at risk for HPV infection and other HPV-related cancers?
HPV Vaccine Knowledge		What do you know about the HPV vaccine? • Where do you get information about the HPV vaccine? • What resources do you, or have you, used to gather more information about the HPV vaccine?
Vaccine Acceptance / Hesitancy		Have others given you information that changes the way you think or feel about the HPV vaccine?
General Health	Healthcare Providers	What are some common talking points used when discussing STD/STI's ?
HPV Knowledge		What do you tell your patients and/or their family about the Human Papillomavirus (HPV)?
HPV Vaccine Knowledge		Can you share how you recommend the HPV vaccine with patients and their parent/guardian?
Vaccine Acceptance/ Hesitancy		How is what you say about vaccinations different dependent on the vaccination? Can you explain any differences when discussing HPV vaccine with male and female adolescents?

Ethical Considerations

This project was reviewed and approved by the EIRB in the United States (IRB00100271). An informed consent form (ICF), previously approved by the EIRB, was provided to all participants.

Consent forms included information about the research project, use of the data, the participant's role in the research, and audio recording of the discussions. Participants were only able to participate in focus group discussions after reviewing and physically signing an informed consent form. Time for questions and review of the informed consent form was provided before beginning the discussions. Participants' real names were not used during FGDs to increase participant anonymity and privacy. Transcriptions of the focus groups discussions were also de-identified of any names or identifying characteristics by the research team to maintain participant confidentiality. After completion of the transcript, the audio file was deleted.

Analysis

FGDs were audio-recorded, verbatim transcribed and imported into MAXQDA Plus 2020 version 20.0.4 (VERBI GmbH, *Berlin, Germany*). Analysis focused on identifying parental and healthcare provider perceptions of communication around HPV vaccination.

The research team collaboratively developed a codebook to capture common themes and patterns within the data. This codebook consisted of codes previously developed by the research team complemented by codes developed solely for this analysis which focused on communication approaches, such as "tailored messaging" and "announcement approach." The research team reviewed and discussed the codebook and it's use throughout analysis to ensure codes were clear and applied to meet code saturation.

An inductive approach was used to identify themes in the focus group discussions. This analysis focused on developing three sets of codes. Codes were either focused on healthcare provider communication, caregiver communication, or both. Codes that focused on both sets of

focus groups targeted communication strategies and approaches to initiate conversations around HPV vaccination. Examples of codes applicable to these three sets and corresponding segments are found in Table 2. Attitudes on communication between the two groups was varied and dependent on several factors including existing biases, approaches used by providers, baseline HPV knowledge of caregivers and emphasis on cancer prevention as a reason to receive the vaccine.

Table 2: Codes, Code Definitions and Segments

Code Name	**Code Definition**	**FGD Group Targeted**	**Segment Example**
Best Practices for Discussing Adolescent Vaccination	Include any information that the provider states "this has worked well," or "this is what we do, and it typically works" in reference to strategies for recommending adolescent vaccinations	Healthcare Providers	"I usually don't say that, "Hey, it's not mandatory. It's, it's not." If you say, if you give them mandatory, non-mandatory, they'll make their own choices. Just tell them the good things about the vaccine. Okay, what else, it's preventing infection, cervical cancer. You show them the genital sexually transmitted infection pictures, you show them the warts, particularly, we've got those pictures that very, you know, dramatic. So of course they get, they get good, uh, we get good response" FGD- Southwest GA Healthcare Providers
Announcement Approach	Information related to providers' presumptive communication about HPV vaccine, such as announcing & expecting the parents will get the vaccine	Healthcare Providers and Caregivers	"We have their, um GRITS record pulled ahead of time and we room the patient and we try and approach with the, this is our plan for today and, you know, um this how we're, with the, with the attitude of this is part of, this is what we're going to do today and if they have any objections we and try to discuss that with them, answer any questions they have and just to, you know, with a positive attitude this part of this is, you know, what your plan is for today, this immunization is what's going to happen today and most of the time they, it goes very well, we have very few that, you know, refuse

			the vaccines. We have a lot, even the 9-11-year old's now are getting the HPV vaccine, we have a lot of them that before 13 years old that have completed their vaccine so it's going really well that way, you know, so." FGD- Southeast GA Providers
Caregiver Confidence in Healthcare Providers	Include any information related to caregivers discussing the trust they feel with providers, or caregivers stating they won't perform a health behavior because of lack of confidence in providers	Caregivers	"And I think a lot for me, when my pediatrician said she gave it to her child I was like ok, well that's ok, you know, as a doctor giving it to her own child. Um now, she could have been you know talking out the left side of her mouth. But you know, it made me feel comfortable to hear and there are things that she had done, that she had not given her kid, or that, things that she doesn't not do with her child that I was like no I think I need to do this with my own child even though you're not. So, I felt comfortable believing of her when she said that she did. And she just made me feel comfortable with that decision." FGD-Atlanta Metro Caregivers

Chapter 4: Results

Demographic Characteristics of Participants

We conducted 14 FGD with n=120 participants total. Amongst those FGD, eight were completed with n=65 caregivers, and 6 were completed with n=55 healthcare providers. Across FGD participant type, most participants (89%) identified as female. Amongst healthcare providers, 13% identified as male and oftentimes these men were either pediatricians, physicians, or pharmacists. Amongst caregiver participants, less than 10% identified as male. Participants in healthcare provider FGDs represented an array of healthcare professions (e.g. nurses, pediatricians, laboratorians). Parents and caregivers reported an average number of children of approximately three. Further demographic information about our participants can be found in Table 3.

Table 3. Participant Demographic Characteristics (n=120)

	Parents/ Caregivers (n=65)		**Healthcare Providers (n=55)**	
	N	**%**	**N**	**%**
Sex				
Male	3	4.6	7	12.7
Female	62	95.4	48	87.3
Average Age	43		47	
Average number of children	3		NA	
Employment Status				

Employed (at least part-time)	40	72.7	55	100.0
Unemployed	11	21.6	0	0.0
Average Years in Practice	NA		15	
GA Region				
Metro Atlanta	23	35.4	0	
South	24	36.9	39	70.9
East	12	18.5	8	14.5
Northwest	6	9.2	8	14.5

Focus Group Discussions with Healthcare Providers

Perceptions that parents don't want to discuss HPV vaccination

In all six provider FGDs, the topic of bringing up HPV vaccination to parents was discussed. A common perception among providers was that parents don't want to talk about HPV vaccination because of its perceived connection with sexual activity. Providers reported that they typically address conversations around HPV vaccination for the first time between the ages of nine and twelve, when patients are due for other adolescent vaccinations, such as Tdap and meningitis (MCV4), and corresponds with the recommended age range. Providers reported that caregivers tended to perceive the HPV vaccination as being recommended at too early an age. Providers discussed how caregivers felt that their children were likely not sexually active, thus making the vaccination unnecessary. Providers said they often felt hesitant to accept the

request of parents to wait until the child is older to vaccinate, as it is necessary to vaccinate children before they become sexually active and are exposed to HPV.

