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A Regional Comparison of Barriers to Communication between Caregivers and Healthcare Providers Regarding the HPV Vaccine in Georgia

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Abstract

A Regional Comparison of Barriers to Communication between Caregivers and Healthcare Providers Regarding the HPV Vaccine in Georgia

By Kaliane Davidson

Background: HPV vaccination rates in Georgia among adolescents remain low despite the availability of the HPV vaccine since 2006. Little research into barriers to communication between healthcare providers and caregivers of adolescents regarding the vaccine has been conducted in Georgia. This research seeks to identify and regionally compare barriers to communication across East, Northwest, and South Georgia.

Methods: We conducted FGDs (n=12) with healthcare providers (n=6) and caregivers of adolescents (n=6) that could be comparatively analyzed across similar regions of the state of Georgia (East, Northwest, and South). Thematic analysis was utilized to identify, analyze, and interpret common themes present across both the healthcare provider and caregiver FGDs. These themes were then compared regionally to identify similarities and differences across Georgia regions.

Results: Our examination finds that across different regions, participants discussed similar themes, however, there were critical contextual differences when identifying barriers to communication. Findings were categorized into three themes: (1) health literacy, (2) lack of trust, (3) sex as a taboo topic. To improve communication between healthcare providers and caregivers across the state, regional needs must be addressed to facilitate the development of community-specific initiatives.

Conclusion: Georgia is a highly diverse state. This diversity is reflected in the variation of HPV vaccination coverage across the state. An understanding of Georgia's regional context is integral to the development of targeted communication and intervention strategies aimed at increasing HPV vaccination uptake and series completion. Improving communication between healthcare providers and caregivers is critical to addressing low HPV vaccination completion in Georgia.

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TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION

1.1 Overview

Human papillomavirus (HPV) is such a prevalent sexually transmitted infection (STI) that nearly all sexually active persons will become infected with it at some point in their lives. Approximately 80 million people in the United States (U.S.) are infected with HPV, with nearly 14 million new infections occurring each year (CDC, 2019c). Half of these occurrences are attributed to those aged 15 to 24 years old, and 80% of the sexually active population will contract at least one HPV strain in their lifetime (CDC, 2019c).

More than 100 strains of HPV have been identified, of which at least 14 are high risk (WHO, 2019). These high-risk infections can cause genital warts or cancer (CDC, 2019c). Nearly 35,000 cases of HPV-attributed cancers occur in the U.S. each year, with cervical and oropharyngeal cancers being the most common (CDC, 2019a). Despite the high prevalence of HPV, many people are unfamiliar with it and how it can be prevented.

The HPV vaccine was introduced in 2006, and until 2011 was only recommended to females (FDA, 2006). After 2011, recommendations were expanded to males (CDC, 2011). The Centers for Disease Control and Prevention (CDC) and the Food and Drug Administration (FDA) recommend vaccination for adolescents between 11-12 years old (CDC, 2011), and research has shown the vaccine to be highly efficacious if received before infection (CDC, 2019c).

HPV vaccination uptake remains low in the U.S. The 2018 National Immunization Survey-Teen (NIS-Teen) found that only 68.1% of adolescents in the U.S. aged 13-17 years had initiated the HPV vaccination, and that only 51.1% were up-to-date on the series (Walker et al.,

2019). This data demonstrated a slight increase from 2017, where 65.5% had initiated vaccination, and 48.6% were up-to-date (Walker et al., 2018). Despite this slight increase in vaccination coverage, overall rates are far from the Healthy People 2020 (HP2020) national target of 80% coverage for adolescents 13-15 years old (Healthy People 2020, n.d.).

HHS Region IV, which includes Georgia, reported the second-lowest HPV vaccine uptake (64.3% initiation, 46.7% up-to-date) across all the regions in the U.S. (Walker et al., 2019). In Georgia, 68.1% of teens aged 13-17 years had initiated the series, and 49.6% were up-to-date (Walker et al., 2019). Compared to other up-to-date coverage rates of adolescent vaccines mandated in Georgia such as the Tetanus, diphtheria, and acellular pertussis vaccine (Tdap) (94.2%) and the meningococcal conjugate vaccine (MenACWY) (94.8%), HPV ranks the lowest (49.6%) (Walker et al., 2019).

To help increase HPV vaccination rates among adolescents, the Georgia Department of Health (GA DPH), in collaboration with CDC, established a Comprehensive Cancer Control Plan that aimed for 50% vaccine completion for adolescents by the end of 2019 (Georgia Department of Public Health, 2014). Results from this initiative have not been released to date. Regional Cancer Coalitions in South, Central, East, Northwest, and West Central Georgia are also working to address community-level needs to increase vaccine uptake through various partnerships (Georgia Department of Public Health, 2018b).

Research has found that properly executed communication and recommendation strategies are critical to HPV vaccine uptake and series completion (Gilkey & McRee, 2016; Holman et al., 2014; Katz et al., 2016; Perkins et al., 2015). There has been limited research into the barriers and motivators to HPV vaccination uptake among adolescents in the state of Georgia

(Bairu et al., 2019; King et al., 2019; Lahijani, 2019; Vu et al., 2019). However, there is a distinct gap in research into specific communication barriers between healthcare providers and the caregivers of adolescents. This research gap is made even more apparent when examining the issue regionally. Georgia is a diverse state (United States Census Bureau, 2019), and to increase HPV vaccine uptake and adherence among adolescents and their caregivers, more research is needed on these specific communication barriers. By identifying local context, community-specific initiatives could be developed that would enjoy greater efficacy in ultimately reducing HPV-related cancers.

1.2 Problem Statement

Despite numerous studies on the efficacy of the HPV vaccine, uptake remains low both in the U.S. and the state of Georgia. The 2018 NIS-Teen reported that only 49.6% of adolescents 13-17 years of age in the state of Georgia completed the HPV vaccination series. This finding is well below the national target of 80% coverage among adolescents (Healthy People 2020, n.d.). When compared to mandated adolescent vaccines in the state, such as Tdap, which has 94.2% completion and MenACWY with 94.8% completion, it is clear that HPV uptake is low (49.6%) (Walker et al., 2019).

The Georgia DPH reports that there are over 1,000 new cases of HPV-attributed cancers each year in the state of Georgia (Georgia Department of Public Health, 2018a). Between 2011-2015, an average of 357 new cases of cervical cancer, 394 new cases of oropharyngeal cancer, and 208 new cases of anal cancer caused by HPV were reported across the state (Georgia Department of Public Health, 2018a).

Effective communication between caregivers and providers is vital because it assists in increasing awareness and encourages acceptance of vaccination (Gilkey & McRee, 2016; Holman et al., 2014; Katz et al., 2016; Perkins et al., 2015). A better understanding of barriers to communication could aid in the uptake and completion of the HPV vaccination series among adolescents. National and state-focused studies have examined the importance of communication between caregivers and healthcare providers, but little is known about barriers to communication in the state of Georgia, especially within a regional context (Bairu et al., 2019; King et al., 2019; Lahijani, 2019; Vu et al., 2019). Further insight into the needs of these regions and the development of community-specific programs to target these populations could increase uptake of the HPV vaccine.

1.3 Purpose Statement

This study seeks to identify and compare barriers to communication regarding the HPV vaccine between caregivers of adolescents and healthcare providers across three regions of the state of Georgia (East, Northwest, and South). Study objectives include: (1) examining barriers to communication regarding the HPV vaccine between caregivers and healthcare providers in the East, Northwest, and South regions of the state of Georgia, (2) further analyzing and comparing the identified barriers across these regions.

Understanding the factors that inhibit communication could further inform regionally targeted strategies to increase the uptake of the HPV vaccine among adolescents.

1.4 Research Questions

1) What are the barriers to communication regarding the HPV vaccine between caregivers and healthcare providers in the East, Northwest, and South regions of the state of Georgia?

2) How do the identified barriers to communication compare across the East, Northwest, and South regions of the state of Georgia?

1.5 Significance Statement

This work will support a deeper understanding of the population-level factors affecting uptake of the HPV vaccine regionally, specifically among caregivers and healthcare providers in the state of Georgia. The focus on effective communication between caregivers and providers is significant because it can assist in increasing awareness and encouraging acceptance of the vaccination. Often providers have the role of the educators and caregivers as the decision-makers for adolescents. Understanding the barriers faced by these parties can aid in the creation of additional evidence-based research and further inform interventions to improve the uptake of the vaccine among adolescents. Probable stakeholders could include academic researchers, advocacy groups, community organizations, healthcare professionals, and advisory communities.

1.6 Definition of Terms

Bible Belt	An area chiefly in the southern U.S. whose inhabitants are believed to hold uncritical allegiance to the literal accuracy of the Bible. (Merriam-Webster, n.d.)
Caregiver	In this study, a caregiver was defined as anyone over 18 years of age responsible for the medical decision making for at least one adolescent between 9 to 17 years of age.
Healthcare Provider	In this study, a healthcare provider included any provider or clinic staff who interacted with patients and their caregivers.

1.7 List of Acronyms

AAFP	American Academy of Family Physicians
AAP	American Academy of Pediatrics
ACIP	Advisory Committee on Immunization Practices
ACS	American Cancer Society
CBOs	Community-Based Organizations
CDC	Centers for Disease Control and Prevention
CG	Caregiver
CME	Continuing Medical Education
DHHS	U.S. Department of Health and Human Services
E	East Georgia
EMR	Electronic medical record
EIRB	Emory University Institutional Review Board
FDA	The U.S. Food Drug and Administration
FGD	Focus Group Discussion
GEORGIA DPH	Georgia Department of Health
HCP	Healthcare Provider
HP2020	Healthy People 2020

HPV	Human Papillomavirus
IDDI	Intervention Development, Dissemination, and Implementation
MenACWY	Meningococcal conjugate vaccine
MMR	Measles Mumps Rubella vaccine
NIS-Teen	National Immunization Survey-Teen
NW	Northwest Georgia
S	South Georgia
STI	Sexually Transmitted Infection
Tdap	Tetanus, diphtheria, and acellular pertussis vaccine
U.S.	United States
VAERS	Vaccine Adverse Event Reporting System
VIS	Vaccine Information Statement

CHAPTER 2: BACKGROUND

2.1 Literature Review

Introduction

At this time, approximately 80 million people in the United States (U.S) have been infected with at least one strain of Human papillomavirus (HPV) (CDC, 2019c). Each year, nearly 14 million people become newly infected, with half of these occurrences between those aged 15 to 24 years old (CDC, 2019c). Given the extensive prevalence of HPV infection, a significant portion of the population will contract at least one strain of HPV in their lifetime (CDC, 2019c).

HPV is most commonly spread through skin-to-skin contact via vaginal, anal, and oral sex with someone who has the virus (CDC, 2019c). Other, but less conventional methods of transmission include digital-anogenital, non-penetrative genital to genital, and shared clothing and towels (Bednarczyk, 2019; Liu et al., 2016). Most HPV infections present asymptomatically and clear on their own by the immune system (CDC, 2019c).

