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Caregivers of Adolescents' Motivators and Barriers to Vaccinating Children against HPV in Georgia

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By

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Bachelor of Science
Santa Clara University
2015

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An abstract of
A thesis submitted to the Faculty of
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Abstract

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By Wintana Bairu

Background: Acceptance of adolescent vaccines, as measured by vaccine uptake, is generally high amongst caregivers. However, this does not routinely extend to HPV vaccines. In the state of Georgia, HPV vaccine coverage rates remain subpar; vaccine initiation 64.3% versus coverage 45.7%; particularly to other adolescent vaccines administered (i.e. Tdap 93.3%) (Walker et al., 2018). The purpose of this study was to identify and examine caregivers', motivators and barriers towards vaccinating their adolescent(s) against HPV in the state of Georgia.

Methods: Focus group discussions (n=9) with caregivers (n=75) were conducted throughout the state. Thematic analysis identified common motivators and barriers towards adolescent HPV vaccine uptake amongst caregivers.

Results: We identified motivators and barriers centralized around themes of healthcare provider relations and trust, presentation of HPV-related information, adolescent's physical sex, and an essential need to protect adolescents. Barriers presented include caregivers being unable to develop a trusting relationship with their healthcare provider, fear of perceived side effects, management of an overload of HPV-related information, inability to prioritize the HPV vaccination, and perceiving the vaccination to be for females. Motivators presented include caregivers' intrinsic need to protect their adolescent, shock-value HPV-vaccination marketing in commercials, and trusting their healthcare provider. Caregiver trust in their healthcare provider has been shown to ease perceived barriers in this study.

Conclusion: Trust in healthcare providers was found to be imperative to mitigating barriers and reinforced motivators to HPV vaccine acceptance and uptake. In improving patient-provider relationships throughout the state of Georgia, caregivers may become more receptive to vaccinating their adolescents against HPV, thus improving uptake and mitigating concerns causing hesitation to decide. Additionally, information and messaging must be streamlined across HPV vaccine educational sources and provided in layman's terms to avoid confusion of otherwise complex and technical detail. While all barriers and motivators are interconnected and posed nuances, trust in provider and clarity of HPV and HPV vaccine related information influenced many caregivers.

Keywords: HPV Vaccine, Human Papillomavirus Vaccine, adolescents, barriers, motivators, caregivers, Georgia

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1.0 INTRODUCTION

1.1 Overview

Human papillomavirus (HPV) is one of the most common viruses that people worldwide are infected with, and has affected approximately 79 million Americans (National Cancer Institute, 2019). There are over 100 different strains of HPV, of which more than 40 have been identified as either high or low risk infections in humans causing either genital warts or various HPV-associated cancers (World Health Organization, 2019). Each year more than 14 million people in the United States (US) will likely be infected with at least one type of HPV (Centers for Disease Control and Prevention, 2018c). HPV vaccination was first recommended as a routine immunization for female adolescents in the US in 2006 and the recommendation expanded in 2011 to include male adolescents (Centers for Disease Control and Prevention, 2011). Although HPV vaccination had been studied decades before licensing and regularly reviewed by the Advisory Committee on Immunization Practices HPV working group (ACIP) and the WHO Global Advisory Committee for Vaccine Safety (GACVS), real-world factors associated with HPV vaccination uptake has limited optimal coverage from reaching levels to protect the general population from HPV and HPV-related cancers (Brotherton J.M.L, 2016). The epidemiology of HPV infections and HPV-related disease post-vaccine licensure is promising, showing a decrease in HPV infection rates, but continues to evolve (Markowitz, Gee, Chesson, & Stokley, 2018; Petrosky, 2015). Despite HPV vaccine advancements, it remains underutilized in the US.

In the state of Georgia, HPV vaccine series completion has been identified between 39.1-49.0% and remains suboptimal (Franco, Mazzucca, Padek, & Brownson,

2019). Researchers looking at factors within Georgia's context regarding suboptimal HPV vaccine uptake highlighted a gap of existing literature on HPV vaccination uptake motivators and barriers of those residing in Georgia, indicating a need to develop further understanding of population level factors affecting uptake of HPV vaccination in the state (Dennison, King, Rutledge, & Bednarczyk, 2019).

The Georgia Cancer Control Consortium (GC3) identified HPV vaccination uptake as a priority in its 2014-2019 Georgia Cancer Plan and set a goal to fully vaccinate 50% of eligible adolescents by the end of 2019 (Georgia Cancer Control Consortium, 2014). This plan aims to (1) increase HPV vaccine uptake in adolescents to the standards of the ACIP and (2) encourage the promotion of HPV vaccine in tandem with other regularly administered adolescent vaccines in pediatric care offices (Georgia Cancer Control Consortium, 2014). The GC3 plan also aims to take an equitable approach by targeting marginalized populations; those without health insurance, racial and ethnic disparities, and income related barriers, addressing Georgia's high diversity population-level diversity (Georgia Cancer Control Consortium, 2014; U.S. Census Bureau, 2018). Currently, a new 5-year plan for 2020-2024 is under development.

With little research done to understand Georgia resident's context, there is not enough evidence-based research available to inform and advocate amongst Georgia communities in a way that is relevant to them. Understanding factors inhibiting acceptance and uptake of the HPV vaccine will better inform future HPV vaccine uptake strategies in Georgia and potentially lead as an example for states with a similar sociodemographic context.

1.2 Background

Human Papillomavirus

HPV is a commonly contracted virus globally amongst humans and is typically cleared by the immune system. Research has shown that 70% of HPV infections are resolved by the immune system alone within 12 months and 91% by 24 months (Winer, 2003). There is no available treatment for HPV infections and although it may clear on its own, a persistent infection lasting 2 years or longer can lead to development of disease, including cancer and genital warts (Alizon, Murall, & Bravo, 2017).

High-risk HPV is used to classify strains of HPV that are associated with cancer development. HPV strains 16 and 18 are the most common strains of high-risk HPV and are responsible for 70% of HPV-associated cancers (World Health Organization, 2019). Other strains of HPV have been associated with six different types of cancer with a significant portion of those cancers associated with HPV-infection; 91% of cervical, 91% of anal, 63% of penile, 69% of vulvar, 75% of vaginal, and 70% of oropharyngeal cancers (Van Dyne, 2018). Low-risk HPV strains are known to either be asymptomatic or cause warts around the affected area, rarely causing disease.

Females are recommended to receive the Papanicolaou test (Pap smear or Pap test), a routine screening for cervical cancer or cervical cancer precursors. This routine screening test may also be used to check for an HPV infection if done with the HPV co-test. Although effective in identifying and reducing the prevalence of cervical cancer, other HPV-associated cancers in infection sites other than the cervix do not have an approved nor recommended testing method. There is also no test to identify HPV infection in males.