> *"And the other is your child can be a virgin on her wedding day, and lo and behold, bridegroom might not be, and bring something devastating to your child, so you know, you have to look at it as a protective measure as opposed to giving consent for sex, you know. You can't stop your child from having sex. I don't care what you do, what you say, you can't stop your child from having sex.* (South GA Providers)

> *"So, we'll think about it." But they don't have an answer when we ask them, "do you know the day when she or he is going to be sexually active?" No one knows the answer, right? So they don't know that one."* (Southwest GA Providers)

> *"Well then of course, this is Mary, most, you know, mammas will say, "well my child is not sexually active", so we don't even, "I don't even want you to have that discussion" so that kind of ties your hands at that point too. So I guess it's just education, we need to educate the parents and kind of get past that."* (East GA Providers)

Both emphasizing virus/cancer prevention and the possibility of future infection through sexual contact (both by the adolescents themselves and future partners) was a common dimension within this topic. When future sexual activity was discussed with caregivers, providers emphasized the importance of discussing the perception of exposure risk. Providers commented it was common for caregivers and adolescents to think "I won't get that." Another common statement was that although the child may not be having sex at the moment, their future partners, mostly stated as future spouse, may carry HPV infection. Preventing cancer was discussed as a way to divert the conversation away from sexual activity. "Just tell them the good things about the vaccine. Okay, what else, it's preventing infection, cervical cancer." (Southwest GA Providers)

Healthcare providers also stated that caregivers had common concerns about the side effects of the vaccine. They described caregivers not wanting to hear about getting their

children the vaccine because of side effects that they had heard from a variety of sources- peers, online blogs, rumors, etc. Providers also described caregivers being concerned that some side effects were yet "unknown", making it more difficult to have discussions grounded in data about low rates of side effects.

> *"…so when I mentioned and I discussed the side effects or something she said, 'oh I definitely don't want that. The side effects or nothing'. Well then you have to tell them that there are side effects with all medications and so we have to discuss, that doesn't mean you wouldn't take Tylenol if you would hear the side effects of Tylenol."* (East GA Providers)

Although providers expressed overall their opinion that caregivers "wanted the best for their kids", they were disappointed in the unwillingness to discuss HPV vaccination. Providers often expressed that they felt it was their responsibility to present facts and discuss vaccination with the caregivers in order to help them understand the benefits of vaccination.

Importance of Strong Engagement with Caregivers

In all provider FGDs, the significance of strong engagement with patients and their caregivers was brought up. Providers discussed strong engagement to connote answering parental questions, advocating for HPV vaccination, and the importance of making strong recommendations. Common questions providers recalled were "Do you think I should get it [the HPV vaccine]?" or "Did you give it to your child?" Providers believed that these questions emphasized that trust in their recommendation was a required parental precursor to uptake of the vaccination series, as well as the caregiver perception that they were making the recommendation in the best interest of the adolescent.

> *"I think when the patient and the family gets comfortable with you. And the more you educate them. When you build that trust like just working in oncology when you build*

> *that, when you let them know that, I treat you as you are my family and I want this to be better for you. They look at it like a different approach."* (Northwest GA Providers)

Physicians discussed feeling rushed to cover multiple topics in a short primary care appointment. They expressed feeling it was difficult to make a strong recommendation and answer questions for every patient with limited time. Many healthcare providers stated that nurses and medical assistants had more time to talk with patients. A nurse from southern Georgia reiterated this sentiment, saying "*And I think it, sometimes, you know, we [nurses] might have a little bit more time than they [physicians] do to educate them [parents/patients] a little bit more. And so it's ours and their responsibility, but we work as a team*." (FGD 11- South Georgia Providers) This resulted in physicians and nurses giving out informational pamphlets and Vaccine Information Sheets (VIS) to take home when they did not have time to have a more in-depth, reciprocal conversation. Even with the provision of written resources, almost all providers emphasized the importance of face-to-face education and clearly answering questions about the vaccine.

> *"At that time the brochure is there, so that, then I would read, what I do is I don't give the brochure to them because I'm afraid they might not even read it, so I read with them every brochure, when I give it to the patient I try to read it. And so then at that time HPV will come up and then I will address."* (East GA Providers)

Other common questions providers stated they were asked were ones about change in doses, side effects, cost and pain.

> *"FACILITATOR: What are the most common questions that parents ask about the HPV vaccine?*
> *PARTICIPANT 5: Side effects (Participants 1 and 3 agree.)*
> *PARTICIPANT 1: How many doses they have to get. They may ask that a lot. How many doses.*
> *PARTICIPANT 3: (Inaudible) And is the third one going to hurt as bad as the first one did"* (Southwest GA Providers)

Ultimately, providers recognized the importance of engaging with caregivers and their patients in conversations around HPV vaccination. Through answering questions, talking about what caregivers already knew about HPV, and providing strong, evidence-based recommendations, they believed they could increase vaccination acceptance. However, many providers still were hindered by parental hesitancy and were unsure how to effectively motivate patients and caregivers who were unmotivated to initiate or continue HPV vaccination. These providers met with hesitancy or refusal to vaccinate often still made another recommendation to the caregiver, understanding the evidence base on importance of provider recommendation.

> *"It's your job to make them take these vaccines or make them understand why they need to take these vaccines, I don't know. And you know, and sometimes they'll be like, 'no maybe next time'. No, no they don't need to wait until next time. I don't know how to get that across there. No, its time for them to take that second shot today, they need to do it today, it's, it's not good for them not to take that shot today. So, I don't exactly know how to make that, you know, make that point."* (Southeast GA Providers)

Best Practices for Discussing HPV Vaccination

According to providers, there were four best practices to communicate the importance of being vaccinated: (1) cancer anecdotes, (2) integrating the adolescent into the conversation, (3) presenting the vaccine as part of the routine schedule, and (4) consistent communication that is a combination of written and face-to-face education.

Cancer Anecdotes

Providers all emphasized that the shift from discussing HPV immunization as preventing a sexually transmitted infection to a cancer prevention vaccination was a positive way to

encourage caregivers to vaccinate their adolescents. They discussed how caregivers often felt uncomfortable discussing their children being sexually active, but stories about unvaccinated individuals developing HPV-associated cancers motivated them.