There are over 100 different strains of HPV (WHO, 2019). At least 14 are identified as high risk (WHO, 2019). High risk infections can cause genital warts or cancer. HPV types 16 and 18 are attributed to causing 70% of cervical cancers and pre-cancerous lesions (WHO, 2019). Persistent HPV infections – those that last two years or more – can cause HPV-associated cancers and/or genital warts (WHO, 2019). Each year, approximately 35,000 cases of cancer in the U.S. are caused by HPV (CDC, 2019a). Cancer of the cervix, vulva, vagina, penis, anus, and

oropharynx are linked to HPV, and of these cancers, cervical and oropharyngeal are the most common (CDC, 2019a).

Despite the ubiquity of HPV, many people are unaware of the disease, much less the methods for HPV infection prevention. In a study by Apaydin et al. (2018), most participants correctly identified HPV as a cause of cervical cancer but incorrectly named testicular, prostate, and ovarian cancer as HPV-related cancers. Unfamiliarity with anal, oropharyngeal, and penile cancers was common (Apaydin et al., 2018).

HPV Vaccination Recommendation

Since being licensed and recommended for use in the US in 2006, HPV vaccination recommendations have evolved over the years. As of 2019, more than 120 million doses of the HPV vaccine have been distributed (CDC, 2019d). The United States Food and Drug Administration (FDA) initially approved Gardasil, a quadrivalent vaccine developed by Merck & Co., Inc. (Merck & Co., Inc, n.d.), in 2006 for females 9-26 years of age, and promoted it as an efficacious means of preventing infection with four common strains of HPV (FDA, 2006). In 2011, the Advisory Committee on Immunization Practices (ACIP) HPV working group began recommending Gardasil for use for males aged 11 – 26, replacing guidance from 2009 for males 9-26 years old (CDC, 2011). Gardasil only protected against cervical cancer and genital warts. In 2014, Gardasil 9 was introduced to protect against the four strains covered by the first generation of the vaccine, along with five additional strains (FDA, 2014). Of these nine HPV types, seven strains cause cervical and other cancers, and two cause genital warts (NIH, 2015).

Initially, the FDA approved the vaccine series to include males 9-15 years old (FDA, 2014). One year later, the FDA approved expanded use to males 16-26 years of age (CDC,

2015). Expanded use of the vaccine, through shared clinical decision making with a healthcare provider, for individuals 27-45 years old was approved in 2018 (FDA, 2018). While targeted to adolescents between 11 to 12 years old, the vaccine can be administered as early as age nine (CDC, 2019a). In 2016, the CDC and ACIP recommended that for 11-12-year-olds Gardasil 9, the 9-valent vaccine, be reduced from three doses to two, taken six months apart (CDC, 2016). Adolescents that started the vaccination after their 15th birthday would still need three doses to complete the series (CDC, 2016). For 11 and 12-year-olds, HPV vaccination is recommended in conjunction with other adolescent vaccines such as Tdap, MenACWY, and the annual flu vaccine (CDC, 2020). Despite ACIP and other professional guidelines, a study by Kulczycki et al. (2016) found that only a little more than half (55%) of surveyed health professionals said they used ACIP or CDC information as their primary sources on HPV vaccination. Research has found that physicians' dedication to parents, as well as personal beliefs and attitudes on HPV vaccination, may be stronger predictors than professional guidelines in recommending vaccination (Kulczycki et al., 2016).

In the United States, from 2006 – when the quadrivalent HPV vaccine was introduced – through 2010, the prevalence of HPV infection decreased 56% among females aged 14–19 years (Markowitz et al., 2013). A review of various studies on the efficacy of the vaccine series found no decrease in protection after vaccination (CDC, 2019d; Deleré et al., 2014). The vaccine series also showed high effectiveness against HPV 16 and 18, the high-risk strains, and cross-protection against strains 31, 33, and 45 (Latsuzbaia et al., 2019).

A recent ten-year study on the effectiveness of the vaccine found substantial decreases in HPV infection among women who were vaccinated with the bivalent or quadrivalent series (Spinner et al., 2019). This study also suggested that herd immunity was a factor in the

protection of unvaccinated women since the prevalence of the same HPV strains also decreased among these women (Spinner et al., 2019). A separate study found that herd immunity was also observed in men and oral HPV infections (Chaturvedi et al., 2019; Mehanna et al., 2019). As HPV vaccination rates continued to increase among men and women, the prevalence of oral infection among unvaccinated men dropped (Mehanna et al., 2019).

The HPV vaccine is largely viewed as safe and effective by regulators (FDA, 2019). The CDC and the FDA are responsible for closely monitoring the licensing process and extensive testing has been completed over the years. From 2006 until 2014, over 67 million doses of the HPV vaccine were distributed across the U.S., and only 25,176 reports of adverse events were reported to the Vaccine Adverse Event Reporting System (VAERS) (White, 2014). Minor side effects such as dizziness, tenderness, redness, and swelling where the shot was administered were most commonly reported (White, 2014). Similar side effects were reported for other adolescent vaccines, such as Tdap, MenACWY, and the flu vaccine (White, 2014).

HPV Vaccination Rates: U.S. and Georgia

In 2010, the U.S. Department of Health and Human Services (DHHS) launched HP2020, an initiative to promote health and disease prevention. HP2020 set a goal for national HPV vaccine coverage at 80% for adolescents aged 13-15 (Healthy People 2020, n.d.). National HPV vaccination rates remain well below the HP2020 target. In 2018, NIS-Teen found that only 68.1% of teens in the U.S. aged 13-17 years had initiated the HPV vaccination and that only 51.1% completed the series (Walker et al., 2019). This indicated a slight increase from 2017, where 65.5% had initiated vaccination, and 48.6% completed the series (Walker et al., 2018).

HPV vaccination rates in the U.S. are comparatively lower than in other developed countries. Some countries, such as Australia and Scotland have reached more than 80% of targeted girls while the U.S. has barely reached 50% (J. Brotherton et al., 2011; J. M. L. Brotherton & Bloem, 2015; Markowitz et al., 2016; Sinka et al., 2014). In southern U.S. states, even lower rates of vaccination have been reported, especially in lower-income and rural communities (Kulczycki et al., 2016).

HHS Region IV, which includes Georgia, had the second-lowest HPV vaccine uptake (64.3% initiation, 46.7% up-to-date) across all the regions (Walker et al., 2019). When analyzing Georgia specifically, 68.1% of teens aged 13-17 years had initiated the HPV vaccination, and 49.6% were up-to-date (Walker et al., 2019). Overall, HPV vaccination rates in Georgia remain well below the national target of 80% HPV vaccination completion (Healthy People 2020, n.d.). Compared to the series completion of other adolescent mandatory vaccines mandated in Georgia, such as Tdap (94.2%) and MenACWY (94.8%), HPV ranks low (Walker et al., 2019).

Georgia is a highly diverse state that includes various cultures, socioeconomic status, and geographic barriers impacting vaccination beliefs, knowledge, and access (Dennison et al., 2019). The U.S. Census Bureau reported that as of 2019, over 10 million people live in Georgia, a 9.6% increase from 2010 (United States Census Bureau, 2019). Females constitute 51.4% of the population, and 23.8% of people are under 18 years (United States Census Bureau, 2019). The racial breakdown is 60.5% White, 32.4% Black or African American, 9.8% Hispanic or Latino, 4.3% Asian, 0.5% American Indian and Alaskan Native, 0.1% Native Hawaiian and other Pacific Islander (United States Census Bureau, 2019). The foreign-born population is 10.1% (United States Census Bureau, 2019). Georgia's median household income is $55,679, and 14.3% of the population lives below the U.S. federal poverty level (United States Census

Bureau, 2019). A reported 88.6% of households have a computer, and 79% have a broadband internet subscription (United States Census Bureau, 2019). Among those under 65 years old, 15.7% do not have health insurance (United States Census Bureau, 2019).

Georgia is a diverse state, and to increase HPV vaccine uptake and adherence to the vaccine series, more research is needed on the barriers affecting vaccination. To date, there has been limited research explicitly conducted with adolescent populations in the state (Bairu et al., 2019; Dennison et al., 2019; King et al., 2019; Lahijani, 2019; Vu et al., 2019). As a result, identifying local context and issues to support the development of policy to address this population has been challenging.

HPV-Related Policies/Legislation: U.S. and Georgia

School entry age into kindergarten is the most common time for assessment of vaccination status (Mellerson, 2018). While vaccination mandates are more common for childhood vaccinations, vaccination mandates for the adolescent age range are less extensive. Laws in all 50 U.S. states require that all children entering school have received state-mandated vaccinations or have an exemption (Bednarczyk et al., 2019; Omer et al., 2018). Exemptions may include medical, religious, and personal beliefs; however, exemption availability and acceptability vary by state, dependent upon the policies of each state (Bednarczyk et al., 2019; Omer et al., 2018).

Since the HPV vaccine has been available, states have responded by introducing policies that promote awareness and education about the vaccine, and that increase its accessibility through additional funding and insurance coverage (Laugesen et al., 2014). As such, HPV vaccination rates vary widely across the U.S. Overall, states that were more conservative

politically, and religious reported lower HPV vaccination rates (Franco, Mazzucca, Padek, & Brownson, 2019). However, these factors were found to have little influence on Tdap and measles, mumps, and rubella vaccine (MMR) completion schedules in the same states (Franco, Mazzucca, Padek, & Brownson, 2019). Unlike other adolescent vaccines like Tdap and MenACWY, HPV is not mandatory for enrollment in schools (Omer et al., 2018). HPV vaccination mandates are uncommon. Currently, the only states that have mandates in effect for HPV vaccination in secondary schools are Rhode Island, Virginia, and the District of Columbia (Bednarczyk et al., 2019; Immunization Action Coalition, 2019).

Georgia DPH established a Comprehensive Cancer Control Plan that addresses the need to increase HPV vaccination rates among all adolescents 13-17 years old, with a goal of 50% vaccine completion by the end of 2019 (Georgia Department of Public Health, 2014). The plan recognizes the need for: (1) healthcare providers to make a strong and clear recommendation to the parents of adolescents; (2) promotion of communication around the HPV vaccine in conjunction with Tdap, MenACWY, and the annual flu vaccine; and (3) culturally appropriate communications campaigns around the vaccine (Georgia Department of Public Health, 2014). The results of this initiative have not yet been released. In addition to the Georgia DPH initiative, regional Cancer Coalitions in South, Central, East, Northwest, and West Central Georgia are also working to address community-level needs to increase vaccine uptake through various partnerships (Georgia Department of Public Health, 2018b).