HPV Vaccination

In 2006, the first HPV vaccine, a quadrivalent vaccine (HPV4) covering types 6, 11, 16, and 18, was approved by the Food and Drug Administration (FDA) and targeted towards the prevention of cervical cancer, cervical cancer precursors, and most genital wart cases (Centers for Disease Control and Prevention, 2011). The ACIP recommended females between 11 and 12 and acceptable for 9 to 26 years old, expanding the general recommendation 2011 to include males ages 9 to 21; for some male populations this recommendation extends to age 26 (Centers for Disease Control and Prevention, 2011). Prevention strategies to cervical cancer were primarily pap smears, or pap tests, that were conducted during a female's routine health visit once sexually active. This is an opportunity for physicians to identify cellular abnormalities, signaling potential presence of HPV, however this does not prevent HPV infections all together nor other HPV-related diseases. HPV vaccination has addressed this gap in prevention methods by targeting specific high-risk and highly prevalent strains. There have been 3 licensed HPV vaccines; bivalent (HPV2) covering types 16 and 18, quadrivalent (HPV4) covering types 6, 11, 16 and 18, and 9-valent (HPV9) covering types 6, 11, 16, 18, 31, 33, 45, 52, and 58; that have been developed and somewhat incorporated into routine healthcare provider visits. HPV9 is the most comprehensive vaccine and remains underutilized in the US.

Caregivers' of Adolescents Motivators and Barriers

Research has been conducted to observe caregiver perceptions of the HPV vaccination, however none in context of the state of Georgia. To address the challenge of increasing HPV vaccine uptake amongst adolescents in Georgia and optimize

intervention initiatives, a comprehensive understanding of their caregivers' motivators must be developed in addition to their barriers.

Adolescent immunization against HPV has been an area for concern for caregivers as to why adolescents need to be vaccinated for a sexually transmitted infection. HPV vaccination was initially marketed as a means to prevent HPV, a sexually transmitted infection. This led to concerns about the potential for increased sexual promiscuity, which may have mitigated the reach to adolescents prior to the onset of sexual activity. In vaccine-prevention strategies, adolescents have a stronger immune response to the vaccine, increasing how efficacious the vaccine may prove. Recommendations from the Center for Disease Control and Prevention (CDC) have stated that the HPV vaccine proves most efficacious when administered between ages 11-15. Studies have shown that by ages 15 to 17, 28% of girls and 32% of boys have had sex at least once (Abma & Martinez, 2017). HPV vaccination works best before exposure to the virus, which requires early vaccination before the statistical onset rather than perceived onset of sexual activity in adolescents.

The 2017 National Immunization Survey-Teen (NIS-Teen) reported a steady trend amongst females nationally of slight improved uptake of the HPV vaccine with increased age (i.e. from 13 to 17 years of age) (Walker et al., 2018). Uptake improved amongst males between ages 13 to 14 years old, however, leveled off with minimal fluctuation in ages 14 to 17 year old (Walker et al., 2018). In the state of Georgia, there is a decrease in uptake amongst all adolescents (i.e. from 13 to 17 years of age) between initiation of the vaccine series and full completion; 64.3% initiated and 45.7% complete (Walker et al., 2018). Coverage for other recommended adolescent vaccines, such as Tetanus, Diphtheria, and acellular Pertussis booster (Tdap) and Meningococcal

conjugate (MenACWY) vaccine, are at optimal coverage, 93.3% and 95.3% respectively in the state of Georgia (Walker et al., 2018). The Georgia Department of Public Health (GDPH) recommends but does not require school children to be vaccinated against HPV, allowing caregivers to opt out of uptake for their children (Georgia Department of Public Health). Currently, the GDPH requires documentation of receipt of Hepatitis B, Polio, Varicella, Tdap, MenACWY, and Measles, Mumps & Rubella (MMR) immunizations for school enrollment of adolescents age 7 and older ("Immunization of School Children," 2014; "Vaccine Requirements for Attending Facilities and Schools in Georgia," 2014). High coverage rates of other adolescent required vaccines show that even as we incorporate those that are excused from vaccinations (i.e. medically or religiously) optimal coverage is achievable for the HPV vaccine.

Vaccine uptake generally faces some common barriers; lack of perceived necessity and vaccine safety concerns (Benjamin & Bahr, 2016). HPV vaccination has been reported to have additional barriers such as lack of knowledge, absence of physician recommendation, gender necessity, and child assumed to not be sexually active, thus contributing to caregiver refusal to vaccinate their adolescent against HPV (Beavis, Krakow, Levinson, & Rositch, 2018)**Error! Bookmark not defined.**. Further investigation on what barriers and motivators towards adolescent HPV vaccination exist amongst caregivers is imperative to bridging the gap between health recommendations and a healthy population.

1.3 Problem Statement

HPV vaccination coverage has been increasing in Georgia and yet remains suboptimal to reducing HPV-associated cancers. The state has 13.1 new cases of HPV-

associated cancers diagnosed per 100,000 people every year, 90% of which are preventable with the HPV vaccination (Centers for Disease Control and Prevention, 2018b; Dennison et al., 2019). Only 45.7% of Georgia adolescents are fully vaccinated during the recommended ages 13-17 years old, lying below the national coverage rate and significantly lower than other recommended adolescent vaccines (i.e. Tdap 93.3% and MenACWY 95.3%) (Walker et al., 2018). The 2014-2019 Georgia Cancer Plan, as set by the Georgia Cancer Control Consortium (GC3) has set a goal to reach 50% vaccine coverage by 2019 (Georgia Cancer Control Consortium, 2014). National studies have shown reported the importance of understanding why parents choose to refuse HPV vaccination for their children, however, in the state of Georgia, little contextual research exists to support evidence-based interventions aiming to improve vaccine coverage (Beavis et al., 2018).

1.4 Purpose Statement

The purpose of this study is to examine the motivators and barriers among caregivers, defined as anyone 18 and older in charge of the decision-making process of one or multiple adolescents' health (i.e. grandparent, aunt, parent, legal guardian etc.), across the state of Georgia towards getting their children vaccinated against HPV.

Objectives:

1) Identify common caregiver motivators to HPV vaccination across the state of Georgia while also developing an understanding for how these motivators may vary across the state.

2) Identify common caregiver barriers to HPV vaccination across the state of Georgia while also developing an understanding for how these barriers may vary across the state.

Stakeholders (i.e. healthcare providers, academics, policy makers, etc.) will be informed with contextual knowledge and enabled to take an evidence-based approach to addressing the state-wide similarities and variations of barriers and utilizing the motivators that arise from this study.

1.5 Research Questions

1) What are common motivators throughout the state of Georgia that caregivers have to vaccinate their adolescent(s) against HPV?

2) What are common barriers throughout the state of Georgia that caregivers have to vaccinate their adolescent(s) against HPV?