> "*Um once you've completed the series you have an 80% protection immunity against cervical cancer, penile cancer, throat cancer. Um and if they're still on the fence I have several like stories of people I've known where, that they didn't realize they had HPV and ended up with throat cancer."* (Northwest GA Providers)

Providers expressed frustration over how the vaccine was initially marketed, and the rumors and stigma surrounding associating HPV vaccination with a sexually transmitted infection. They discussed in depth how framing the vaccine as a cancer prevention tool appeals to caregivers and their wishes to protect their children.

> *"I think that, the way that it was marketed really did it a, a huge injustice. I have seen recently though, on television, they've come up with some new commercials and it targets children, adolescents, and they're they, they do emphasize the cancer prevention piece, and I think that's great. You know, because that's what parents need to hear. You know, yes, it does help prevent certain sexually transmitted diseases, but you can help your child not get a cancer. You know, what parent wouldn't want to do that? You know, so? I try to emphasize that when I'm talking to them about it."* (South GA Providers)

Additionally, providers discussed "getting the positive stories out there." These positive stories were mentioned by providers to include positive experiences of vaccination and reduction in HPV-related cancer incidence. They mentioned that many caregivers reiterated rumors about side effects and negative experiences, but not many had heard of positive experiences with the vaccine. Providers articulated the need for more information and knowledge sharing on the benefits of the vaccine, which they believed would lead to less resistance.

Adolescent Engagement in Vaccine Decision Making

Providers discussed in FGDs that they had observed adolescents were the one's advocating for their own vaccination. Providers recognized this and then appealed to both caregivers and adolescents as potential vaccine decision-makers. Providers stated this strategy proved to be effective at increasing acceptance of the vaccination.

> *"I mean not only do I talk to the parent but I tell the patient you know this is your body, this is what it's about. You know, and so when they understand the complications that can happen from, for potentially not being, you know, vaccinated, most of the time they're on board.."* (Northwest GA Providers)

> *"And when they [adolescent patient] ask you, when they look at the sexually transmitted pictures, and they see the genital warts and they ask, "How do you get rid of them?" Well when you start to describe that process, they hold out that arm."* (Southwest GA Providers)

Providers also discussed how a large portion of the adolescents they saw were very concerned about injection-site pain. They mentioned that adolescents often tried to dissuade their caregivers from vaccinating them by complaining about short-term pain impacts.

> *PARTICIPANT: "My daughter she'll try to talk me out of it."*
>
> *FACILITATOR: "Mm, is it just because they don't want the shot they don't want the pain?"*
>
> *PARTICIPANT: "Yeah it's the pain."* (Southwest GA Providers)

Providers emphasized the importance of appealing to the adolescent about the long-term benefits of vaccination, in an effort to outweigh their hesitation about the pain of an injection.

> *"And the kids are at an age too, they know more than what you think they know. I mean, they hear worse at school and on the streets so um, cuz I mean not only do I talk to the parent but I tell the patient you know this is your body, this is what it's about. You know, and so when they understand the complications that can happen from, for potentially not being, you know, vaccinated, most of the time they're on board."* (Northwest GA Providers)

Presenting the HPV Vaccine as Part of Routine Schedule

Providers in the FGDs understood what a strong recommendation was, and how to make one. They discussed how to make caregivers understand why the vaccine was important and the urgency to complete the vaccine series before sexual initiation.

> *"PARTICIPANT 5: Like you got to make these, it's your job to make them take these vaccines or make them understand why they need to take these vaccines, I don't know and you know, and sometimes they'll be like, 'no maybe next time', no no they don't need to wait until next time, I don't know how to get that across there. No its time for them to take that second shot today, they need to do it today, it's it's not good for them not to take that shot today.*
> *PARTICIPANT 1: Strong recommendation is the most important."* (Southeast GA Providers)

However, a majority of focus group participants touched on the impacts of telling caregivers that the vaccine was "optional" and how that affected their recommendation quality. Providers speculated that caregivers did not want to get the vaccine for their children because it is not required for school, and therefore they view it as less important or unnecessary. A nurse manager in east Georgia talked about the detrimental effect of not recommending the vaccine strongly or presenting it as optional:

> *"I mean it's recommended but not required as far as for school. And so that automatically puts, that wall goes up where it's like well I'm not going to make them get it then if it's not required."* (East GA Providers)

Conversely, other providers described that presenting the vaccine as part of the group of other adolescent vaccinations that are highly recommended at the time can help frame the conversation more positively.

> *"Exactly, exactly. Now I will say to the parents, they need tetanus, HPV, meningitis. That's what I will say. They need these three. And they are apt to get.* (South GA Providers)

Additionally, providers described focusing on the positive aspects of the vaccine when initiating the conversation. Providers once again emphasized cancer prevention and the importance of vaccinating early to avoid exposure to HPV.

> *"If you say, if you give them mandatory, non-mandatory, they'll make their own choices. Just tell them the good things about the vaccine. Okay, what else, it's preventing infection, cervical cancer. You show them the genital sexually transmitted infection pictures, you show them the warts, particularly, we've got those pictures that very, you know, dramatic. So of course they get, they get good, uh, we get good response."* (Southwest GA Providers)

Combination of written and in-person communication

Providers in this study discussed using multiple strategies to appeal to the wide array of communication wishes of their patients and caregivers. They reported that while some caregivers were happy with a presumptive approach to vaccination that day along with a required VIS sheet, many others required a gentler, more conversational approach. Overall, providers recognized the limitations of a lack of consistent and tailored communication. They described the potential pitfalls of focusing only on one strategy- whether it be pamphlets/VIS sheets or only answering a few questions and not providing the caregiver with more information. Providers recognized that some caregivers may find the VIS and other informational pamphlets difficult to understand. In these situations, providers believed that caregivers may not feel capable of asking further questions or making a decision to vaccinate or not.

> *"you're [the caregiver] not going to read it unless it's in plain, easily readable language for someone to understand."* (FGD 14- Southwest GA Providers)

Providers discussed what communication that was engaged and meaningful between the parent and provider looked like and how that would be beneficial during vaccine decision-making.

> *"I think that strategy may work in certain practiced environments, but each practice would really need to engage more with families and, how do I like to be informed and what is my preferred avenue of communication."* (FGD 15- Southeast GA Providers)

Providers also emphasized how consistency in their messaging can help encourage vaccine-hesitant caregivers to consider coming back, discussing their options more, and eventually initiating the HPV series. A combination of consistent communication, written information, discussion with providers and follow-up appointments worked well for providers at a practice in South Georgia.