In 2014, the Georgia DPH Immunization Program implemented a communication campaign funded by the CDC to increase HPV vaccination coverage among teens in the state (National Public Health Information Coalition, 2014). The campaign “Talk to Your Doctor about Vaccinating Your Sons and Daughters Against HPV” was displayed as ads on various

transportation modes across the Metro-Atlanta region in locations such as bus shelters, interiors of busses and trains, and train stations (National Public Health Information Coalition, 2014). During the six month campaign period, it was estimated that over 55 million impressions were made on the public, and about 2,000 adolescents in the region received the vaccine (National Public Health Information Coalition, 2014).

Perceived Motivators to HPV Vaccination Among Caregivers: U.S. and Georgia

For caregivers, the existence of a healthcare provider as a source of information and a strong and clear recommendation from that healthcare provider are both critical components to HPV vaccination acceptance (Gilkey et al., 2019; Gilkey & McRee, 2016; Kulczycki et al., 2016). Successful messages that can lead to vaccination provide reassurance to caregivers and address common questions or concerns (Opel et al., 2013). Common topics of discussion between caregivers and providers include diseases prevented by the HPV vaccine, vaccine safety and side effects, information about cancer prevention, and same-day vaccination (Calo et al., 2018; Dorell et al., 2013; Lindley et al., 2016). Caregiver perception of sexual activity often also guides the willingness of caregivers to vaccinate their children (Dela Cruz et al., 2017). The promotion of discussion among caregivers and their children should occur regardless of the parent's belief in their child's sexual activity (McRee et al., 2012).

Educational materials could be used as a tool to further communication. They should not only be distributed but should be discussed between caregivers and physicians (Dela Cruz et al., 2017). A study among caregivers in Hawaii found that they favor materials that are culturally tailored and feature anecdotes of locals regarding motivators and barriers to vaccination (Dela Cruz et al., 2017).

There is currently limited research into motivators of HPV vaccination among caregivers in the context of the state of Georgia. A recent study by Bairu et al. (2019) found that some perceived motivators of caregivers include the caregiver's responsibility to protect their adolescent, which includes managing the adolescents health and having them vaccinated (Bairu et al., 2019). Caregivers also indicated a social responsibility to vaccinate and mentioned the desire to support herd immunity as a means to protect adolescents who were not vaccinated (Bairu et al., 2019).

Despite being perceived as a barrier to some caregivers, the Merck "Did You Know?" commercial was found to be a motivator among caregivers who believed that it brought the issue to the limelight and educated the public (Bairu et al., 2019). Some caregivers even mentioned to their providers that the commercial was a catalyst for vaccinating their male child (Bairu et al., 2019).

Positive communication skills and the healthcare provider's reputation among the community were factors associated with trust in the provider (Bairu et al., 2019). Providers felt that trust placed in them by caregivers led to greater acceptance in their recommendation (Bairu et al., 2019).

Perceived Barriers to HPV Vaccination Among Caregivers: U.S. and Georgia

According to CDC Director Robert R. Redfield, "1 in 4 parents who received a medical recommendation for the HPV vaccine chose not to have their child vaccinated" (CDC, 2019b). Parental perceptions of the HPV vaccine have been well studied (Dempsey et al., 2016; Dorell et al., 2013; Gilkey et al., 2019; Javanbakht et al., 2012; Lindley et al., 2016). Studies have found that some parents who note a lack of knowledge about HPV and the preventive options have

contributed to low vaccine uptake and adherence (Barnack et al., 2010; Dennison et al., 2019; Dilley et al., 2018; Krakow et al., 2017; Kumar et al., 2019) (Apaydin et al., 2018). Studies have also found that a recommendation for vaccination is not always made by providers (Hughes et al., 2011; Perkins et al., 2014). This missed opportunity creates a barrier to vaccination.

A study by Gilkey et al. (2019), exploring sources of parental concern regarding the HPV vaccine, found that one-third of parents ranked potential long-term side effects of the HPV vaccination as their biggest worry. Other prevalent concerns included perceived newness of the vaccine, motives of drug companies, short-term side effects, and that HPV vaccination may be unnecessary (Gilkey et al., 2019). Further, parents expressed additional barriers such as the fear of promoting risky sexual behavior as a result of receiving the vaccination, vaccine costs, and overall misinformation from social influences, the internet, or social media (Dilley et al., 2018; Gilkey et al., 2019; Holman et al., 2014; Kornides et al., 2018).

The readability of messages also presented as a barrier to some parents. Low health literacy disproportionately affects marginalized populations and impacts over one-third of U.S. adults (Schillinger, 2002). Some parents claimed that they were not able to fully comprehend the educational materials provided to them (Calo et al., 2018). Interestingly, this same study found that messaging encouraging HPV vaccination is often more challenging to understand than anti-vaccine messaging (Calo et al., 2018).

Research has largely focused on HPV vaccination for females (Johnson et al., 2017). The feminization of HPV has also resulted in caregivers not being as aware of the need to vaccinate their male children (Bairu et al., 2019; Franco et al., 2019; Holman et al., 2014). Often the burden of HPV screening, vaccination, and treatment is left to females or the caregivers of

females. Some caregivers reported that healthcare providers recommended the vaccine to their male children less often or not at all (Franco et al., 2019; Liddon et al., 2010; Lindley et al., 2016; Newman et al., 2013). It has been found that females generally are more likely than males to complete the vaccination series despite males having a higher likelihood of contracting HPV during their life (Franco et al., 2019; Gilkey & McRee, 2016). More needs to be done to share the burden of disease regardless of gender and to address further the low perceived risk of HPV infection among males and their caregivers.

In Georgia, some caregivers recognized that vaccines, in general, have a positive impact on health and the wellbeing of their adolescents. However, these beliefs did not seem to encompass the HPV vaccine (Bairu et al., 2019). Barriers to vaccine uptake include confusing and often difficult to understand information around the vaccine (Bairu et al., 2019). Caregivers specifically expressed a lack of health literacy when doctor's terms, as opposed to layman's terms, were used in addition to what they viewed as conflicting information around the vaccine between new and previously released information (Bairu et al., 2019).

While some caregivers viewed the Merck "Did You Know?" commercial as a motivator to vaccine update, others saw it as an impediment that focused on shaming parents and fear-mongering (Bairu et al., 2019). Lack of diversity among those featured in the commercial also contributed to a negative outlook (Bairu et al., 2019). Due to the fairly recent approval of the HPV vaccine, especially when compared to other vaccines, issues surrounding vaccine safety and side effects were also prevalent and warranted more research (Bairu et al., 2019).

Caregivers also indicated that they viewed their adolescent's physical sex as a barrier. While the HPV vaccine was largely focused on female prevention of cervical cancer, some caregivers of males were unaware of the possible cancer risks to males (Bairu et al., 2019).

The caregiver provider relationship was explored from many angles. Lack of trust through past negative experiences with providers was discussed in addition to racial discrimination (Bairu et al., 2019). Some parents noted that lack of communication was an additional barrier, recalling the differences of when doctors used to spend more time face-to-face with every patient, aiding in the cultivation of a relationship (Bairu et al., 2019).

Identified Strategies for Increasing HPV Vaccine Uptake

Research has been done to identify perceived barriers among caregivers to HPV vaccination, yet examining how caregivers prefer to receive vaccination information has not been given as much attention (Bednarczyk, 2015). A potential solution to increase HPV uptake is to encourage communication between all stakeholders, including adolescents, their caregivers, and healthcare professionals (Bednarczyk, 2015). Communication between these stakeholders should be promoted to increase access to the HPV vaccine, develop trust, and further education (Bednarczyk, 2015).

Healthcare providers have reported that the negative perceptions and attitudes of caregivers towards vaccination are barriers in providing the vaccine to adolescents (Holman et al., 2014). Further, research has found that some providers undervalue the importance of some vaccines to parents (Healy et al., 2014; Holman et al., 2014). A strong and clear HPV vaccine recommendation by healthcare providers is commonly associated with parental acceptance to vaccinate their child (Bednarczyk, 2015; Dempsey et al., 2016; Kempe et al., 2019). To better

address barriers to vaccination among parents, providers could personalize and tailor their communication approach based on their relationship with the patient and caregivers, and knowledge that they may have on what may constitute as barriers and concerns for the caregiver (Leask et al., 2012). This remains true even among caregivers who were initially unsure in their decision making about vaccination (Dempsey et al., 2016; Kempe et al., 2019). It has been recommended that providers use targeted interventions for vaccine-hesitant caregivers that address negative beliefs rather than solely focusing on increasing knowledge (Lindley et al., 2016).

Communication, combined with the distribution of education materials, especially among vaccine-hesitant caregivers, contributed to higher reported levels of caregiver vaccine acceptance among providers (Reno et al., 2019). Successful approaches include providers advocating for the development and distribution of educational materials that address barriers – specifically around vaccine safety – cited by caregivers, and that openly state potential side-effects (Gilkey et al., 2019). It has been recommended that providers also continue to integrate the vaccine as part of the recommended vaccine schedule, stressing the importance of vaccination before sexual debut and the impact it will have long-term as a tool for cancer prevention (Gilkey & McRee, 2016). Additionally, providers should make strong patient-specific recommendations that are focused on the needs of each caregiver and their adolescent (Bairu et al., 2019). Healthcare providers should also encourage parents to schedule for vaccination in advance of future visits (CDC National Prevention Information Network, 2018).

Not much is known about the reasons for “secondary acceptance” of the HPV vaccination by caregivers (Kornides et al., 2018). This acceptance occurs when caregivers consent to vaccination after declining initially (Kornides et al., 2018). A study by Kornides et al. (2018)

found that almost half of the caregivers surveyed reported secondary acceptance of HPV vaccination at a later healthcare visit, and another quarter mentioned the intent to vaccinate over the next year. Findings from this study suggest that an initial high-quality recommendation is correlated with secondary acceptance as well as aging of the child and caregivers gaining additional information about the vaccine in follow-up visits (Kornides et al., 2018).

Perceived Motivators to HPV Vaccination Among Healthcare Providers: U.S. and Georgia

Studies have revealed various perceived motivators to HPV vaccination among healthcare providers. Providers see a shift to cancer prevention from the prevention of a sexually transmitted disease as a major motivator among caregivers to have their adolescent vaccinated for HPV (McCave, 2010; Perkins et al., 2014). Providers also discussed caregiver perceptions of the vaccine changing over time from being viewed as a "new vaccine" to something more common and routine for adolescents to receive (Perkins et al., 2014). As a result of this transformed perception, caregivers more commonly brought up the vaccine to providers (Perkins et al., 2014).

Georgia-specific research has been limited. A recent study by King et al. (2019) found that perceived motivators by healthcare providers include when caregivers understand educational materials about the vaccine and their concerns are addressed. Education that addresses side effects and safety information is especially important (King et al., 2019). Trust developed through communication or knowing that their provider vaccinated their own children for HPV was also perceived to be a motivator to vaccination (Bednarczyk et al., 2018).