1.6 Significance Statement

The findings of this study will be used to inform healthcare professionals, academics, community organizers and policy makers on the motivators and barriers of Georgia caregivers of adolescents' have towards vaccinating their children against HPV. Developing this understanding is key to addressing low HPV vaccine uptake in Georgia in a context specific methodology. Caregivers traditionally function as the most immediate gatekeepers between healthcare providers and adolescent health. An in-depth understanding of their perceptions permits healthcare providers, academics, community organizers, and other stakeholders to address common barriers and utilize

motivators to cater a state-specific response to optimize HPV vaccination coverage in Georgia.

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 ("Bible Belt," 2019)
Caregivers	For this study, a caregiver was defined as anyone 18 and older in charge of the decision-making process of one or multiple adolescents' health (e.g. grandparent, aunt, parent, legal guardian, etc.)
Coverage	The total group covered (completed series of vaccination) ("Coverage," 2019)
Initiate	To cause or facilitate the beginning of (start the vaccine series) ("Initiate," 2019)

List of Acronyms

ACA	Affordable Care Act
ACIP	Advisory Committee on Immunization Practices
CDC	Center for Disease Control and Prevention
eIRB	Emory University Intuitional Review Board
FG	Focus Group
FGD	Focus Group Discussion
GC3	Georgia Cancer Control Consortium
GACVS	WHO Global Advisory Committee for Vaccine Safety
GDPH	Georgia Department of Public Health
HPV	Human Papillomavirus
HPV2	Bivalent HPV vaccination
HPV4	Quadrivalent HPV vaccination
HPV9	9-valient HPV vaccination
IRB	Institutional Review Board
MenACWY	Meningococcal conjugate vaccine
MMR	Measles, Mumps & Rubella vaccine
MMWR	Morbidity and Mortality Weekly Report
MSM	Males who have sex with males
NCVIA	National Childhood Vaccine Injury Act of 1986
NIS-Teen	National Immunization Survey-Teen
PRAA	Physicians for Rural Area Assistance Program
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
Tdap	Tetanus, Diphtheria, Pertussis vaccine
US	United States

2.0 BACKGROUND

2.1 Literature Review

Introduction

Caregivers preconceived beliefs impact the interactions with healthcare providers and how successful advocacy efforts for HPV vaccination will be and is closely tied with sociodemographic factors (Newman et al., 2018; Reiter, Brewer, Gottlieb, Mcree, & Smith, 2009). HPV vaccination rates were significantly impacted by religiosity, sex education policy, gender, and political ideology when compared with vaccines requiring similar uptake doses (i.e. Tdap and MMR vaccinations) (Dennison et al., 2019; Franco et al., 2019). Research has also shown a mistrust in the healthcare system, perceived cost, perceived risk, and lack of knowledge regarding the vaccine to be additional barriers preventing or causing caregivers to hesitate vaccinating their adolescents (Newman et al., 2018; O'Leary et al., 2018; Yaqub, Castle-Clarke, Sevdalis, & Chataway, 2014).

Mistrust in the Health System

Caregiver and healthcare provider attitudes and beliefs about vaccines are known to play a significant role in HPV vaccination uptake and healthcare policies surrounding the vaccination (Perkins, 2012). Globally research has shown that increased physician recommendations would improve attitudes towards the HPV vaccination and increasing uptake amongst adolescents (Brewer & Fazekas, 2007; Brown, Gabra, & Pellman, 2017; Dela Cruz, Braun, Tsark, Albright, & Chen, 2018; Dela Cruz, Tsark, Chen, Albright, & Braun, 2017; Newman et al., 2018; Reiter et al., 2009). US-specific research, nation and state-level, finds physician recommendations to have the single greatest effect on

caregiver uptake of HPV vaccines for caregivers' adolescents, increasing perceived HPV vaccine benefits (Brown et al., 2017; Dela Cruz et al., 2018; Newman et al., 2018). Literature does not currently exist on caregiver responsiveness to specific types of healthcare providers (i.e. general practitioner, nurse, and obstetrician-gynecologist). Understanding this gap may provide greater insight into opportunities to improve uptake of the HPV vaccine.

Contrary to these findings, some studies have found feelings of mistrust with the new vaccines and hesitancy with their physician (Galbraith-Gyan et al., 2019; I. T. Katz et al., 2016; Yaqub et al., 2014). This feeling of mistrust in the African American community has been largely speculated as a result of the Tuskegee Syphilis Study where African American men were used to observe the natural course of untreated syphilis, however no widespread proof exists (R. V. Katz et al., 2008; R. V. Katz et al., 2009; Matthews, Sellergren, Manfredi, & Williams, 2002). Immigrant communities shared a preference for healthcare providers of a similar ethnic background or are culturally-sensitive, reiterating a need for representation in research and public health advocacy initiatives (Ko, Reuland, Jolles, Clay, & Pignone, 2014; Ko et al., 2018; Lee, Riesche, Lee, & Shim, 2018). Finding a provider of similar ethnic or cultural background eased patients to believe that their provider was looking at them from a more holistic point of view, considering what brings them comfort and having a greater unsaid understanding of their background.

Source of Health Information

Research studies analyzing where caregivers get their health information has shown a stark mistrust in pro-vaccine sources which may re-direct caregivers towards

more informal sources like social media (Buller et al., 2019; Ortiz, Smith, & Coyne-Beasley, 2019; Quinn & Lewin, 2019). Across diverse caregiver backgrounds, research often found that there is a strong interdependence on others for knowledge and confirmation regarding new health recommendations (Buller et al., 2019; Ko et al., 2018). A study observing mothers' interactions on Facebook regarding pro and anti-HPV vaccine messaging found that mothers posted on content that lined up with their beliefs (Buller et al., 2019). These mothers did not provide facts or any detail regarding why they are pro or anti HPV vaccination which may suggest an un-informed stance on the matter and an inability to engage in factual discourse. Other sources functioning as motivators and barriers are unspecified in other studies, left generalized as the internet. A systematic review found that social media has increasingly functioned as a source for health information, improving awareness of HPV and the vaccine yet not increasing uptake (Ortiz et al., 2019).

Sexual Activity

HPV vaccination was initially marketed towards females and as a preventive measure from HPV-associated cancers, the most common of which is cervical cancer. Stigma surrounds HPV as a sexually transmitted infection, although it can be spread by skin-to-skin contact and does not require sexual penetration (Liu, Rashid, & Nyitray, 2016). Caregivers were consistently reported in the literature to fear that the initiation of HPV vaccination in their adolescent will condone sexual activity, especially amongst girls (Brewer & Fazekas, 2007; Buller et al., 2019; Holman et al., 2014). A shared barrier amongst caregivers was that they found the recommended age range for uptake to be too young (Brewer & Fazekas, 2007; Holman et al., 2014; Kashani et al., 2019). This

may indicate that the stigmatization surrounding the HPV vaccine is a barrier to caregivers vaccinating their adolescent at the earlier recommended age, for fear of sending a sexually permissive message to their children.