> *But you gotta stay in communication with them, okay we'll talk about it later, give em the information, let them read it, explain to them, they'll bring it back to them say okay.* (FGD 11- South GA Providers)

Providers agreed that utilizing different approaches and tailoring communications were the best strategies. Providers identified the best practices they had either observed or utilized to communicate the importance of and initiate HPV vaccination among young adolescents. They identified hesitancies of parents and caregivers to discuss topics related to sex and sexually transmitted infections, as well as perceptions of safety and side effects associated with the vaccine..

Focus Group Discussions with Caregivers

Perceived Importance of HPV Vaccination

Caregivers throughout the state of Georgia felt that the importance of HPV vaccination was not fully expressed by physicians, especially if the vaccination was discussed as optional. Participants explained that the presentation of HPV vaccination as an opt-in choice caused hesitation in accepting the vaccine. When physicians presented the vaccine as a choice, the recommendation quality suffered.

> *"it's like, 'oh, this is a vaccine that you probably would want your child to have'. Um so it's not explained very well."* (Metro Atlanta Caregivers)

> *"When I took my daughter for her you know her shots, and they'll tell me, you know they give you a list of what's required and what's optional and she'll just let me make my decision.*" (Southeast GA Caregivers)

Participants stated that when faced with the option of vaccination, adolescents often pushed back on accepting. Caregivers discussed that they often didn't take the wishes of their children into account if they were educated on the benefits of HPV vaccination.

> *"But when she turns 16 she can get this optional shot. I was like, well she's gonna get it, she was like no, they said optional (laughter)*
> *I said you got to have it, I say it's gonna be good for you in the long run, but she's like if 'I ain't got to I definitely heard that when they said optional, and I know what that means when they say optional.'*
> *And so I'm like ok whatever . I tell her she got to have it she be done with it. Cause she knows if she's got to do she'll do it."* (Southwest GA Caregivers)

When providers gave caregivers a recommendation for the HPV vaccination, caregivers often pushed back for reasons of not having enough knowledge about the vaccine, fear of side effects, or concerns about the safety of the vaccination. Parents and caregivers discussed being unsure of the recommendation because of their knowledge that the vaccination was not

required for their child. Even though the HPV vaccine has been approved just as long as TdAP and other required adolescent vaccines, a caregiver in East Georgia stated that she perceived the vaccination as "newer" than other vaccinations. This concern ultimately made her not vaccinate her children against HPV.

> "*My children have not had the HPV vaccination and my primary concern, I did not do the research I should have and I do trust my primary physician, um but my concern with it was it was one of the newest vaccinations out there and I was afraid of the long-term side effects not the immediate, but versus measles and mumps, people have been taking that 30, 40, 50 beyond years, and I was just worried of what kind of side effects were there that they hadn't found yet and just take my chance not getting them vaccinated wait and see*." (East GA Caregivers)

Caregivers expressed favorable opinions of their providers when they felt like the vaccine was not "forced" on them. Strategies which providers used to initiate the conversation, answer questions and recommend the vaccine were discussed in both caregiver and provider FGDs. However, the opinions and strategies both FGD groups reported varied widely.

> *"My doctor gave me the pamphlet and said you need to read and decide if it's something you want to do or not. They didn't try to force it to me and they didn't strongly encourage or discourage."* (East GA Caregivers)

> *"They started pushing me and I do not give it and will not give it but um they started pushing me, like it was a very heated conversation in my pediatrician's office because I opted not to do it."* (Northwest GA Caregivers)

Caregivers feeling pressured to accept vaccination was also mentioned during provider focus groups. Providers expressed difficulties finding a middle ground between communicating the importance of vaccination, but also respecting the rights of the caregiver to make decisions. These hesitancies of providers and caregivers however, seemed to not affect required vaccines. Often the caregivers perceived required vaccines as "safer." They discussed how this stemmed from distrust in the healthcare system.

> *"Where in especially in low income areas and things of that nature they will test, use them as test cases, and not really give them whatever this is that they are supposed to be giving them. And then, or pretend to treat them and not really treating them and seeing how bad it can actually get and things of that nature. And um, so yes that made me very wary especially when something first comes out. And they want to spread it everywhere and all of that. It makes me have a second thought because when they have done stuff like that in the past it was not totally honest."* (Metro Atlanta Caregivers)

Importance of Peer Influence

A common frustration voiced among caregivers was that the doctor did not provide them with enough information, leading caregivers to seek more information and opinions about HPV vaccination elsewhere, mostly from friends or family. Many caregivers reported searching for more facts and information from reputable sources such as CDC, Mayo Clinic and vaccines.gov. A majority of caregivers also felt that it was important to discuss the vaccination amongst their friends and peers, especially with others who may have already made a decision related to HPV vaccination for their child. Caregivers reported being highly motivated by the opinions and perceptions of friends and family as it related to HPV vaccination. One caregiver from the Atlanta Metro area was initially skeptical of her son being offered the vaccine at age 10 but was convinced through the recommendation of co-workers.

> *"I had conversations with some co-workers um that have kids. You know, my age, my son's age and they were like [Real Name Stated], you need to read more into it because there's a lot going on out there that um are happening with our kids. Um, and they're getting HPV [infection], um they're getting different diseases because of HPV. And I did a little bit more research and um at the next visit when he turned 11 I went ahead and had it done."* (Metro Atlanta Caregivers)

Additionally, the line of communication from peers can often precede interactions with healthcare providers concerning HPV. Providers talked about how this knowledge base of

opinions, facts and rumors can cloud their recommendations and make it difficult to reach caregivers at an ideal time to answer questions and facilitate discussions. Caregivers discussed how the lack of time spent with providers yearly made it difficult to talk about more than one vaccination or health concern. However, they could discuss health related topics with peers more often.

> *"I mean, I sure talk to a lot more friends than I talk to my doctor, I talk to my doctor once a year, I talk to my friends every day."* (East GA Caregivers)

Caregivers often reported that a common source of information for them about HPV vaccination was internet blogs or social media. Caregivers seemed to view these as akin to peer recommendations, stating that they trusted other mothers and their opinions on the vaccine. Many caregivers often supplemented internet, social media sourced material with other information from verified scientific sources.

> *"I, I, you know, I started with a google search and I read um I read some of it, I guess what would be referred to as "mommy blogs", other mothers that might blog about parenting and things like that. Um there was a ton that you could really read either way, but then I tried to read some more reputable type information, you know, how long it had been out, um the research, opinions from doctors."* (Northwest GA Caregivers)

Largely, concerns about the vaccine from peers sparked fear and uncertainty within caregivers. However, those who had strong positive opinions about HPV vaccination after speaking with healthcare providers often did not let peer influence outweigh the need to protect their children from infection and related cancers. A parent in Northwest Georgia stated: *"Peer pressure I don't think would, deter me or would influence me in either direction because I would be looking at what I thought was best for my child."*

Communication Approaches

This sub-section focuses on three different communication strategies identified that facilitated conversations between caregivers and providers throughout the transcripts. Results within this section were discussed in both caregiver and providers FGDs, highlighting the importance of both to each set of participants involved in our research.