Perceived Barriers to HPV Vaccination Among Healthcare Providers: U.S. and Georgia

In the U.S., providers cited caregiver perceptions and concerns about the "newness" of the vaccine as a barrier to vaccination (Perkins & Clark, 2012, 2013). Providers also believed that caregivers were concerned about the young age at which the vaccine was recommended, which was viewed as potentially encouraging sexual maturation prematurely (Perkins & Clark, 2013). Lack of school mandates for vaccination was also a perceived barrier (Perkins & Clark, 2012).

A recent study by Cunningham-Erves et al. (2019) identified the most common barrier as caregiver concerns of vaccine safety, followed by caregivers believing that their child is not at risk of contracting HPV through sex (Cunningham-Erves et al., 2019). Other less mentioned barriers included concerns about vaccine efficacy and the cost of vaccination (Cunningham-Erves et al., 2019).

Studies identifying perceived barriers among healthcare providers in Georgia have been minimal. A recent study recognized cultural and religious barriers that included belief in abstinence (King et al., 2019). Other studies have identified providers believing in a negative perception by caregivers of how the vaccine is linked to promoting or condoning sex (Perkins & Clark, 2013; Vu et al., 2019). Possible parental concerns about potential side effects, which often were a result of the influence of alternate sources of information such as the media and internet, were also identified as barriers in another study (Bednarczyk et al., 2018).

Identified Strategies for Increasing HPV Vaccine Uptake

A provider recommendation that includes a "clear, strong message" is a leading strategy to increase HPV vaccine uptake (Head et al., 2017; Perkins et al., 2014). A provider recommendation that included bundling the HPV vaccine with other adolescent vaccines such as

Tdap, MenACWY, and tetanus was also identified as a potential strategy to increase uptake (Perkins et al., 2014; Thomas et al., 2013). Providers sharing tailored information for different cultural and religious backgrounds was also successful (McRee et al., 2014; Thomas et al., 2013).

In addition to using a guide to lead discussion, it may be beneficial to create the opportunity for providers to address caregiver concerns regarding the vaccine by utilizing a screening tool to proactively identify concerns (McRee et al., 2014). Additional information could also be provided to caregivers before clinical visits, so caregivers have the opportunity to review the information in advance (McRee et al., 2014).

Additional tools such as increasing providers' education on HPV and active vaccination tracking via electronic medical record (EMR) reminder systems to initiate conversation could also be beneficial (Dilley et al., 2018). A more inclusive recommendation process that promotes communication between various stakeholders in the decision making process such as healthcare professionals (i.e., pediatricians, obstetricians and gynecologists, general practitioners, family practitioners) and adolescents with their caregivers could positively impact vaccination rates (Barnack et al., 2010).

Provider lack of knowledge about the recommended number of vaccine doses may contribute to under vaccination (Lindley et al., 2016). Additional resources, such as educational materials both in print and via the web, have been developed by various organizations such as the CDC and the American Cancer Society (ACS) to offer guidance on how to recommend the HPV vaccine and answer any questions that may arise (Calo et al., 2018).

Knowledge Gap

What is needed to address the knowledge gap

While the barriers of HPV vaccine uptake in the U.S. have been explored in-depth, more research is needed to study and increase uptake in the state of Georgia. Evidence-based strategies that address vaccine hesitancy through policies, caregiver education, or provider communication techniques are needed (Henrikson et al., 2015; Sadaf et al., 2013). To address these challenges, further investigation into the communication between caregivers of adolescents and healthcare providers could help provide a deeper understanding of the barriers and motivators to HPV vaccination across the state. A richer understanding of the state and regional context could be beneficial to improving vaccination initiatives specific to the community at hand.

CHAPTER 3: MANUSCRIPT

3.1 Contribution of the Student

I coded qualitative data in the form of previously transcribed transcripts from focus group discussions that were part of an environmental scan of HPV and HPV vaccination in Georgia. I used the coding to identify and further analyze the themes present in the data. These themes were compared regionally across the state of Georgia to produce my findings. This thesis comprises my findings for the fulfillment of my Master of Public Health Degree. My thesis committee consisted of Dr. Robert A. Bednarczyk and Adrian King, who provided guidance and support throughout the entire process.

3.2 Background

HPV vaccination rates in Georgia remain well below the HP2020 target goal of 80% coverage (Healthy People 2020, n.d.). According to the 2018 NIS-Teen, up to date coverage of the vaccine statewide among adolescents 13-17 years old was 49.6%, whereas two mandated adolescent vaccines Tdap and MenACWY were 94.2% and 94.8%, respectively (Walker et al., 2018).

Research has shown that the vaccine is highly efficacious if received before HPV infection (CDC, 2019c). The vaccine protects against more than 100 strains of HPV, some of which cause genital warts or cancer (WHO, 2019). Approximately 35,000 cases of HPV-attributed cancers occur in the U.S. each year, with cervical and oropharyngeal cancers being the most common (CDC, 2019a).

Communication and vaccine recommendation have been linked to increased HPV vaccine uptake and series completion (Gilkey & McRee, 2016; Holman et al., 2014; Katz et al., 2016; Perkins et al., 2015). Little research into communication barriers between healthcare providers and caregivers of adolescents regarding the vaccine has been conducted in the Georgia context. The results of the study can be used to improve the effectiveness of programs aimed at HPV-related cancers by identifying the context of regional concerns and enabling initiatives specific to the community.

3.3 Methodology

IRB Approval

This research project was reviewed and approved by the Emory University Institutional Review Board (EIRB).

Methods

The research team conducted 23 total focus group discussions (FGDs) across the state of Georgia between April – July 2018. The goal of this research was to gain an understanding of the knowledge, attitudes, and perception related to HPV vaccination among caregivers of adolescents and pediatric healthcare providers across the state of Georgia.

Our research included FGDs that were composed of healthcare providers and caregivers that could be comparatively analyzed across similar regions of the state of Georgia. The goal of this research was to identify and compare barriers to communication regarding the HPV vaccine between caregivers and healthcare providers across three regions of Georgia: East, Northwest,

and South. Our findings can be used to address these barriers and further inform regionally targeted interventions to increase the uptake of the HPV vaccine among adolescents.

All FGDs employed a participant-type (e.g., healthcare provider, caregiver of adolescent) specific semi-structured focus group discussion guide. All FGD guides were reviewed for clarity and applicability by the Intervention Development, Dissemination, and Implementation (IDDI) Shared Resource at Winship Cancer Institute of Emory University. FGD guides and informed consent documents were reviewed and approved by the Emory University IRB.

Participant Eligibility Criteria

Eligible participants consisted of caregivers of adolescents and healthcare providers who resided in Georgia and could both speak and write in English. Eligible caregivers were also required to be at least 18 years of age and be the primary caregiver for at least one adolescent between 9 to 17 years of age. Eligible healthcare providers included any provider or staff who directly interacted with patients and their caregivers and was also 18 years or older.

Participant Recruitment

The research team identified regional cancer or immunization coalitions throughout the state of Georgia, who agreed to assist in the recruitment for the research project. Gatekeepers were utilized since the research included individuals throughout various parts of the state, and the research team did not have the needed ties or community relationships to conduct effective recruitment from afar. A staff member from each organization was selected to act as a recruiter for the study. Staff from these organizations distributed materials provided by the research team to assist with recruitment. Materials included a flyer template detailing the project and the scope

of participant involvement, eligibility criteria, and proposed FGD dates and times within each community. Each participant was offered a $30 gift card for their participation.

Informed Consent Process

Each participant was provided with an informed consent form created by the research team and approved for use by the EIRB. The consent form stated that the FGD would be recorded and that anything discussed, including names or potentially identifying information, would be kept confidential and be de-identified during transcription. Participants were advised that involvement in the FGD was completely voluntary and that they could choose not to answer any question they were not comfortable with, and they could leave the FGD freely at any time. Participants were given time to review the form, ask questions, and ultimately provide written consent with their signature, if they chose to participate in the study. Participants only participated in the research study after providing written consent, via signing the informed consent form.

Focus Group Facilitation

All FGDs took place in a private location at a set time that was previously coordinated by the recruiter from the participating regional coalition. FGDs were conducted in three regions of the state of Georgia. FGDs in South Georgia (S) were completed in Albany, Blakely, and Savannah, Georgia. FGDs in Northwest Georgia (NW) were completed in Calhoun and Summerville, Georgia. Lastly, FGDs conducted in East Georgia (E) were facilitated in Sylvania and Warrenton, Georgia.

Participants were given an overview of the study that included being advised on the time commitment of approximately 1.5 – 2 hours and reviewing consent forms and ground rules (e.g., respect of differing opinions, maintaining confidentially of discussions, no phone call, etc.). The facilitator addressed any questions of the participants before beginning the FGD.

For caregivers of adolescents, the FGD guide focused on general health questions such as seeking healthcare, healthy habits, and immunizations. HPV-specific questions were asked to gather information on participants' knowledge and views. An activity was also conducted to gain further insight into the barriers and motivators of HPV vaccination initiation. Participants were asked to rank, in order of importance, motivators and barriers they identified in choosing whether or not to vaccinate their adolescent.

For healthcare providers, the FGD guide was centered around methods of communication with caregivers of adolescents regarding general health topics, sexual health, and immunizations. HPV topics focused on how and when the conversation was initiated, as well as the providers' perceived barriers and motivators to vaccine uptake among adolescents. Questions in the guide included "What are some of the most common talking points that you have during a general adolescent health exam or appointment?" and "What are some common questions that parents or guardians ask you about the HPV vaccine?" and "What do you specifically say when you recommend the HPV vaccine?"

Analysis

Audio files were transcribed, verbatim, by the research team. After the audio files were transcribed, they were de-identified and uploaded into MAXQDA 2018 (*VERBI GmbH, Berlin, Germany)* for qualitative analysis. To guide the analysis, a codebook was developed that utilized

a deductive approach based in grounded theory. Further, it defined each theme, code, and sub-code and provided inclusion and exclusion criteria. Transcripts were coded by the research team using the developed codebook, and additional codes were developed inductively as new themes emerged during analysis. All transcripts were coded until saturation was reached.

A thematic analysis of the transcript data was conducted to identify, analyze, and interpret common themes present across both the healthcare provider and caregiver FGDs. These themes were then compared across their respective FGDs by region. Data analysis focused on (1) the knowledge and views of caregivers of adolescents towards HPV and the HPV vaccine in each region, (2) methods of communication around HPV and the HPV vaccine between healthcare providers and caregivers in each region, (3) comparison of the identified communication barriers regionally.

3.4 Results

In total, 12 FGDs with a total of 107 participants were included for analysis. These FGDs were divided into healthcare provider (HCP) and caregiver (CG) specific groups (six HCP, six CG). Overall, 55 healthcare providers and 52 caregivers were included in the research. Participants represented three regions of Georgia: South, Northwest, and East.