Perceived Risk

Research has shown conflicting findings as to whether or not family history of cancer and genital warts is a motivator for caregivers to vaccinate their adolescent against HPV (Brewer & Fazekas, 2007; Brown et al., 2017; Buller et al., 2019). Family history of HPV-associated diseases and symptoms may be a motivator for some caregivers as their perceived risk of contracting HPV may be higher than others. Other studies identified a trend of caregivers wanting to protect their adolescents, however did not have the right information nor saw the risk-benefit in the vaccination (Dela Cruz et al., 2018; Galbraith-Gyan et al., 2019; Holman et al., 2014; Widdice et al., 2018). Public health strategies to improve vaccine uptake will require a greater contextual focus in order to demystify some caregiver beliefs on the HPV vaccine.

Perceived Cost

Cost has been perceived as a barrier for caregivers' vaccinating their adolescent against HPV (Brewer & Fazekas, 2007; Holman et al., 2014; Lee et al., 2018; Newman et al., 2018). A cross-sectional study was conducted amongst parents in an area with high cervical cancer prevalence and found cost and insurance coverage to be the greatest barriers to vaccinating their children against HPV (Reiter et al., 2009). The re-emergence of this barrier may suggest that report cost is more withdrawn from the health care system in terms of health insurance or knowledge of the system. Beyond the health care system are free vaccination programs (i.e. Vaccines for Children) that have

not been able to address the significance of cost as a barrier to HPV vaccine uptake in adolescents due to uncertainties of how to utilize the program (Kepka et al., 2018).

Uncertainty if health insurance covers the HPV vaccination for adolescents was also common among concerns about vaccination costs (Kepka et al., 2018; Reiter et al., 2009). Out-of-pocket costs present an additional barrier to caregivers as health insurance coverage remains low and health insurance companies are slow to update their coverage to new HPV vaccination uptake recommendations (Newman et al., 2018). The Affordable Care Act (ACA) mandates that ACIP recommended vaccines be fully covered under all health plans to mitigate this perceived barrier ("Obamacare Preventive Care," 2018).

Sex of Adolescent

The lack of acceptance received by the HPV vaccine, particularly in comparison to other vaccines, is further disparaged by various demographic factors. Globally HPV vaccination amongst adolescents is at suboptimal levels and differs notably based on the child's sex, 46.5% girls and 20.3% boys (Newman et al., 2018). This disparity between the sexes has been noted to be a result of the lack of understanding and skewed marketing of the vaccination towards females. The HPV vaccination was initially made available and primarily marketed towards females, however the inclusion of males in the recommendation alone did not truly enforce the feminization of the vaccine (Franco et al., 2019). An Australian study observed herd immunization develop, protecting males as a result of a female vaccination program (Patel et al., 2018). The benefits of herd immunity neglects the impacts of HPV on males, benefits of HPV vaccination of males,

places responsibility of HPV prevention on females, and ignores males who have sex with males (MSM) (Patel et al., 2018).

There is a tendency for physicians to address prevention methods to those they perceive most at risk which limits awareness and uptake initiatives amongst males (Newman et al., 2018). HPV has long been associated with cervical cancer and vaccinations have been communicated as a prevention method to cervical cancer. In 2015, an MMWR report identified oropharyngeal cancer in males as having surpassed cervical cancer in terms of total cases reported despite rates of smoking decreasing (Chaturvedi et al., 2011; Van Dyne, 2018). These new prevalence rates call for further research and improvement in developing strategies to better incorporate males in HPV-related cancer prevention.

Culture, Religion & Politics

States with the lowest HPV vaccine uptake and completion rates were found to be highly conservative and religious (Franco et al., 2019). The Bible Belt is an informal region in the Southern United States described as being highly religious ("Bible Belt," 2019). National and state-level studies have consistently reported lower HPV vaccine acceptability amongst highly religious participants (Birmingham, Macintosh, Vaughn, & Graff, 2019; Franco et al., 2019; Quinn & Lewin, 2019). In a qualitative study of mothers of adolescents that immigrated to the U.S. from the Horn of Africa, a predominantly Islamic and Christian region, a general consensus was uncovered that social, cultural, and religious factors affect parental vaccination of their children (Ko et al., 2018). The concept of fatalism was discussed in one focus group discussion that captures a similar sentiment to caregivers of denominations that hold theological objections to

vaccinations and other medical procedures (Ko et al., 2018; Pelcic et al., 2016; Vanderpool, Dressler, Stradtman, & Crosby, 2015). Discussions about sex was noted as unacceptable to engage in with children based on cultural and religious beliefs amongst US-born and immigrant caregivers (Ko et al., 2018; Quinn & Lewin, 2019). Denominations under the Christian faith, except Catholicism, were reported to be adamant about not vaccinating their daughters for the HPV vaccine (Brewer & Fazekas, 2007).

Demographic factors which have been traditionally expected to impact vaccine uptake were trumped by politico-religious factors (i.e. caregiver rights and theological objections to vaccinations) in the context of HPV vaccination (Franco et al., 2019). Conservative caregivers were more likely than liberal caregivers to not vaccinate their adolescents for the HPV vaccine, although still willing to utilize other adolescent vaccines (Brewer & Fazekas, 2007; Constantine & Jerman, 2007; Franco et al., 2019). Significant political disapproval and criticism surrounds legislation requiring adolescents to be vaccinated against HPV due to ideologies and beliefs surrounding acceptable sexual behavior. A study focusing on African-American mothers noted that the politicization of the HPV vaccine by government figures acted as a barrier to vaccinating daughters (Galbraith-Gyan et al., 2019).

Georgia is one of approximately 8 states that is fully encompassed by the Bible Belt and faces similar religious factors that impact policies and societal beliefs regarding vaccine uptake. Religion and rurality of communities, both prominent in Georgia, are less likely to vaccinate than urban parents (Birmingham et al., 2019; Buller et al., 2019; Franco et al., 2019). Adding to this is Georgia's foreign-born population, making up 10%

of the general population (U.S. Census Bureau, 2018). No research has been done to further examine caregiver motivators and barriers towards vaccinating their adolescents against HPV in the unique context of Georgia. Research to assess this gap in knowledge can better inform the state in their public health interventions and strategies to improve HPV vaccine uptake.

Reaction to School Mandates

School-mandates for the HPV vaccine have not been established nation-wide as other adolescent vaccines have been for children to be enrolled in school, sustaining coverage rates. These mandates have been proven to be an effective policy to achieve optimal vaccine uptake and remain a missed opportunity to address coverage rates (Dempsey & Mendez, 2010). Between 2006 and 2015, 27 states and Washington DC introduced HPV-vaccine legislation requiring mandates for adolescents to have initiated the vaccine series for school enrollment. Only 3 enacted the legislation for females; Virginia, Rhode Island, and Washington DC; of which Rhode Island the only to enact HPV-vaccine legislation for both female and male adolescents (Keim-Malpass, Mitchell, DeGuzman, Stoler, & Kennedy, 2017).