Written Information

The approaches providers used to employ VIS sheets and other written education methods differed. Caregivers' perception and understanding of communication aids like pamphlets and VIS sheets was dependent upon how much providers explained and discussed the content.

> *"When my doctor advised it, he gave me a pamphlet to read and I read about it and then … but I never got that far."* (East GA Caregivers)

> *"That's when you tell them, you know, you explain it to them. And they go and take their time, and read and go over with somebody else, or they take it home with them. If they do not understand it when they come back, you say, I can explain this to you more in depth if you got any questions, yes. Cuz we always say if you have any questions or need to review these before, you know, you decide."* (South GA Providers)

One common complaint by caregivers was that all of the written materials amounted to an overload of information, especially combined with any personal research or peer recommendations they may have received. Providers stated that they were required to give VIS sheets, but often liked to distribute additional practice-designed information about vaccination.

> *"You know, those vaccine information sheets they just get thrown away to the side, they want to hear what you have to say they don't-, so what we've done is um, made them*

> *look like pizza menus, on a ring, we just kind of made them, we laminate, we laminate them and I broke them down myself."* (Southeast GA Providers)

However, caregivers reported feeling overwhelmed with the short amount of time to digest information before deciding whether to vaccinate their children.

> *"But you know they give you this sheet with all the stuff and it's like they want you to digest it in that small amount of time."* (Metro Atlanta Caregivers)

When caregivers were given extra time to digest the written information provided and prepare questions to ask, caregivers reported more positive experiences and the ability to discuss vaccination with their children beforehand.

> *"My uh, pediatrician is very thorough, so she'll let you know ahead of time, hey read this pamphlet on HPV or whatever it is so next time you' re ready for that shot. So my daughters they always say, not in depth, but they' ll say why do I have to take this, why I don' t want to take this we always have those kinds of conversations"* (Metro Atlanta Caregivers)

Quite often, providers commented that their use of pamphlets or HPV-vaccine specific literature was in response to a caregiver expressing doubts about vaccinating their adolescent. VIS sheets are required when the caregiver consents to vaccination, but providers often discussed using these sheets in lieu of a strong recommendation to educate the caregiver. Providers reported hoping the caregiver would read and synthesize the information themselves and come to the decision to vaccinate.

> *"And that's what I do with my parents. When they give me a 'no', I give them information. I give them information to take home."* (South GA Providers)

> *"If they are still on the fence I'll give them a VIS sheet and I'll let Dr. [Real Name Stated] talk to them."* (Northwest GA Providers)

Additionally, when hesitant caregivers were presented with VIS sheets or other pamphlets, they discussed how it spurred them to go home and continue their own research on the topic.

> "*I get it from, like I said, the health department. They always giving out these fact sheets or whatever and then I go and Google*" (Southwest GA Caregivers)

Even providers were aware of this happening but didn't seem to engage the caregivers as much in conversation or employ other communication approaches, choosing instead to send them home with literature.

> *"Gardasil has a great like one-page flyer that we have in our clinic that's got information about the vaccine and the human papillomavirus and at the bottom it has some ve-, the very graphic pictures and a lot of the times if they don't consent today I'll fold that up and put it on mom's hand, and say, "Here's just some information."* (Southwest GA Providers)

However, some providers did employ a more engaged approach with literature. According to both caregivers and providers, taking time to explain the written information sources improved understanding more than handing the materials to caregivers and having them read the information on their own. A provider in Northwest Georgia discussed academic articles in depth with patients. This produced positive results, according to a nurse in the FGD:

> *"Our physician had an article that she would give out that um that the parents would read and about vaccines. And something it said it's like 'you know if everybody wants a cure for cancer, this could potentially be, you know, the HPV vaccine could potentially be the cure, no it's not 100% but we're working towards that'. So that changed a lot of minds when she would put it forward when she would put it out that way."* (Northwest GA Providers)

Results of these discussions on written communication tools such as pamphlets, VIS sheets and peer-reviewed articles identifies that caregivers do, in fact, read these materials and utilize them to ask questions or prompt discussions for additional information. But when providers do

not explain or encourage further discussion of the materials, caregivers expressed that this motivates them to look up more information on their own. Most positive outcomes, such as acceptance of vaccination or further discussion, came from providers sitting down with patients and caregivers, providing them with literature and then taking the time to explain and answer questions.

Perceptions of Announcement Approach

Participants' opinions on this strategy of communication were misaligned: providers believed that the announcement approach was beneficial and aided in attaining higher vaccination rates, whereas caregivers felt that the approach was pushy and did not provide space or time for them to ask questions if they were uncertain.

> *"We try and approach with the, this is our plan for today and, you know, um this how we're, with the, with the attitude of this is part of, this is what we're going to do today and if they have any objections we try to discuss that with them, answer any questions they have and just to, you know, with a positive attitude this part of this is, you know, what your plan is for today, this immunization is what's going to happen today and most of the time they, it goes very well, we have very few that, you know, refuse the vaccines."* (Southeast GA Providers)

One caregiver described how she felt "forced" into accepting the vaccine for her daughter.

> *"I don't think we got a choice really with the um with the HPV vaccine with her. Um …yeah I don't think we did, and I'm not too sure that I would have gotten it to be honest with you. It's like now at this point she's about to be 19 and I'm sure she's maybe, I don't know, you know, I don't want to talk about it really but going into that area of yeah sexuality.. Am I happy that she would be protected, yeah, but how do I know this vaccine is actually protecting her from anything? I don't even know that."* (Metro Atlanta Caregivers)

Providers discussed how the announcement approach was an effective strategy for increasing HPV vaccination uptake as it was discussed with other required adolescent vaccinations Tdap

and MCV4. Providers reported higher acceptance of the HPV vaccine when recommended following the announcement approach and only a little pushback. While providers reported only minor pushback from caregivers, they did report that some caregivers are "just gonna dig their heels in no matter what" and not accept the vaccination.

> *"Exactly, exactly. Now I will say to the parents, they need tetanus, HPV, meningitis. That's what I will say. They need these three. And they are apt to get."* (South GA Providers)

Caregivers, on the other hand, expressed contempt for the announcement approach, saying they felt the choice to vaccinate their children against HPV or take time to research on their own was taken away from them. Many reported a strong appreciation for providers who gave them a choice or took time to explain the benefits and potential side effects of vaccination. A few reported an extreme aversion to feeling forced to accept the vaccination on the day the conversation was initiated. This feeling of having no say in the matter of vaccination often made caregivers say they were less likely to accept the vaccination that day.