This research sought to understand the varying perspectives of healthcare providers at all levels of practice. Thus nurses, clinical managers, physicians, pediatricians, medical assistants, front-desk staff, and any other patient-facing staff members were included in the focus group discussions. The majority (71%) lived in the Southern Region of the state. Nearly half (44%) were experienced health care providers with ten or more years of experience. For caregivers, most (89%) were from the East or Southern Regions of the state. Caregivers were mostly female

(94%), and all were at least 21 years of age. **Table 1**. Describes the socio-demographic characteristics of the participants in further detail.

Overview

To identify and compare barriers to communication between healthcare providers and caregivers regionally, a comparative thematic analysis was conducted to highlight themes discussed throughout HCP and CG FGDs. The identified themes were selected because they were inherently present across all the HCP and CG FGD that were analyzed. These themes were compared across the three regions in Georgia (South, Northwest, and East). The findings highlight three common themes discussed by the participants: (1) ineffective education and low health literacy, (2) lack of trust, and (3) sex as a taboo topic. These findings are presented as themes further stratified by region to facilitate comparison of the FGDs. This research provides insight into these themes and how they compare to each other across three demographically diverse regions of Georgia, providing a greater understanding of how they may impact demographic groups or regional populations differently.

Health Literacy

One of the major themes that emerged among caregivers in all three regions was the effectiveness of the education by healthcare providers. Education largely seemed to be ineffective, evidenced by the gaps in caregivers' ability to identify reliable information and sources to gain education on HPV and the HPV vaccine. In regions where education was present through the distribution of informative materials, some caregivers reported little comprehension, a problem that providers felt was due mainly to low health literacy in the region. As a result,

some caregivers turned to alternative sources of information for education, a choice which seems to have further impacted the caregiver – provider relationship negatively.

Education and Communication

South Georgia

Healthcare providers in South Georgia discussed the importance of actively educating caregivers and recommending the HPV vaccine. As a way of describing this active education one provider spoke about the need to encourage in-person communication and dialogue in the provider-patient relationship: "*those vaccine information sheets they just get thrown away to the side, they want to hear what you have to say*…". (S, HCP) One provider stated, "*it's our responsibility to give education*." (S, HCP) Consistent communication and messaging around the HPV vaccine were also recognized as tools to encourage vaccine uptake. For some providers, this consistency was provided through follow-up recommendations made during subsequent visits or when other opportunities presented themselves. One provider stated, "*…it's a little hard but the thing is, if you are persistent every time they come, you talk to them about HPV vaccine, and uh they do, they do say yes sometimes, 50% …*" (S, HCP)

When caregivers in South Georgia were questioned about their HPV awareness, it became evident through gaps in their knowledge that communication around HPV vaccination with their provider had not been effective or had not occurred all together. These knowledge gaps emerged from a perceived lack of provider communication – "*…our providers aren't talking about it*" one caregiver noted (S, CG) – to claims that providers did not strongly recommend the vaccination or provide sufficient information. One caregiver explained, "*My first introduction was commercials, information through the television…a couple years ago it was a*

big new one and I kept seeing it and kept seeing it, and I was like 'ok you're only telling me glimpses but I'm curious enough to wanna know' so then afterwards then I began to inquire with the doctors when I would go for his doctor's visits...". (S, CG) Another caregiver expressed their desire for more educational information after missed opportunities in receiving this information: "*...lack of knowledge yeah…because we're big on…health fairs... so a lot of people like our providers [redacted] and [redacted] I feel like they need to have pamphlets and information on their tables because they are our providers*." (S, CG)

Northwest Georgia

Healthcare providers in Northwest Georgia recognized the importance of needing to "*educate parents*". One provider explained in detail their approach to communication around the vaccine: "*Well if they've never had it before and it's their first time um I always tell them that 'now you're at the age uh for the recommended HPV [vaccination]. Um start it at 11 so if we can start today then you'll come back in 6 months and then you'll be done'...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…So you know, and so and 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*." (NW, HCP) Not only was educating parents important to providers, but a focus on repetition and follow-up was discussed. As one provider stated regarding the importance of a follow-up recommendation if the vaccine was initially declined, "*I think it's our job to bring it up every year, or every visit you know depending on where they are but if we just kind of ignore, we look at our notes and see that they denied it the last time and just don't bring it up I think we do them a disservice."* (NW, HCP)

Contrarily, some caregivers recalled conversations around HPV vaccination with their child's healthcare providers, which did not result in a very strong recommendation and lack of follow-up. One caregiver stated, "*I actually had this conversation with another parent that, like her pediatrician didn't push it [HPV vaccine] at all. Like offered it and she was like, 'no I don't think we're going to do that', and they were like ok. And moved on*." (NW, CG)

East Georgia

As in South and Northwest Georgia, providers in East Georgia also recognized the need to "*educate parents*". One provider described their process, "*…yes I do provide education at that time so if they change their mind and or think about it later they know*." (E, HCP) Providers across the region differed in the types of sources they found educational and the materials they chose to offer. One provider explained their approach: "*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*." (E, HCP) Another provider added: "*And sometimes I do give them a brochure to take, so those brochures do have and we do have extensive education reading material, or each of these are in our system the CSCF, that's really incredible, very good help for us to educate them.*" (E, HCP)

When caregivers were asked about HPV, it was evident many did not know much about the topic. More so than in any other region, caregivers in East Georgia reported a lack of knowledge or understanding of the importance of the HPV vaccine. When asked about what they knew regarding the HPV vaccine, these caregivers stated, "*I don't know anything about it. I don't know… Nothing. Participant 6: I don't know anything about the vaccine, I'm just being honest. Participant 5: I'm just finding out about the vaccine. Participant 3: Yeah me too. Just*

finding out." (E, CG) Reported lack of knowledge related to HPV vaccination in this region potentially identifies a glaring gap in communication between provider and caregiver as it is evident that the education provided by providers is not memorable or effective.

Similar to Northwest Georgia, a lack of awareness of the risk of HPV to males was present among caregivers. A caregiver recalled, "*even when you take your sons to the doctor, you know…taking them to the doctor they don't put an emphasis on [HPV] for boys. I don't think I've ever, ever, taken my sons to the doctor and had them sit down and had this conversation about HPV, ever*." (E, CG) Also, similarly to Northwest Georgia, some caregivers reported a passive recommendation for the HPV vaccination from their child's healthcare providers. An East Georgia caregiver described their experience: "*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*." (E, CG) These passive recommendations may not appropriately convey the importance of the HPV vaccine compared to other vaccines.

Health Literacy

Various informational sources were discussed as tools by both healthcare providers and caregivers for further education on the HPV vaccine. These sources ranged from educational courses in schools to traditional distributed medical informational materials such as Vaccine Information Statement (VIS) and pamphlets. Alternative sources of education, such as social media, "*Dr. Google*", WebMD, and YouTube, were also mentioned. Both providers and caregivers were aware of the benefit of having access to information that is easily understandable to the community and in-turn, facilitate making appropriate health decisions.

South Georgia

Misinformation, through various media sources, was cited as an additional barrier to dialogue between healthcare providers and patients. In two different cities in South Georgia, providers mentioned "*Dr. Google*" specifically as a source of potential misinformation as patients and their caregivers regularly reported using Google for information. Providers also alluded to this plethora of potentially incomplete or inaccurate information as negatively impacting the trust and confidence that caregivers placed in providers and ultimately questioning their medical advice. One provider in South Georgia stated, "*…often times people that are very very educated that have read on their own and they maybe have the belief that they know better than their provider…they don't come in and automatically trust their provider, you know?*" (S, HCP)

Conversely, some caregivers felt that turning to these alternative sources of information provided vaccination guidance in a more readily comprehensible language. One caregiver in South Georgia, when referring to YouTube as an informational tool, said it was "*more visual*" and enabled easy searches for information, which could be helpful for people. Another noted that through Google, they could look up everything they needed to know.

In some areas of South Georgia, healthcare providers discussed their awareness of inherent knowledge gaps among residents. One provider in South Georgia recalled, "*…I think it's a big knowledge deficit mostly, in this area, and, and this area in particularly, in particular, it is very low income, you can just drive through the streets of [name of town] and see the blight as you go through…*". (S, HCP) The gaps in knowledge are further widened when patient education strategies rely mainly on the distribution of health materials such as pamphlets, fact sheets, and websites due to low comprehension of said materials. Providers indicated that these distributed educational materials are often written in technical language that may pose challenges

to understanding. Another South Georgia provider stated, "*If you only have a 9th grade education, and your child brings you a pamphlet home, do you understand even what you're reading.*" (S, HCP) Caregivers in these areas were also aware of these health literacy gaps. One described that materials were beneficial and educational for them when they used "*layman's terms, not doctors terms*" and noted that "*[we] don't want it to go over our heads. We'd miss it*." Further punctuating the point, they added, "*I want my child to understand it if they read it.*" (S, CG)

As a way to mitigate these challenges, providers attempted to create and encourage dialogue with caregivers to gauge their knowledge levels. One provider in South Georgia stated, "*I like for families to voice to me um what is the thing that creates worry, or risk, or harm for their child…because it helps me understand honestly based on the lingo and depth of knowledge where I should start in my discussion with the patient and family, because physicians are typically really bad about using medical jargon and lingo that doesn't really effectively drive home the message for the family...*" (S, HCP)

East Georgia

Some caregivers in East Georgia expressed difficulty in identifying reliable sources of information and, at times, distinguishing truth in conflicting information. The internet often was cited as a source of inconsistent information. Common websites included WebMD, and "*Dr. Google*", and Wikipedia which was referenced as "*Wackopedia*". One caregiver stated, "*That's the problem though you can keep on looking until you find the answer that you want so how do you know what's real, and what you want*." (E, CG) Alternatively, some caregivers expressed

confidence in other websites, "*I go to Johns Hopkins, Mayo Clinic, those sites you can find good information and I feel like those are trustworthy.*" (E, CG)

Specifically, in East Georgia, caregivers cited too much inconsistent information and not enough long-term research around the HPV vaccine as barriers to having their child vaccinated. As one noted, "*I've been doing research here and there and unfortunately there is so much conflicting information it's really hard to get a grasp on [the vaccination] so I've not done it yet*." (E, CG)

A provider in East Georgia highlighted the importance of adequate education for patients to counter false sources of information in these rural areas: "*…you're offering them something they don't have a clue about cause a lot of our patients… like you said they come from a rural area, and a lot of them are undereducated so they have no idea what this new vaccine is. They see stuff on TV that kind of scares them so they are kind of hesitant to give it to their kids*." (E, HCP)

Lack of Trust

Throughout all the regions trust was seen as a predictor to a positive provider – patient relationship. When caregivers did not trust their child's provider, they were less inclined to adhere to their recommendations. Across these regions trust was discussed as being built through open communication and the development of rapport. In some regions trust was built initially through time spent during each healthcare visit and was ultimately deepened in the long term as the provider engaged with various generations of a family. As one caregiver stated, "*if they [kids] got a doctor that they remain with, grew up with, then it's easier for them to talk to them and open up*." (CG, S)

Building Trust through Communication

South Georgia

Providers in South Georgia primarily acknowledged the importance of building trust through open communication. A provider in South Georgia stated, "*so having the bedside manner and the skillset to be able to talk to the patient in a way that, or the patient's family, understands what it is that you're trying to say …it's important to acknowledge the patients' feelings because they're not gonna do it [vaccinate] if they don't trust you*." (S, HCP)

Providers also mentioned the importance of being well versed in the topic that they were speaking to patients about as an extension of building trust, further adding to the patient's ability to trust the provider. Consequently, these providers mentioned losing credibility with caregivers if they did not have information when asked. A provider in South Georgia recalled, "*You need to be correct, one. And, two, be confident in how you communicate with families, not in an antagonistic way um but you have to be viewed as an expert. It just takes one encounter where you and your team are not viewed as experts and you are immediately no longer valued in that discussion, my opinion is discounted.*" (S, HCP) Caregivers in the same region echoed these concerns and revealed being apprehensive if their provider was unable to answer their medical questions. One caregiver in South Georgia recalled a negative experience they had with their child's provider, "*My son he was 14, I forget what shot they were trying to get him to get, but the shot he was supposed to get but I didn't get it, she the lady couldn't explain to me what it was for*." (S, CG) The perception by caregivers of a healthcare provider's lack of knowledge can negatively impact the trust caregivers have in these professionals.