Research done on caregiver perceptions of school-mandated vaccinations has shown conflicting results. Results from a cross-sectional study has shown significant results stating that school required vaccines were among the most influential factors towards parental acceptance of the HPV vaccine, second to physician's recommendation (Davis, Dickman, Ferris, & Dias, 2004). Researchers have taken a look at the state-level characteristics and found religion to play significant role against HPV vaccine uptake and disapproval of school-mandates amongst politically conservative states

(Birmingham et al., 2019; Buller et al., 2019; Franco et al., 2019). Lack of school-mandates and exemptions from school-mandates can interfere with public health initiatives to increase HPV vaccine uptake, exacerbating disparaged populations where religious and political beliefs impact vaccine uptake (i.e. The Bible Belt).

Georgia State Context

Georgia's highly diverse society requires an in-depth, contextual look at caregiver motivators and barriers towards HPV vaccination uptake amongst their adolescents (Dennison et al., 2019). Capturing the perceptions and beliefs of marginalized populations in Georgia is a reoccurring theme throughout the systematic review and highlights the need for in-depth research to be conducted with hard to reach populations. Understanding the cultural norms of the diverse populations within Georgia can lead to better targeted HPV vaccine advocacy. In any advocacy efforts, an educational component should be included to bridge the gap of knowledge and reduce stigmatization. The implications of this review highlighted the diversity within Georgia and necessity to understand the diverse motivators and barriers which may exist among marginalized populations in order to improve HPV vaccine uptake.

Conclusion

Throughout the literature, caregivers' mistrust in the health system, politico-religious ideologies, cultural beliefs, gender bias, cost, and perceived risk have been identified as motivators and barriers towards HPV vaccine uptake amongst adolescents. A lack of knowledge, causing stigma surrounding the vaccine was persistent throughout research which has been conducted. Participants in research studies often noted information as critical, highly valued, and requested more. The literature indicates that

more motivators and barriers remain unknown as to why caregivers are or are not vaccinating against HPV. Throughout all the literature uncovered, much provides no emphasis on Georgia parents or adolescents specifically, and as such more research is needed. A significant need for Georgia-specific research exploring these common themes, and more, is required to develop a contextually appropriate understanding of caregiver motivators and barriers towards HPV vaccination. This understanding will aid HPV-related stakeholders in developing culturally appropriate interventions, health education programs, targeted messaging, and vaccine promotion techniques for Georgia residents.

3.0 MANUSCRIPT

3.1 Contribution of the Student

As the primary author, I conducted qualitative coding and analysis of previously facilitated and transcribed focus group discussions conducted in an environmental scan of Georgia by Adrian King (thesis committee member). I then turned my findings and other literary research into a comprehensible thesis for the completion of my Master of Public Health degree. Dr. Robert A. Bednarczyk and Adrian King served as my thesis committee, providing constant support through edits and feedback.

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Background: Acceptance of adolescent vaccines, as measured by vaccine uptake, is generally high amongst caregivers. However, this does not routinely extend to HPV vaccines. In the state of Georgia, HPV vaccine coverage rates remain subpar; vaccine initiation 64.3% versus coverage 45.7%; particularly to other adolescent vaccines administered (i.e. Tdap 93.3%) (Walker et al., 2018). The purpose of this study was to identify and examine caregivers', motivators and barriers towards vaccinating their adolescent(s) against HPV in the state of Georgia.

Methods: Focus group discussions (n=9) with caregivers (n=75) were conducted throughout the state. Thematic analysis identified common motivators and barriers towards adolescent HPV vaccine uptake amongst caregivers.

Results: We identified motivators and barriers centralized around themes of healthcare provider relations and trust, presentation of HPV-related information, adolescent's physical sex, and an essential need to protect adolescents. Barriers presented include caregivers being unable to develop a trusting relationship with their healthcare provider, fear of perceived side effects, management of an overload of HPV-related information, inability to prioritize the HPV vaccination, and perceiving the vaccination to be for females. Motivators presented include caregivers' intrinsic need to protect their adolescent, shock-value HPV-vaccination marketing in commercials, and trusting their healthcare provider. Caregiver trust in their healthcare provider has been shown to ease perceived barriers in this study.

Conclusion: Trust in healthcare providers was found to be imperative to mitigating barriers and reinforced motivators to HPV vaccine acceptance and uptake. In improving patient-provider relationships throughout the state of Georgia, caregivers may become more receptive to vaccinating their adolescents against HPV, thus improving uptake and mitigating concerns causing hesitation to decide. Additionally, information and messaging must be streamlined across HPV vaccine educational sources and provided in layman's terms to avoid confusion of otherwise complex and technical detail. While all barriers and motivators are interconnected and posed nuances, trust in provider and clarity of HPV and HPV vaccine related information influenced many caregivers.

Keywords: HPV Vaccine, Human Papillomavirus Vaccine, adolescents, barriers, motivators, caregivers, Georgia

3.2 Background

Acceptance of adolescent vaccines, as measured by vaccine uptake, is generally high. However, this does not extend to HPV vaccines. In the state of Georgia, HPV vaccine coverage rates remain subpar; vaccine initiation 64.3% versus coverage 45.7%; particularly to other adolescent vaccines administered (i.e. Tdap 93.3% and MenACWY 95.3%) (Walker et al., 2018). Research has shown that barriers towards uptake are closely tied to caregiver perceptions of how high the risk is, cost, and a general distrust in the healthcare system (Newman et al., 2018; O'Leary et al., 2018; Yaqub et al., 2014). A lack of public knowledge and understanding regarding HPV vaccination allows for the persistence of these perceptions that there is more harm than good that may come from vaccination and a confusion as to who vaccination is for. Many of these barriers have been identified in various national and geographic specific studies, however none in Georgia. These studies found that contextual understanding of populations is key to understanding caregiver motivators and barriers towards HPV vaccination in their adolescents (Dennison et al., 2019; Kepka et al., 2018; Ko et al., 2014). Georgia has a vastly diverse population and requires state-specific research to properly identify motivators and barriers that impact Georgia residents.

3.3 Methodology

IRB approval

This study was reviewed and approved by the Emory University Institutional Review Board (eIRB).

Methods

The research team conducted 9 focus group discussions (FGDs) with parents of adolescents across the state of Georgia between April – July 2018. The research focused on understanding the motivators and barriers of HPV vaccination uptake from the perspective of parents of adolescents. The research team developed a semi-structured focus group guide, which was reviewed by the Winship Cancer Institute's Intervention Development, Dissemination Shared Resource. The same focus group discussion guide was used for all focus group discussions.