> *"Um and I just told her that that it was still my choice and that I wasn't comfortable with it. And she said, to me, 'well I give it to my kids', and I said well that's fabulous but that's your choice, I don't want to get it."* (Northwest GA Caregivers)

Tailored Messaging

Some providers reported utilizing tailored messaging, or strategically constructing recommendations to specifically address characteristics and concerns of patients and caregivers, when making HPV vaccination recommendations. Due to broad variations in age, socioeconomic status and health literacy among patients and their families, providers discussed

how they adapted communication around HPV to address the needs and concerns of specific populations.

The topic of health literacy, language barriers and low-income level was brought up in regard to the required VIS sheets and other informational resources . Providers seem to circumvent these barriers by creating and utilizing new materials that are easy to comprehend and with visual aids.

> *"Yeah, but I broke them down into age groups so it [doesn't] matter what your education level is I can just hand this to you and you can read it before the doctor comes and make yourself notes on a little pad and paper if they want to."* (Southeast GA Providers)

When caregivers believed that messaging was tailored to them and their child's needs, it was met with positive feedback.

> *"And my pediatrician because my daughter is 12 so she just had it at her physical in March and like she did it so eloquently. So it wasn't just to me it was to my daughter explaining what it was. She talked about the oral implications. That she did it in an age appropriate way and I was like oh my god I need to record you and like, you know (laughter. So I think it's important for physicians and pediatricians to be able to relay the information to the parent and the child because they should be informed too."* (South GA Caregivers)

Providers reported working to engage adolescents and make caregivers feel understood and acknowledged. Their "bedside manner" was an important factor in establishing trust to encourage initiation of the vaccine.

> *"Whether it's a vaccine or an illness. So having the bedside manner and the skillset to be able to talk to the patient in a way that, or the patients family understands what it is that you're trying to say. And you do it in a way that is not unkind or condescending because people, again, have like long held beliefs and if you are trying to deliver um a methodology of care that conflicts with those long held beliefs, um it's important to acknowledge the patients' feelings."* (Southeast GA Providers)

Caregivers emphasized that when they perceived the providers personalizing messages to them and their children, it spurred a sense of trust and comfort, because they felt understood and like the provider had the best interest of their children in mind. A significant factor leading to positive views of the vaccine identified by caregivers and perceived uptake identified by providers was a communication approach that emphasized a combination question answering, needs specific to that adolescent, and compassionate understanding of hesitancy in accepting vaccination.

Chapter 5: Discussion

This study used qualitative data to understand attitudes and perceptions of the communication strategies around HPV vaccine recommendations used by both caregivers and healthcare providers across the state of Georgia. These data underscore the importance and influence provider recommendations have on HPV vaccine decision-making by caregivers. However, study findings from caregiver FGDs also showed that external factors, such as peer influence and perceptions of vaccine schedules, have pertinent influence on the decisions made.

There is a complex interplay between provider and caregiver perceptions of communication approaches, recommendation quality, and hesitation from both parties in discussing vaccination to combat HPV and HPV-related cancers. Both the provision and receipt of information bilaterally is key to a strong understanding of the importance of vaccination and

how to properly tailor recommendations (Bednarczyk, Chamberlain, Mathewson, Salmon, & Omer, 2018; Gerend et al., 2013). To effectively strengthen communication between key stakeholders in the vaccination process- caregivers, adolescents and providers- strategies must seek to address key barriers in addressing hesitations and benefits for each relevant participant in this process.

Hesitation in discussion of HPV vaccination

Quantitative studies have found that among undecided caregivers, a majority express hesitancy at least once in receiving HPV vaccination for their adolescent children (L. A. Shay et al., 2018; VanWormer et al., 2017). Among caregivers, vaccine hesitancy is not universal and may vary depending on the vaccine, how it is presented, and other factors on the day of appointment (Larson, Jarrett, Eckersberger, Smith, & Paterson, 2014) . Ultimately, a strong provider recommendation remains the utmost predictor and motivator of HPV vaccine uptake by caregivers (Gilkey et al., 2015; M. B. Gilkey & A.-L. McRee, 2016; Meers, Short, Zimet, Rosenthal, & Auslander, 2017; Ylitalo, Lee, & Mehta, 2013).

In FGDs in this study, both caregivers and providers expressed hesitancies in initiating conversations around HPV vaccination. Hesitancies from providers were grounded in their perceptions of the caregiver and adolescent's opinions of HPV and hesitations. When providers in the FGDs discussed caregivers solely perceiving the vaccine as protection against an STI instead of HPV-related cancers, it led the providers to not recommend the vaccine effectively. This leads caregivers to perceive the vaccine as unimportant if the provider does not place

emphasis on HPV vaccination benefits. However, caregivers often reported wanting to discuss the vaccination and ask questions about side effects, safety and cancer prevention.

Our results highlighted that hesitation from caregivers in initiating conversation on HPV vaccination can lead to providers perceiving this hesitation in communication as the caregiver not wanting to vaccinate their children. Additionally, provider hesitation has been shown to often convey ambivalence to caregivers (Gilkey et al., 2015). While the bilateral nature of this communication challenge is important, providers can utilize evidenced based strategies and agency precedent to improve their recommendation quality. The Centers for Disease Control and Prevention's ACIP and the Community Preventative Services Task Force both recommend standing orders for vaccination (ACIP, 2000) (Coalition, 2020). Standing orders authorize nurses, pharmacists, and other providers to assess a patient's immunization status and administer vaccinations according to a protocol approved by the attending physician (Coalition, 2020). Standing orders work by enabling assessment and vaccination of the patient without the need for clinician examination or direct order from the attending provider at the time of the interaction (Coalition, 2020). Practices can introduce standing orders to streamline vaccine workflow and allow for providers other than physicians to make high-quality, consistent recommendations along with other adolescent vaccinations and then immediately initiate the vaccine series.

Additionally, utilizing communication around cancer prevention benefits both the caregiver and provider in vaccination discussions. Caregivers have reported increased confidence in HPV vaccination following discussions around preventing HPV-related cancers (Shah et al., 2019). In the FGDs, Georgia providers reported using cancer prevention messaging

as a way to avoid conversations about sexual transmission of the virus. This framing has been well documented to encourage discussion and curb hesitance in discussing HPV vaccination for young adolescents with caregivers about (Greenfield et al., 2015). These findings provide further evidence on the importance of framing HPV vaccination as a cancer prevention tool.