A unique challenge described by caregivers in rural South Georgia was the "*rotating door of providers*" which created barriers to establishing a relationship with their healthcare provider. One caregiver mentioned the presence of only one pediatrician in a neighboring town due to the departure of others seeking to practice in an urban city. Some caregivers expressed the desire for healthcare providers that had a historical knowledge of their health, which in some cases meant knowledge spanning multiple generations of the caregiver's family. Some caregivers associated these more long-term types of relationships as a reason to trust the recommendation and advice of their provider. When speaking about whose opinion they trust, one caregiver stated, "*Especially if you've been going to that doctor for a while and they seem generally concerned about that child because, like, my daughter she actually grew up with that doctor and so she acts as if she's the mother to that child...*" (S, CG)

Northwest Georgia

In Northwest Georgia, the importance of establishing rapport between the provider and caregiver was a point of focus. There was mention by some rural caregivers that if their provider vaccinated their own child for HPV or, if the provider did not have a child, but would vaccinate their child if they did, then caregivers would be more inclined to follow suit. Other caregivers did not feel the same way, noting that ultimately, they made their decisions based on their own knowledge and beliefs. A caregiver in Northwest Georgia recalled an exchange with their child's provider, "*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…*" (NW, CG)

Some caregivers mentioned that the rapport with their provider was diminished when they felt like they were not being listened to. A caregiver in Northwest Georgia spoke of a

negative experience, "*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 [vaccinate for HPV]*." (NW, CG) On the other hand, providers discussed their belief in communication as a gateway to knowledge and education. Another participant discussed the provision of information and education in improving their rapport with patients, "*I don't think it's trying to persuade somebody, I just think it's just giving them the knowledge. Um here's these options you do have your choice to make. I mean you don't have to do this but here are some options. And I think just giving the person the options they can go back and research it themselves*." (NW, HCP)

East Georgia

Providers in East Georgia were aware of the confidence and propensity to trust that some caregivers had in their child's healthcare provider. "*Participant 3: I think that's one advantage maybe in a rural area. Its small, and cuz people never move so there is already that trust, there's already some groundwork for it there…Some of them will ask, 'Do you, you think I should get [HPV vaccine]?' Participant 7: 'Did you give it to your child', or something like that. And I'll be like yeah, so then that makes them feel like okay, I can give it to their child…*" (E, HCP) This sense of trust between caregivers and their child's healthcare provider was viewed as necessary for building rapport, similar to Northwest Georgia.

Also comparable to Northwest Georgia, some caregivers associated trust with feeling like they were being listened to: "*For me, trusting my doctor is how much they are listening to me, so when I talk about communication, it's not just what they tell me, it's are they truly listening to my concern, are they willing to research further, to find out what, what I want to know*." (E, CG) Ultimately, trust was how some caregivers determined which medical advice, or sources, to

follow. As one caregiver said, "*You have to go to a doctor that you trust the most and… I end up, you know, picking what's best.*" (E, CG)

Time

South Georgia

In South Georgia, specifically, providers mentioned face-to-face time spent with patients as a barrier to communication. One provider cited a few instances where the attending physician did not have the time to have in-depth conversations with the patient, so education fell to nurses or other staff, further impeding rapport between the physician and caregiver, which could potentially create a burden on the time management for nurses. Other providers in the region echoed similar issues caused by time constrictions. For them, the limited time spent with patients left little opportunity to talk through the patient's concerns, let alone introduce and provide education on the HPV vaccination. One provider explained, "*Time is definitely a factor. Because they're here with a sick visit, okay, so you know, we get, we get fifteen minutes, ten minutes in between patients. So, in that ten minutes we've got to address that day's issue and on the top of it, HPV vaccine. And if they've already refused the vaccine, we need more time, so, definitely that's another factor.*" (S, HCP)

East Georgia

Providers in East Georgia also recognized the critical role that time plays in promoting the HPV vaccination. The brief amount of time spent between healthcare providers and caregivers was seen as a barrier to building rapport and enabling communication, further impacting the trust relationship between both parties. A caregiver in East Georgia recalled how

much the patient-provider relationship has changed over the years, "*…doctors ain't like they was back in the days when we was growing up…I don't want to sit and go the doctor's office and sit there for 30 minutes, he comes in for two minutes, then he's back out the door*." (E, CG)

Sex as a Taboo Topic

A common belief expressed by both providers and caregivers throughout the state was that the discussion of sex, especially as it related to adolescents and young adults, was taboo and not common. This belief created barriers in talking about HPV and the HPV vaccine. In some regions, this barrier was a direct result of religion and the practice of abstinence. Some caregivers mentioned that the vaccine was potentially viewed by other caregivers in the region as potentially promoting sexual promiscuity among teens.

South Georgia

Healthcare providers in South Georgia were acutely aware of how the perception of sex as a taboo topic created barriers to communication and acceptance of the HPV vaccine. One provider in South Georgia recalled the public's reception of the HPV vaccine when it was first introduced, "*People were just appalled that, why would you want a 12-year-old or something to be um vaccinated for a sexually transmitted disease*." (S, HCP) Some providers recognized the barrier created by the association with sex and adapted their communication to focus more on cancer prevention. One provider recalled, "*they don't want to talk about it um, but when you shift the focus to what the benefit is from a cancer perspective, it makes it more palatable I think to parents*." (S, HCP)

East Georgia

In East Georgia, providers and caregivers discussed a similar view of 'sex as taboo' as a communication barrier. One provider believed that caregivers "*do not want to hear that their child is grown enough to be sexually active, I think yes, I agree, they just don't want to discuss.*" (E, HCP) Another stated, "*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*." (E, HCP)

One caregiver described this barrier as prohibitive to conversation around HPV, "*it's sex related, or that word sex is in the way you can contract it, it kind of says, you know, from a parent's standpoint, 'ok my child is not sexually active so, you know, we don't have to worry about that'… If it was passed by like a cold with just casual touching or just being in the air, I don't think there would be as much negative um, you know, response with getting the vaccine or talking about it either*." (E, CG) Caregivers also spoke about censored sex education classes that generally pushed abstinence as barriers to education and communication with their child, "*A lot of parents have a problem with sex education being taught in the school. (Group agreement: oh ya, that's true) They have big problem with that.*" (E, CG) Nevertheless, caregivers in this region were aware and spoke openly about how children were having sex. Another caregiver stated, "*…let's be real, you know, kids have sex, (group agreement: mhm) they do. And they're having sex uneducated*." (E, CG) Caregivers largely expressed the belief that while they were aware that adolescents were having sex, some caregivers in the region might oppose this viewpoint due to apprehensions in speaking about sex, particularly with their child.

<u>Religious Morality</u>

South Georgia

Across South Georgia, providers discussed the notion that caregivers believed that the vaccine gave permission and encouraged sex. A provider in South Georgia stated, "*Parents think they are protecting their child from the information, and protecting their child from having too much information and considering that if they give them the vaccination then it actually is a stamp that says to their child that they can have sex…*" (S, HCP) Another provider in South Georgia recalled an example of the interaction with caregivers: "*…let me put it this way. We are so and so [Religion] followers, okay? And my daughter or my son is not going to have sex before that age [age of recommended vaccination]. So, it's like religious belief which is being converted to their practices*." (S, HCP) One provider, who was currently practicing in rural South Georgia, described the inherent differences in sex education and communication between South Georgia and an urban area in the Northeast United States: "*But um, down here it's very, it's difficult. Because first of all, in [urban city in another state], the kids have condoms. You can come grab a condom and it's good…You know, and it's different here. God forbid you mention a condom.*" (S, HCP) Most caregivers were aware of the moral opposition to HPV vaccination that was voiced in this region, likely influenced by the Bible Belt.

Despite providers believing moral norms stemming from religion were a strong determinate of a caregiver's willingness to vaccinate their child against HPV, some caregivers noted that while this impacted their decision making, others were very clear in their belief that it was archaic and irrational to believe that adolescents were practicing abstinence. A caregiver in South Georgia said, "*I just went to a meeting at the high school and they're like we've got 21 girls pregnant this year*." (S, CG) Some caregivers were strong supporters of sex education classes that went beyond abstinence and taught about sexually transmitted infections, including education on HPV.

Northwest Georgia

Similar to South Georgia, providers in the Northwest region appeared to anticipate barriers in talking about the vaccine with caregivers due to perceived moral values of abstinence among the community. One provider stated, "*Participant 8: [Name of town] is kind of in the 'Bible belt' and they're very big on abstinence until you're married and so a lot of people kind of feel like if you're even recommending it or suggesting it then you're…Participant: Condoning [sex]*." (NW, HCP) A caregiver in the same region voiced a similar communication style grounded in abstinence from their healthcare provider. This caregiver, however, voiced concerns that their child would not be protected if they did not get vaccinated and would be susceptible to HPV, "*I had a physician just said you know, you can pray. Just pray for your child that they will stay, you know, abstinent until they get married. But in this day and age you know that the percentage of that happening is very slim so, what if she decides to stay that way but she meets somebody and she marries somebody that has it. Now she's come in contact and she's not protected."* (NW, CG).