Participant Recruitment

The research team sought out and collaborated with immunization and regional cancer coalitions throughout the state of Georgia. Staff members from each coalition received approval from their organization to assist with the research project and in the recruitment of participants. The research team provided a recruitment flyer template, eligibility criteria, and potential FGD dates to each organization involved to assist with participant recruitment (i.e. distributing fliers in congregations, school parent associations, etc.).

Participant Eligibility Criteria

Participants eligible for this study included caregivers of at least one adolescent between the ages of 9 to 17 years old. For this study, a caregiver was defined as anyone in charge of the decision-making process of one or multiple adolescents' health (examples include grandparent, aunt, uncle, parent, etc.). Caregivers themselves must be at least 18 years of age and reside in the state of Georgia. Participation for the study

requires each caregiver to be able to read, speak, and understand the English language to be able to fully consent to participate in the focus group discussions.

Informed Consent Process

A consent form was provided for each participant and time was provided after for participants to read over the document and ask clarifying questions. The interviewer informed focus group participants that all responses would be kept confidential. Participants were informed that the FGD audio will be recorded, transcribed verbatim, and de-identified for analysis. The interviewer stated that FGD participants may terminate their consent at any time of the study and do not have to participate in any questions they are not comfortable discussing. Participants indicated their consent to participate through providing a signature on the informed consent form. Participants were compensated for their participation with a $30 gift card and thanked for their time.

Focus Group Facilitation

All FGDs were conducted face-to-face, each taking 1.5 hours on average to complete, at a predetermined private location and designated time as set by a participating organization staff member. The facilitator provided an overview of the purpose of the FGD and clarified any additional questions that participants had before facilitating the FGD. The research team was primarily interested in gathering data on the perceptions, views, and beliefs caregivers of adolescents have towards HPV and the HPV vaccine using questions such as “What do you know about the link between HPV and HPV-related cancers?” and “Have others given you information that changes the way you think or feel about the HPV vaccine?” . An activity was facilitated during the

FGD to encourage further discussion on caregiver motivators and barriers towards vaccinating adolescents against HPV and how influential each motivator or barrier is for them. Participants were thanked for their time and provided with the contact information of the research team and eIRB that they may utilize if they have any questions or concerns after the FGD.

Analysis

The research team transcribed all audio files verbatim and de-identified. All de-identified transcripts were stored in a limited access and password protected HIPPA compliant server. Transcripts were uploaded to MAXQDA 2018 for qualitative analysis. Data analysis was guided by grounded theory, focusing on the perceptions, views, and beliefs caregivers of adolescents have throughout the state of Georgia towards HPV and the HPV vaccine (Charmaz, 2006).

The research team developed a comprehensive codebook using a deductive approach, defining and illustrating patterns and common themes presented throughout the data. Thematic analysis, based on repetition of themes and presence of patterns, was employed to develop a more comprehensive understanding of the data. Using an inductive approach, further coding was conducted to capture any additional themes that emerged throughout the raw data. Inductive codes were added to the research team's codebook and coding was used to uncover common motivators and barriers until saturation was met.

3.4 Results

Introduction

The motivators and barriers found in this study were centralized around themes of healthcare provider relations and trust, presentation of HPV-related information, adolescent's physical sex, and an essential need to protect adolescents. Trust in healthcare providers persisted as a key factor to both HPV-vaccine acceptance and general vaccine confidence.

General Vaccine Confidence

Caregivers expressed a general belief that vaccines provide an overall benefit to their adolescents' wellbeing. A caregiver from Southeast Georgia shared, "…overall, I think they're healthy, and, all of my children have all of their shots." (FG8). Sentiments that this is a community effort were commonly expressed, noting the importance of herd immunity to protect all adolescents. A caregiver from South Georgia shared, "That's kind of mandatory I think if they are in school, certain ones. To make sure they can, to enroll and things like that. Besides HPV though. (Group laughter)." (FG9). However, this general trust in vaccinations seems to not extend to the HPV vaccination and opens the question as to what barriers influence this exception.

Barriers to HPV Vaccination Uptake in Adolescents

An Overload of HPV-Related Information

Sensitization to HPV related information resulted in caregivers responding in three different ways: to vaccinate against HPV, to choose not to vaccinate against HPV, or to not decide. Caregiver reaction to sensitization seemed to depend, in large part, on

the source of the information which the caregiver received information from and whether or not the caregiver trusted that source of information. A common issue presented by caregivers impeding their ability to determine what information was good information was that, while plenty information is available through many sources, information may be unclear or difficult to understand and could conflict with information previously presented.

Often times caregivers expressed that a majority of the information they had received on HPV, outside of healthcare facilities, came from television commercials or online. When caregivers were probed on the commercials that they had seen, the MERCK© commercial was homogenously identified by its quote "Did You Know?" Most caregivers involved in the research study recognized the "Did You Know?" commercial and believed that it had an impact on communal perceptions of HPV. Some caregivers reported the commercial as accusatory towards parents, playing on their emotions by placing them in a hypothetical situation of guilt for not vaccinating their adolescent. A caregiver from East Georgia said, "To me it felt like it was saying 'this is all your fault', you're the reason I have cancer, you're the reason I have whatever, it's your fault." (FG18). The use of scare tactics has resulted in caregivers basing some of their decision on HPV vaccination uptake on their perception of the commercial. The commercial was found to be "almost offensive" and dissuading many caregivers (FG12). A caregiver from Northwest Georgia said, "It's a real turnoff… I don't feel any positive wanting to take my child by that commercial." (FG12). When caregivers were asked how they would like information to be presented, many caregivers asked for more factual and truthful information.

Caregivers from Metro Atlanta and some from South Georgia, majority African American, expressed a homogenous distaste for the MERCK© commercial's methods of persuasion, finding it to be manipulative (FG 6, 8, 9, 17). A caregiver from South Georgia recalled, "All the ones I've seen have um Caucasian people in it. I haven't seen any African American." (FG9). Another noted, "The commercials are convincing though. Although I feel they don't resonate with my culture." (FG9). Some caregivers reported that they were motivated by the commercial, however did not see the African American community represented, posing concern as to who the HPV vaccine was truly meant for.

Often caregivers reported that there was information accessible to them, however this included a lot of misinformation that created confusion. Some caregivers went on to do their own research after being initially informed of the HPV vaccination. Caregivers listed social media, WebMD, and "Dr. Google" as the most commonly used tools for informal research. A caregiver from East Georgia said, "That's the problem though you can keep on looking until you find the answer that you want so how do you know what real, and what you want." (FG18). As caregivers discussed sifting through information, a caregiver from Southwest Georgia requested, "Layman's terms, not doctor's terms, yew. Mhm, don't want it to go over our heads. We'd miss it." (FG16). Caregivers unfamiliar with the medical terminology used and the presentation of research findings reported being confused as to what the main message was. Information in layman's terminology appropriate enough for adolescents to understand was often requested.