HPV as recommended: perceptions of this distinction and the importance of strong recommendations

A common point of ambiguity identified by both caregivers and providers were the recommendation guidelines for HPV vaccination. Caregivers did not know what to make of the recommendation as optional, sometimes thinking it is less important for their children as a result (Kao, Schneyer, & Bocchini, 2014; Ventola, 2016). Providers were unsure what strategies would be most effective to convey a strong recommendation if they are unable to state that the vaccine is required. As previously emphasized, there is a large body of research asserting that a strong provider recommendation is the best predictor of HPV vaccination (Lau, Lin, & Flores, 2012; Ylitalo et al., 2013).

Research has shown that through introducing the vaccine presumptively rather than through an elective introduction, providers can increase vaccine uptake (Fenton, Eun, Clark, & Perkins, 2018). This approach was used to prompt strong recommendations by providers in the discussions. However, caregivers in this study occasionally challenged this strategy, asking questions about why the vaccine was not required and questioning its efficacy and safety. Caregivers also discussed feeling “tricked” by this strategy and that they felt it didn’t provide an opportunity to ask questions or discuss the vaccine.

Several caregivers reported delaying their child's HPV vaccination, most reporting that they felt initiating between ages 11-13 was "too young." Although no providers in the FGDs recommended delays in vaccination, provider suggestions delaying vaccination have been shown to result in caregivers not vaccinating their children that day (Fenton et al., 2018). It is critical for providers to strongly recommend vaccination within the indicated age range, as the HPV vaccine series should be completed before onset of sexual activity (Petrosky et al., 2015) . CDC states that clinicians should recommend HPV vaccination in the **same way** and on the **same day** that they recommend other vaccines for adolescents. Scripts, answers to common questions, and a video series called "How I Recommend" are all available on the CDC website for clinicians to access (CDC, 2019a). One research study that assessed HPV recommendation quality measured strength of endorsement, prevention message and urgency (Gilkey et al., 2016). It found that caregivers who received high-quality recommendations were more likely to initiate and complete the series for their adolescents, even when they were vaccine-hesitant at the first appointment (Gilkey et al., 2016). These materials and videos should be widely disseminated to all providers who can provide HPV vaccines to adolescents and young adults within the recommended age range. Additionally, all providers, such as pediatricians, gynecologists and general practitioners, who regularly recommend HPV vaccination should receive training on the importance of strong recommendations and how to make recommendations for HPV vaccination effectively.

The best practices identified by the providers in this study align with key findings in previous research on HPV vaccine uptake (Krawczyk et al., 2015; Meers et al., 2017). By emphasizing HPV vaccination as cancer prevention and a routine vaccination to be given along

with MCV4 and Tdap in early adolescence, providers in this study were able to give a strong recommendation that they felt assisted caregivers in understanding the benefits of vaccination effectively (Krawczyk et al., 2015).

Our results also identified additional best practices which are less documented in previous research. Namely, providers explained the importance of adolescent engagement in HPV vaccine decision making and a combined communicative approach of providers utilizing written resources and explaining their content face-to-face with caregivers (King 2020, unpublished data) (Reno et al., 2019). Along with a strong recommendation, explaining written resources to caregivers and adolescents due for the HPV vaccine may provide needed encouragement and the ability to directly address questions and hesitations. Explanation will also ensure that caregivers and adolescents understand the information on the resource and the importance of vaccination. These findings emphasize the need for more research on specific local contexts, such as the state of Georgia, to better understand the factors and considerations involved in HPV vaccination recommendation and acceptance.

Sources of information: peers, sheets, and conversations

As depicted in the results, sources of information and caregiver perceptions of these sources play a crucial role in developing an understanding of the importance and necessity of HPV vaccination. Caregivers reported three main sources of information: peers, VIS sheets and other written information, and conversations with healthcare providers.

Peers, including friends and family members, played a large role in caregiver's opinions on HPV vaccination, especially if those who were relaying information had children of their own. Although a negative comment or rumor expressed by a peer may not be the sole barrier

to vaccination, when information expressed by providers and peers contradicts one another, it was enough to make caregivers question what was best for their child. Providers can recognize this source of information and initiate conversations about HPV vaccination, such as discussing upcoming adolescent vaccines at an earlier age. Early age at initiation of HPV vaccination has been associated with higher rates of on-time series completion (St Sauver et al., 2016). Additionally, providers can initiate conversations about health messaging and the importance of receiving health information from reputable sources. Caregivers discussed not only getting information from peers in-person, but also online through social media and "mommy blogs." Providers can ask questions such as "what have you heard about HPV?" and "From where?" These conversations can also provide an opportunity for interactions that boost a level of trust and rapport while providing time for providers to address and help calm any fears or refute false rumors about HPV vaccination. Relationship longevity, trust and a sense that the provider cared for the wellbeing of their child were also identified as important factors for caregivers when deciding whether or not to vaccinate (Bairu 2020, unpublished data).

It is required by law for all providers to distribute Vaccine Information Statements (VIS) to the patient or their caregiver prior to vaccination (CDC, 2019).The VIS sheet for HPV contains information on HPV infection, the importance of vaccination to prevent associated cancers and genital warts, risks of reaction, who to contact if there is a serious reaction, and information about the National Vaccine Injury Compensation Program (VICP) (CDC, 2019c). Additionally, for multi-dose series vaccines such as HPV, a VIS must be given before each dose. Previous research has shown that VIS have been perceived as helpful on presenting information about HPV (Gilkey et al., 2017; Lockhart et al., 2018). There is a large amount of information on VIS,

and over half of the information presented is on the risk of adverse reaction and the VICP. If other resources provided by the practitioner focus solely on the benefits of vaccination and don't mention risk of reaction, or if conflicting information is presented, caregivers may become overwhelmed and unsure what to trust.

Caregivers in our study often reported being confused by the sheer amount of information they were expected to digest regarding HPV and HPV vaccination, especially on the day of vaccination. They were often given the required VIS sheets and other informational material on HPV, either developed by the practice or other health education sources, at the same time. Additionally, providers discussed how the written information, such as VIS sheets, fact sheets, or brochures, can be helpful when caregivers initially express hesitation in vaccinating their child. This method of providing the written information as an expedient way to hopefully encourage vaccination was met with frustration by caregivers. This amount of information, provided at or near the same time, commonly overwhelmed caregivers and can result in indecision by the caregiver or even frustration. Caregivers reported frustration most often when they felt they weren't being listened to and their questions weren't being answered. This method described by both caregivers and providers shows that it is often utilized in Georgia, even when evidence contradicts this approach (Glanz, Kraus, & Daley, 2015). A strong recommendation combining the provision of written information, answering questions, and describing the benefits of vaccination should be utilized to ensure the correct information is received by caregivers. One caregiver in our results reported her child's pediatrician asked her to read an informational HPV pamphlet before coming to the appointment. This allowed for the caregiver to discuss vaccination with her adolescent

beforehand and be prepared to ask questions at the appointment. Although no clinical organizations have guidelines on providing material before caregivers arrive for the appointment, it could prove to be a key tool in saving time and strengthening recommendation quality through allowing more time for caregivers and providers to discuss the vaccine in-depth.