East Georgia

While some providers in East Georgia echoed a perceived awareness of the desire by caregivers for their adolescents to be abstinent, similarly to Northwest and South Georgia, some providers also disclosed that recommending abstinence was not a viable solution since adolescents were likely having sex. "*You can still recommend abstinence, but for me it's a waste of- (laughter), it's halfway uncomfortable because nobody is but it's not, it's not a bad idea to bring that up*." (HCP, E) Some caregivers presumed that their child was not vulnerable to an HPV infection because they were not sexually active. One caregiver when speaking about

possibly wanting to wait until their child was older to have them vaccinated said, "*I mean you're 11 now, to 12, 13, 14, even 15, their bodies are just becoming young ladies to where you wait until they're 16 or 17 and pray to God they're not sexually active*." (CG, E) Another caregiver said, "*if you refused the vaccine it was like 'not my kid, my kid isn't going to be doing that*'." (CG, E)

3.5 Discussion

Introduction

Although the barriers and motivators to HPV vaccination among adolescents in the U.S. have been widely studied (Apaydin et al., 2018; Dela Cruz et al., 2017; Gilkey & McRee, 2016; Holman et al., 2014; Javanbakht et al., 2012; Katz et al., 2016; Sadaf et al., 2013), little is known about these factors within the diverse population of the state of Georgia. Recent research has started to fill these gaps in knowledge (Bairu et al., 2019; King et al., 2019; Lahijani, 2019; Vu et al., 2019), however, there lacks a comparative regional analysis of barriers affecting HPV vaccination uptake among adolescents in the state. A regional analysis is important because Georgia is both highly diverse (United States Census Bureau, 2019) and has varied HPV vaccination uptake across the state (Walker et al., 2019). For interventions to be successful at increasing uptake and maintaining adherence, programs must be developed to target and communicate effectively to specific populations. Therefore, this study seeks to identify and compare barriers to communication regarding the HPV vaccine between caregivers of adolescents and healthcare providers across the East, Northwest, and South regions of Georgia.

Our examination of these factors found that across different regions participants discussed similar themes, however, there were critical contextual differences when identifying

barriers to communication. The themes included (1) ineffective education about HPV compounded by low health literacy inhibiting access and comprehension of educational material, (2) caregiver lack of trust in their provider, and (3) apprehension towards discussing the vaccine given possible connotations of sexual promiscuity.

Health Literacy

Both caregivers and providers across all three regions presented that communication around the HPV vaccination has not been clear. Despite healthcare providers in all the regions discussing – often in detail regarding their own practices – the importance of communication and education about HPV and the HPV vaccine with caregivers and adolescents, Conversely, our results clearly indicate that caregivers either do not remember or report never receiving HPV vaccination recommendations. These gaps in communication demonstrate that current educational efforts by providers may not be perceived as effective or create a memorable impression on caregivers.

Research has shown that effective health communication and education is a catalyst for creating and reinforcing behavior change (Arlinghaus & Johnston, 2017). While one of the primary outcomes of effective communication and education is an increase in knowledge – an essential first step towards addressing vaccine hesitancy, knowledge alone is not enough to change vaccination behaviors (Goldstein et al., 2015; Jarrett et al., 2015). Effective communication and education produce a complete understanding of why vaccination is important and how it will result in a desirable health outcome (Arlinghaus & Johnston, 2017). Based on this, if regional healthcare providers engage in effective, dialogue-based, communication and education with adolescents and caregivers, vaccination uptake could increase in the East, Northwest, and South regions of Georgia. Regarding communication in

particular, providers should focus on creating opportunities with caregivers that focus on initiating dialogue about the importance and efficacy of the vaccine. Caregivers and adolescents should be encouraged to voice their concerns, and the resulting discussion could be beneficial in changing behaviors and increasing vaccination uptake.

Additional training for providers related to the HPV vaccination recommendation could also have a positive impact on uptake. In the South and East regions, specifically, caregivers discussed turning to alternate sources of information about the vaccine to help mitigate their gaps in knowledge. While alternate sources may seem beneficial because they are more accessible to caregivers, they may not always provide accurate information. The inability to identify good information and sources makes these caregivers particularly vulnerable to inaccurate and potentially harmful information. If providers are properly trained, then they should be able to confidently address questions that caregivers may have and provide a strong vaccination recommendation.

Healthcare providers in the South and East regions expressed concern about alternate sources as well, not only because they may provide possibly inaccurate information, but also because they claimed these alternate sources negatively impact the patient-provider relationship. Providers stated that alternate sources can degrade a caregiver's confidence and trust in their provider. Some providers mentioned that some caregivers were adamant about questioning the provider's medical advice because they found information on the internet that supported a contradictory viewpoint. Providers offering a strong, scientifically based recommendation for vaccination is essential to engage in positive, trust-building discourse with a caregiver.

Considering the need for more easily accessible information, a viable strategy for providers in these regions would be to translate traditional written material into media sources such as pictures and videos that could be shared at medical clinics as well as via websites and social media. For example, Winship Cancer Institute at Emory University successfully developed animated video tools to improve patient comprehension of 26 terms that medical staff frequently use when talking about prostate cancer treatment (Emory University Woodruff Health Sciences Center, 2014). This type of visual tool to address health literacy could be adapted to address HPV vaccination.

Throughout our research, a clear need for understandable information and communication methods was described by participants. Healthcare providers in all three regions discussed distributing educational materials to caregivers and patients. In the South and Northwest regions, providers specifically mentioned the use of vaccine information statements (VIS) sheets. However, providers in the South and East regions expressed awareness that some distributed educational materials are not utilized, acknowledging that educational gaps exist in these communities. Accordingly, the distribution of educational materials in the South and East regions has not been shown to be effective due to caregivers' low comprehension of the medical jargon in these materials. While VIS provide information on vaccines and are required by law to be distributed to patients prior to every dose of specific vaccines, additional supplemental information via provider-developed materials specific to the patient population still need to be provided.

Another option could be to develop community-specific educational materials, which would be beneficial to bridging education gaps and improving communication between caregivers and providers. These materials could be developed by community members who

know the community best, such as providers in the region in partnership with community-based organizations (CBOs) (King et al., 2019). These materials must be tailored so that they are easy to understand by members of the community, targeted to the needs of adolescents and their caregivers, and culturally appropriate (King et al., 2019). Materials also need to be written in language that is easily understood at a proper comprehension level (Kirrsch et al., 2002). These educational materials should also be used solely as a complement to the discussion providers have with caregivers and adolescents; they should not act as a substitute.

Across all three regions, healthcare providers acknowledged the importance of revisiting the vaccine recommendation at subsequent visits if a caregiver refuses the provider's initial recommendation. Providers saw this follow-up as valuable to start early on with other vaccines and build over time, so by the time that HPV comes up, open communication has been established, and vaccination seems routine. One communication strategy supported by the US CDC, Georgia DPH, and other researchers is recommending HPV vaccination at the same time, and in the same way, as other adolescent vaccines can increase uptake (Berkowitz et al., 2015; Dunne et al., 2014; Georgia Department of Public Health, 2014; Perkins et al., 2014)

However, various caregivers in the Northwest and East regions, mentioned that their provider never followed-up regarding the HPV vaccine again after they initially declined it. Providers in these areas should be encouraged to continue following-up with caregivers and adolescents about vaccination at future visits. Protocol could be developed to track this follow-up to ensure that the vaccine is recommended for all appointments if it has been previously declined. A caregiver then would be required to sign a form stating that they are declining the vaccine every time. Providers should be trained on this active follow-up process and communication. Since lack of follow-up was not brought up widely in South Georgia, it may be

worthwhile to see if the techniques they are using to track and follow-up with patients could be adapted to the Northwest and East regions. Provider follow-up has been found to be important to vaccine acceptance (Gilkey & McRee, 2016; Kornides et al., 2018), and previous research has found that parents who initially refuse HPV vaccination will likely accept if it is discussed at future appointments (Kornides et al., 2018). Follow-up communication should promote open dialogue that facilitates trust between the provider and caregivers/adolescents, highlights vaccine importance, addresses concerns, and closes with a recommendation for vaccination (Kornides et al., 2018).

Some caregivers in Northwest and East Georgia recalled feeling like the vaccination recommendation by the provider was aggressive. This finding may be a result of the "announcement" approach (Brewer et al., 2017). In this type of approach, providers communicate in an assuming manner that caregivers should want to vaccinate their child instead of engaging in dialogue that creates space for discussion and potential further education. Despite previous research finding that the announcement approach has been successful in improving vaccination uptake (Brewer et al., 2017), this study presents that some caregivers instead felt discomfort with this type of approach, which ultimately affected the trust they had in their provider. As a way to address these concerns, the state or provider organizations such as the Georgia Chapter of the American Academy of Pediatrics (AAP), could consider promoting communication training for providers that encourages them to facilitate continuous dialogue with patients and caregivers – a dialogue that provides space to voice concerns. This training could be in the form of Continuing Medical Education (CME) for providers to earn continuing credits. Collaboration with AAP and American Academy of Family Physicians (AAFP) would be critical to ensure these credits include a certain number of hours focused on communication and

effective discourse with patients and caregivers. This type of training could be integrated into medical curricula and incorporate modules in active listening, acknowledgment of concerns, engagement and vaccine recommendation. In the medical setting, all staff engaging with patients should be trained, so they are comfortable talking about the vaccine and can share a consistent message.

Lack of Trust

Trust is critical to decision making about vaccination (Bairu et al., 2019; Koski et al., 2019). Caregivers in East and South regions valued time spent with their healthcare provider as a pathway towards developing trust. Some caregivers in the South region valued provider relationships involving in-depth knowledge of a family or patient's medical history that often spanned generations, while others in the East region spoke of the importance in building a trusting relationship with a provider through time spent together in a medical appointment. Trust-based relationships are important because they facilitate providers' abilities to make recommendations and improve patient adherence to these recommendations. Trust provides the space for caregivers and providers to have productive communication allowing for shared decision-making.

In South Georgia, caregivers especially valued trust built over time with their provider, often developed across generations. However, when compared with other regions in this study, it was identified that developing trust-based relationships was uniquely difficult to South Georgians due to the Physicians for Rural Areas Assistance Program that compounds underlying problems concerning healthcare access in this largely rural and expansive region. This program incentivizes recent graduates of medical school programs to practice in rural parts of Georgia after graduation. After a set number of years, their loans are forgiven. Many caregivers felt that

after completion of the program, providers left to practice in urban regions, such as Metro-Atlanta, given a likelihood of increased income and opportunities that may not be present in smaller rural towns. This "rotating door of providers" inhibited the development of rapport, which compromised trust between healthcare providers, adolescents and their caregivers. The state of Georgia may want to consider revising its Physicians for Rural Areas Assistance Program (Georgia Board of Health Care Workforce, n.d.) to extend its program beyond a two-year commitment and instead provide additional incentives. Prior research has found that financial incentives positively influence the retainment of providers in rural areas (Goodfellow et al., 2016). Possible incentives provided for the Physicians for Rural Areas Assistance Program could include longer terms to complete loan forgiveness (e.g., after 2 years, 50% is forgiven; after 4 years, 80% is forgiven; after 5 years, 100%), housing subsidies, individual and business tax incentives, and career support services to encourage medical professionals to remain in rural areas after completion of the program. Caregivers in rural areas revealed a preference of providers having a comprehensive knowledge of the patient and family. While this program is beneficial for the provider and brings quality physicians to rural areas, it prohibits the formation of long-term bonds with caregivers and adolescents.