Fear of Perceived Side Effects of HPV Vaccination

Though HPV vaccination has been approved and recommended for adolescents since 2006, perceived "newness" of the vaccination causes hesitance to uptake. A

caregiver in Metro Atlanta said, “Cause um I was leaning towards no based on what I don’t think we’ve had enough years of the vaccine being around to know the long-term effect and that was my concern.” (FG8).

Alongside the perceived “newness” of the vaccination, concerns of vaccine safety and potential side effects were described as barriers to HPV vaccination uptake by caregivers. Caregivers explained that much of what they know about the HPV vaccination comes from anecdotal information from their family and peers, as opposed to medical advice from a healthcare provider. Some caregivers reported anecdotal information and stories of adolescents that did get the HPV vaccination and had debilitating reactions and side effects from the vaccine. A caregiver from Northwest Georgia recalled, “Cause there is actually a young lady from here, local, they didn’t believe in it or something and then and she went and got them [HPV vaccination] done without her parents knowing and she’s ended up being paralyzed from the waist down.” (FG12). Caregivers were aware that although expected side effects exist with any form of medical treatment, they were concerned that there has not been enough research done post-market to know the unexpected side effects of the vaccination.

Closely tied with the perceived newness of the vaccine, caregivers were hesitant towards uptake out of fear of debilitating and life-threatening side effects. Caregivers express a strong need to protect their child, part of which is to do no harm. Caregivers of adolescents with pre-existing health conditions, such as diabetes, food allergies, or some other “hidden issue,” expressed additional concerns on how the vaccination may affect their somewhat weakened immune system (FG17). A caregiver from Southeast Georgia said, “Because really the vaccine is not for everybody. Everybody can’t tolerate it in their

system" (FG13), adding to this fear that maybe the vaccine has unknown side effects that may interact with certain individuals differently than others.

Adolescent's Physical Sex

Sex of the adolescent seemed to create some difference in the perspectives of caregivers related to relative risk of HPV infection for their adolescent. As HPV vaccination was first recommended for female adolescents only, this continued belief pervades caregiver assumptions of who is at risk for HPV infection and who should be vaccinated. A female caregiver from Southeast Georgia said, "taking them to the doctor they don't put an emphasis on it [HPV vaccination] for boys." (FG13). Caregivers exhibited an apparent misunderstanding of why the HPV vaccination is recommended for boys as exhibited by continual emphasis on the connection between HPV and cervical cancer, but no male specific cancer (i.e. penile). Caregivers did, however, note that HPV related commercials (e.g. "Did you know?") which included male adolescents motivated them to question their provider on the benefits of HPV vaccination for their male children. Caregivers did express that the vaccination is largely focused on female adolescents, especially by providers, and thus furthers a narrative that males do not need the vaccination.

Prioritization of the HPV Vaccination

Some caregivers expressed that they didn't believe that their child was susceptible to the HPV virus due to the likelihood that their child is abstinent, a common expectation among caregivers in Georgia. A caregiver from East Georgia said, "if you refused the vaccine it was like 'not my kid, my kid isn't going to be doing that'." (FG18). Due to this, many caregivers likely misjudge their child's perceived risk of HPV.

A caregiver from Southeast Georgia reflected, "[F]rom 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." (FG13). Interestingly, other caregivers involved in FGDs explained that many young people and adolescents in their communities are involved in pre-marital sex and even explained that STDs and teenage pregnancy were an issue in many communities throughout the state. A caregiver from Southeast Georgia said, "Yes. And then another thing, sex is cool now [group agreement: mhm] … For kids, it's the thing to do, (group laughter) it really is, so it's probably more HPV… [cross talk] So it's cool and being pregnant now is just a thing you know, having a baby is just a thing." (FG13). Some caregivers in Southwest Georgia discussed;

"PARTICIPANT 2: I think they shouldn't be [having pre-marital sex] but I'm sure they are.

PARTICIPANT 1: Yeah, I know a 14-year-old just had a baby.

PARTICIPANT 3: I just went to a meeting at the high school and they're like we got 21 girls pregnant this year." (FG3).

Some caregivers noted that religion can impact their decision-making regarding HPV vaccine uptake. While caregivers discussed the expectation that adolescents practice abstinence, they also expressed that this idea was misguided and somewhat dated. A caregiver from East Georgia said, "You can't control, nowadays it doesn't matter. You can raise your child in a good Christian home… They're going to get rebellious, because it's that age." (FG18). A few caregivers reported that even if adolescents followed religious values such as waiting until marriage to have sex, they

still would not be protected from contracting HPV. One caregiver from East Georgia posed a potential scenario, "[T]his young lady who has done everything that she was supposed to do… has now married this man, but he happens to be carrying the HPV, which now gets transmitted to her. So, I think that's something we need to kinda throw on the table too." (FG18). Therefore, the caregiver posed that HPV promotion should solely be promoted as cancer prevention to remove the focus on HPV from a sexually transmitted disease to potentially cancer causing.

One caregiver from Northwest Georgia reported concerns regarding the makeup of the vaccination and concerns that it may not align with their religious beliefs. "I think maybe even the ingredients, because we don't do anything that's not kosher. So, if it's an un-kosher vaccine it's going to heavily influence our decision." (FG12). Few caregivers reported that religion took precedence over perceived health risks.

Adding to this perceived low risk of contracting HPV infection, school sex education courses lack appropriate focus on HPV resulting in caregivers, and adolescents, believing that the HPV virus is not a serious issue. School sex education courses place an emphasis on widely known viruses, neglecting to inform students of other viruses, prevention methods, and their importance. One caregiver from Southeast Georgia said, "Cause they think AIDS is the only thing that can kill you…. And the only thing worth worrying about." (FG13). Some caregivers also shared that a proper focus on the HPV vaccination may not be provided by healthcare providers at CDC recommended ages. A caregiver from Southeast Georgia recalled, "I remember, the doctor tellin' me, 'well this is something you have to look at, but it's not gonna be anything serious'… that's the mindset that I had, um and it was like 'well if I contract something well I guess

HPV is the best thing to get'" (FG13). In this study's findings, information and knowledge has not been presented as desired by caregivers, compromising perception of risk and prioritization of the HPV vaccine.

Caregivers also expressed the need to balance pressing matters (e.g., work, travel, extracurricular activities, etc.) with doctor appointments and vaccination decisions. A caregiver from Metro Atlanta noted, "I mean we're adults it's hard to stop, it's hard to get the appointment…now I got to get another appointment, what do you mean I have to take another day off." (FG6). Caregivers expressed a difficulty in stopping their responsibilities to their children to schedule and go to appointments for the series of shots. Some also elaborated that long work hours and household duties exhausted what time they have during the week. Caregivers explained that the necessity to bring the adolescent to two, potentially three, appointments for the HPV vaccine series puts a strain on their busy schedule and would prefer if the vaccination could be given during normal yearly check-ups.