Caregivers should be encouraged by providers to ask questions and seek information from healthcare providers or sites like the CDC or the American Academy of Pediatrics (AAP) as an initial source. Providers should also make it possible to facilitate conversations around HPV vaccination during appointments, through providing resources ahead of time or scheduling extra time for discussion.

Message delivery: presumptive and tailored approaches

When initiating conversations about HPV vaccination with caregivers, providers described using the presumptive, or announcement approach (Brewer et al., 2017). This approach involves providers announcing the child is due for the vaccination at that appointment. (Brewer et al., 2017; Malo et al., 2018). The CDC endorses this approach, and studies have associated it with higher rates of vaccine uptake (CDC, 2019) (Brewer et al., 2017). Providers throughout the FGDs utilized the announcement approach habitually but would often use other strategies following the announcement based on the parent's initial reactions.

Caregivers in this study sometimes reported feeling frustrated and tricked by the announcement approach. They felt it took away their ability to ask questions or state any hesitancies with vaccinating their child against HPV (Vu 2020, manuscript submitted for publication) (Shen & Dubey, 2019). These results point out that usefulness of the

announcement approach relies on many factors, including established relationship and trust with the physician, previous knowledge of HPV and perceived agency to say no to the recommendation (Brewer et al., 2017; Opel et al., 2015). A provider who begins with a firm announcement approach may later have to adapt to a more reassuring conversational format utilizing motivational interviewing if the caregiver is hesitant (Meers et al., 2017). Providers in the FGDs reported adapting their communication to hesitancies of the caregiver. Understanding these factors is key for providers to utilize this communication strategy when recommending adolescent HPV vaccination (Amanda F. Dempsey et al., 2018). Providers should be well-versed in providing a presumptive recommendation, but also be prepared to have conversations and answer questions about HPV.

Tailored messaging refers to the personalization of messages for an individual based on his or her beliefs, traits or abilities (Kreuter, Strecher, & Glassman, 1999). Current evidence on tailored interventions to increase HPV vaccination uptake mostly centers on adult, independent men and women who were not previously vaccinated in the recommended age range (Bennett et al., 2015; Gerend et al., 2013). Tailored messaging is often utilized in the framework of the Health Belief Model, to address perceived barriers to adopting a health behavior, such as vaccination (Janz & Becker, 1984). However, when caregivers are often gatekeepers for health decisions for adolescents in their care, personally relevant information and individual barriers may vary between adolescent and caregiver.

In this study, positive reactions for tailored messaging to both the caregiver and adolescent were discussed during caregiver focus groups. When compared to an announcement approach, tailored messaging utilized more of a conversational, question and

answer approach to discussing parental concerns. The understanding of vaccine hesitation- from cultural perspectives, peer influence or other aspects- was key to the success of tailored messaging when simpler communication strategies are unsuccessful in promoting vaccination. When sources of information at the practice level, such as the written materials previously discussed, are tailored to the adolescent or caregiver, it could prove effective to uptake of vaccination (Gerend et al., 2013).

Conclusions, Strengths and Limitations

Provider HPV communication studies have been largely quantitative, and many utilized national samples (Brewer et al., 2017; M. B. Gilkey & A.-L. McRee, 2016; Kornides et al., 2018; Malo et al., 2018). Among qualitative studies, many focused on only providers or caregivers, not both (M. B. Gilkey & A.-L. McRee, 2016; Meers et al., 2017). Additionally, there have been few studies that focus on specific local contexts, such as the state of Georgia (Dennison et al., 2019).

This study adds to the body of evidence on the importance of a strong provider recommendation in the uptake of HPV vaccination. The results also identify the need for providers to be well-versed in various strategies to promote HPV vaccination and be well-prepared for adapting their recommendation style based on the needs of the caregiver or adolescent. Our conclusions also emphasize the importance of additional information sources, such as written material and peer influence on caregiver perceptions. Finally, these results provide needed context specifically on how caregivers perceive different approaches providers use to initiate vaccine conversations. Although strategies such as the announcement approach are useful in increasing HPV series uptake, they may be damaging to provider/caregiver

relationships and trust in this context. Providers decisions to utilize and address these strategies must be informed by local culture and practices.

These conclusions have a few limitations. First, discussions with caregivers and providers were dependent on recall of communication during the last appointment when HPV vaccination was discussed. All of the caregivers who participated in the FGDs were directly responsible for the health decision making of at least one adolescent. However, some of these children had completed their adolescent vaccinations, and some caregivers may have been recalling conversations which occurred some time ago. Secondly, these data are not representative of all caregiver/provider interactions in the state of Georgia but may be transferrable to similar interactions regarding HPV vaccine communication. This is the first study we are aware of that provides a comparative view of current strategies used by providers and caregiver perceptions of those strategies in the state of Georgia.

Strengths of this study include the qualitative methods used for data collection. Focus group discussions provided an environment to receive nuanced answers about a complex topic which often varies from community to community. Additionally, the ability to compare discussions bilaterally between caregivers and providers afforded the research team an opportunity to identify gaps between reported successful practices and the opinions of caregivers who received recommendations and vice versa with what caregivers expected or wanted from their providers and what their providers thought they wanted.

Chapter 6: Implications and Recommendations for Future Research and Practice

Further research is needed on some of the key themes discussed in this thesis. Factors influencing caregiver perceptions about HPV vaccination, such as peer influence and the impact of strategies for providers to present written materials are important. Future research efforts could also consider exploring interventions and evaluations of caregiver hesitancy if the HPV vaccine was made mandatory at adolescence for school entry, as has been done in Georgia for MCV4 and Tdap.

In practice, providers would benefit from trainings on how to make effective evidence-based recommendations specific to concerns about the vaccine for HPV (L. Aubree Shay et al., 2016). Due to the nature of its recommendation in vaccine policy, unique barriers exist in communicating both the importance of vaccination and the risk of infection in adulthood. Practice-level guidance on the use of written factual information, such as VIS, may additionally be developed to help address the concerns caregivers expressed on how information was presented to them during visits. Finally, tailoring interventions and messaging to both caregivers and adolescents could prove positive in increasing vaccine uptake, particularly in states with diverse socioeconomic contexts. Community assessments and further environmental scans can address these barriers to effective tailoring of communication and materials.

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