Whereas caregivers in South Georgia focused on time when speaking about trust, caregivers in Northwest and East Georgia felt that trust was built through rapport, and especially feeling like they were being listened to. While some providers in Northwest Georgia viewed sharing a personal anecdote as a potential way to gain a caregiver's trust, it was not received this way by some caregivers. Some caregivers mentioned that their provider sharing stories of their child being vaccinated for HPV came across as forceful. This incongruity in experiences illustrates that employing communication techniques to effectively assess caregivers and

adolescents during appointments to discover what they see as important with a focus on preventative health is essential (King et al., 2019). Education by the provider can then be aligned with their caregiver/adolescent's beliefs and values, aiming to increase vaccination uptake.

Providers in South Georgia discussed instances where trust was lost with caregivers and adolescents. These instances included not being very knowledgeable on certain medical topics, especially not being able to answer questions posed by caregivers and adolescents. Caregivers in South Georgia agreed that if they feel their provider is not knowledgeable on a health topic, then they are more likely to lose trust in them. Providers should be up to date on information regarding the vaccine and confident in their ability to broach the subject and speak about it. Improving the knowledge and confidence of caregivers could be done through CME, including online courses and attending educational events such as conferences. Health clinics could consider training all front-facing staff to have a base-level knowledge of vaccination services offered so they can provide information to patients if needed.

Sex as a Taboo Topic

Both providers and caregivers in all regions expressed the perception that the HPV vaccine is regarded as being linked to sex and promiscuity, and as a result, is considered a taboo topic in their region. This consideration of the vaccine being taboo is held even if the providers and caregivers themselves did not link the vaccine to sex and promiscuity. More so than in East Georgia, South and Northwest Georgia presented that this universal viewpoint was because of religious beliefs and influenced by the Bible Belt.

Providers in all regions widely discussed the heightened sensitivity in discussing topics that intersected with sex, such as the HPV vaccine, with caregivers. It appears these providers were

anticipating barriers from caregivers who believed that their children were not having sex. However, caregivers in these regions generally acknowledged that they know adolescents are having sex. Provider hesitancy to talk about sex has been previously identified as a large barrier to HPV vaccination (Gilkey & McRee, 2016), and providers could benefit from additional training to talk about sensitive topics such as sex. Further, medical school curricula should also include these types of classes. This perception by providers that caregivers are more hesitant towards discussing the vaccination than they actually are has been previously identified (Gilkey et al., 2017). Imposing protocols and procedures to always recommend vaccination for the recommended ages would help hinder providers from imposing their personal point of view regarding what they believe caregivers want to discuss.

3.6 Limitations

As with most research, our study has limitations. First, the limited number of FGDs across the regions presents the need to conduct further research to gain a more comprehensive view of perceptions throughout the state. Our limited view provides a starting point for further research to be conducted, which could further elaborate on the ideas discussed within this paper.

Second, recruitment efforts may have allowed for selection bias. Since this was a convenience sample, recruited by partner organizations, the generalizability of the findings is limited to those participants, but do present a view of the issues important to caregivers and providers in each region related to HPV vaccination. The number of participants could have also been more evenly distributed between regions and further diversified to include more males overall. Third, participants were asked to recall past events and conversations, which may have

introduced a potential source of recall bias. Also, some participants may have given answers that they found to be socially appropriate in the FGD, creating social desirability bias.

Last of all, the findings of this study are not generalizable to other areas of Georgia or different states. Nevertheless, future research in Georgia or other states could draw from this study.

However, our study has many strengths. First, it helps address the current gap in literature on regional barriers to communication between caregivers and providers regarding the HPV vaccine in Georgia. This study also has a wide geographical reach across the state that allowed for comparative analyses within the regions to be conducted.

3.7 Conclusion

This novel study assesses barriers to communication between healthcare providers and caregivers regarding HPV vaccination at the regional level in East, Northwest, and South Georgia. Communication between providers and caregivers is critical for successful HPV uptake and series completion among adolescents. Based on our results, we have found similarities and key differences between the East, Northwest, and South regions regarding health literacy, the lack of trust in the provider-caregiver relationship, and the topic of sex.

CHAPTER 4: PUBLIC HEALTH IMPLICATIONS

Most HPV-attributed cancers are highly preventable with the HPV vaccine. While vaccination rates are slowly increasing each year, there is still much work to be done. Within the state of Georgia, there is only limited research into the regional context of vaccination acceptance, including motivators and barriers to vaccination, and more research is needed to foster a robust understanding of the needs held by the state's diverse population. A more complete understanding of regional context would be integral to the development of targeted intervention strategies aimed at increasing vaccination uptake.

Understanding the healthcare provider – caregiver relationship, especially as it is related to communication, is important because the efficacy of this communication is critical to addressing vaccine hesitancy. Caregivers are the gatekeepers for the health of adolescents and introducing caregivers to the HPV vaccine concurrently with other adolescent vaccines could help facilitate acceptance. Active communication and listening, education, trust, and the breaking down of misconceptions concerning the vaccine all are key elements that contribute to a strengthened patient-caregiver relationship.

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APPENDIX

Table 1: Participant Demographic Characteristics (N= 107)

	n	%		n	%
Health Care Providers (*N*=55)			**Caregivers (*N*=52)**		
Region			**Region**		
South	39	71%	South	24	46%
Northwest	8	15%	Northwest	6	12%
East	8	15%	East	22	42%
Gender			**Gender**		
Male	7	13%	Male	3	6%
Female	48	87%	Female	49	94%
Age			**Age**		
21-30 Years	6	11%	21-30 Years	4	10%
31-40 Years	12	22%	31-40 Years	17	44%
41-50 Years	18	33%	41-50 Years	9	23%
51-60 Years	8	15%	51-60 Years	6	15%
60+ Years	10	19%	60+ Years	3	8%
Employment Type			**Employment Status**		
Nurse	15	27%	Employed	27	52%
MA, PA	4	7%	Unknown	25	48%
Nurse Practitioner	2	4%	**Number of Reported Children**	148	
Physician (Primary, Pediatrician, OBGYN, etc.)	6	11%	# Male Children	59	
Practice Manager / Administrator	3	5%	# Female Children	64	
Clinical Staff	6	11%			
Other Patient Facing Practice Staff	19	35%			
Years in Practice					
Less than 10	11	20%			
10-19	12	22%			
20+	12	22%			
Missing	20	36%			

Table 2: Representative Participant Quotes

	South Georgia		**Northwest Georgia**		**East Georgia**	
	Provider	Caregiver	Provider	Caregiver	Provider	Caregiver
1. Health Literacy	If you only have a 9th grade education, and your child brings you a pamphlet home, do you understand even what you're reading.	Participant 6: That's right, layman's terms, not doctors terms, yes. Mhm, don't want it to go over our heads. We'd miss it. Participant 4: I want my child to understand it if they read it.	I think it's our job to bring it up every year, or every visit you know depending on where they are but if we just kind of ignore, we look at our notes and see that they denied it the last time and just don't bring it up I think we do them a disservice.	I actually had this conversation with another parent that, like her pediatrician didn't push [HPV vaccine] at all. Like offered it and she was like, 'no I don't think we're going to do that', and they were like ok. And moved on.	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.	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.
	it's our responsibility to give education.	...lack of knowledge yeah…because we're big on…health fairs... so a lot of people like our providers [redacted] and [redacted] I feel like they need to have pamphlets and information on their tables because they are our providers	Well if they've never had it before and it's their first time um I always tell them that now you're at the age uh for the recommended HPV [vaccination]. Um start it at 11 so if we can start today then you'll come back in 6 months and then you'll be done...I have several like	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 [vaccinate for HPV].	…you're offering them something they don't have a clue about cause a lot of our patients… like you said they come from a rural area, and a lot of them are uneducated so they have no idea what this new vaccine is. They see stuff on TV that kind of scares them about stuff	I've been doing research here and there and unfortunately there is so much conflicting information its really hard to get a grasp on [the vaccination] so I've not done it yet.

			stories of people I've known where, that they didn't realize they had HPV and ended up with throat cancer…So you know, and so and 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.		that we're telling them about so they are kind of hesitant to give it to their kids.	
2. Lack of Trust	…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…it's important to acknowledge the patients' feelings because they're not gonna do it [vaccinate] if they don't trust you.	Especially if you've been going to that doctor for a while and they seem generally concerned about that child because, like, my daughter she actually grew up with that doctor and so she acts as if she's the mother to that child...	I don't think it's trying to persuade somebody, I just think it's just giving them the knowledge. Um here's these options you do have your choice to make. I mean you don't have to do this but here are some options. And I think just giving the person the options they can go back and research it themselves.	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 [vaccinate for HPV].	Participant 3: I think that's one advantage maybe in a rural area. Its small, and cuz people never move so there is already that trust, there's already some groundwork for it there…Some of them will ask, "Do you, you think I should get [HPV vaccine]?" Participant 7: 'Did you give it to your child', or something like that. And I'll be	For me, trusting my doctor is how much they are listening to me, so when I talk about communication, it's not just what they tell me, it's are they truly listening to my concern, are they willing to research further, to find out what, what I want to know.

					like yeah, so then that makes them feel like okay, I can give it to their child…	
	You need to be correct one. And two be confident in how you communicate with families, not in an antagonistic way um but you have to be viewed as an expert. It just takes one encounter where you and your team are not viewed as expert and you are immediately no longer valued in that discussion, my opinion is discounted.	My son he was 14, I forget what shot they were trying to get him to get, but the shot he was supposed to get but I didn't get it, she the lady couldn't explain to me what it was for.				
3. Sex as a Taboo Topic	…let me put it this way. We are so and so [Religion] followers, okay? And my daughter or my son is not going to have sex before that age [age of	I just went to a meeting at the high school and they're like we got 21 girls pregnant this year.	Participant 8: [Name of town] is kind of in the 'Bible belt' and they're very big on abstinence until you're married…and a lot of people kind of feel like if	I had a physician just said you know, you can pray. Just pray for your child that they will stay, you know, abstinent until they get married. But in this day and age	They do not want to hear that their child is grown enough to be sexually active, I think yes, I agree, they just don't want to discuss.	A lot of parents have a problem with sex education being taught in the school. (Group agreement: oh ya, that's true). They have big problem with that.

	recommended vaccination]. So it's like religious belief which is being converted to their practices.		you're even recommending it or suggesting it then you're basically, you know..you're …Participant: Condoning [sex]	you know that the percentage of that happening is very slim so, what if she decides to stay that way but she meets somebody and she marries somebody that has it. Now she's come in contact and she's not protected.		
	Parents think they are protecting their child from the information, and protecting their child from having too much information and considering that if they give them the vaccination then it actually is a stamp that says to their child that they can have sex…	I just went to a meeting at the high school and they're like we've got 21 girls pregnant this year.			…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.	…let's be real, you know, kids have sex, (group agreement: mhm) they do. And they're having sex uneducated.