Unable to Develop Trusting Relationship with Healthcare Provider

An apparent distrust in healthcare providers was articulated by many caregivers. Causes of limited trust in healthcare providers, and the healthcare system, varied from personal beliefs and values, to negative personal experiences with providers, alongside the influence of stigmatic racial undertones for some.

Some caregivers felt that discussion of vaccination with providers had become far too coercive and forceful which, in turn, dissuaded many from trusting the provider's opinions and recommendations. A caregiver in Northwest Georgia said, "I sometimes

feel like um, not with every physician, but with some physicians we've become numbers… And dollar signs." (FG12). Another caregiver from Northwest Georgia recounted, "[S]he said, to me, 'well I give it to my kids', and I said well that's fabulous but that's your choice, I don't want to get it… I finally looked at her and said if you really want to go there, we can cause were there, I'm not giving it but if you want to continue to discuss it, to which then she stopped. But it was a very pushy, you know, kind of," (FG12). Caregivers expressed a need to be heard and listened to in order to feel as though trust was built into their relationship with the healthcare provider. Most caregivers highlighted the importance of healthcare provider willingness to respectfully communicate and consider their opinions and values when discussing vaccination concerns.

Caregivers often reported that a poor or lacking relationship with their healthcare provider negatively impacted their likelihood to vaccinate for HPV. A caregiver from East Georgia noted that "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." (FG18). Some caregivers reported that patient-provider relations are not as strong as they used to be, severely impacting patient-provider communication.

Some caregivers reported that the poor patient to provider ratio available near their towns negatively impacted any chance of developing a trusting patient-provider relationship. A caregiver from East Georgia said, "they burned out, are they done, are they just going through the motions of the day or are they truly there, truly invested." (FG18). A group of caregivers in Southwest Georgia reported that it was difficult to keep

physicians in their region long-term because of the Physicians for Rural Areas Assistance Program (PRAA). This program is a loan forgiveness program, sending physicians to rural parts of Georgia to practice for a minimum requirement of one year and eligibility to renew for 3 more terms. A caregiver from Southwest Georgia said, "Normally they come down here [for maybe 5 years] to pay off their debts [medical student loan forgiveness program]. I mean they're good while they're here but- you can't blame them for doing that." (FG3). The caregivers from this region reported understanding why physicians participated in this program, however it disrupted chances of building long-standing relationships with physicians in the community.

Caregivers in rural parts of Georgia reported accessibility to trusted doctors to further strain their chances of building a long-standing relationship, due to distance ranging from 30 minutes to a 4-hour drive. A caregiver from Southwest Georgia elaborated, "You go to [town], and now there is one doctor, for almost everybody in that whole [town] a pediatrician, [she] is by herself… She is gone, gone to Atlanta." (FG3). Another caregiver from Southeast Georgia explained, "I used to go drive all the way to Atlanta just to be seen, so I just think you got to make sure that the doctor is up on what he says." (FG16). Some caregivers reported an uncertainty that they will be seen by a doctor, which was preferred, once they arrive at the clinic. A caregiver from Northwest Georgia said, "He [physician] was based in [city] and then has opened up I think 3 or 4 of them [clinics]. But after he started opening those my little brother never saw him again, like it was a nurse practitioner and a lot of moms don't like that, I don't, I like my daughter to see her doctor." (FG12).

The Tuskegee Syphilis experiment was reported by some caregivers from the Metro Atlanta area as a historical event that shaped a lot of African Americans' distrust in the healthcare system. One caregiver from this region explained, "And um, so yes that made me vary wary especially when something first comes out and they want to spread it everywhere and all of that. It makes me have a second thought because when they have done stuff like that in the past it was not totally honest." (FG8). The perceived newness of the HPV vaccine was worsened by the historical aftermath of the Tuskegee Syphilis experiment.

Some caregivers that did trust their healthcare provider reported it to be compromised due to a distrust in the healthcare system itself. A caregiver from Southeast Georgia reported that "they [pharmaceutical companies] just want to get that money… they are a shady mechanic like you can't really trust them." (FG16). Not all caregivers placed the blame on healthcare providers, but rather on the system itself. A caregiver in East Georgia explained, "I feel like doctors are slaves to insurance, I think the insurance has changed, I don't think the doctors have changed." (FG18). Another participant from East Georgia agreed, "Insurance dictates what doctors can and cannot do, they tell them what medicines to prescribe and that's insane." (FG18). Some caregivers identified that healthcare providers were subjected to the financial strains of the insurance system that prioritizes money over the patient. These caregivers reported that as well intentioned a doctor may be, they believed that the medication or treatment they receive was reflective and limited by their insurance coverage.

Motivators to HPV Vaccination Uptake in Adolescents

Protection for Adolescent

Caregivers reported that they highly prioritized doing everything in their power to protect their adolescent (FG 3, 6, 12, 13, 16, 17, 18). A caregiver from Northwest Georgia explained, "Parents will come in and say, 'well what do you think about this and what do you think about that?', and I'm like well if it's mine I'm still in that category where you vaccinate. I mean I'm just that type of mama, I'm gunna, do whatever I can do to shield my child from getting whatever is out there." (FG12). Many caregivers expressed an essential need to protect their adolescents, and most caregivers saw the desire to protect as a motivator to vaccinating their adolescents. Some caregivers, even without full knowledge of the vaccination, reported placing their faith in the recommendations of healthcare providers and established health institutions like the Centers for Disease Control and Prevention. Some still expressed concerns with the vaccination, however, were more concerned with what would happen to their adolescent if they did not vaccinate them. A couple caregivers from Metro Atlanta discussed, "PARTICIPANT 4: I just finally gave in with [Real Name] because because I was wanting to rather be safe than sorry for her. I don't know if that's the right decision or not.
PARTICIPANT 1: Yeah, I think it's better safe than sorry.
PARTICIPANT 4: Right. And now I have a son and I'm like, yeah you know, I don't know if I'm, but I probably will cause I'd rather be safe than sorry." (FG6).

Some caregivers reported being motivated by concerns of unvaccinated adolescents infecting their adolescent. A caregiver from Southeast Georgia stated, "Another motivator is, for me, is the fact that other parents don't immunize their

children and my child coming into contact with them and it exploding into something totally worse. I'm not saying that my choice should be anybody else choice, but for me I want to be safe if I can rather than to be sorry." (FG16). Caregivers from Metro Atlanta discussed topics related to herd immunity and social responsibility to vaccinate; "Participant 3: socially responsible… because uh if we could eradicate for everybody you don't want to be the one out there that…

Participant 5: That caused it. Like a lot of kids out there, a couple of kids who died, you know, they were exposed to a child who didn't have it…. I like to think community concern." (FG17).

Ultimately, caregivers felt it was a responsibility of theirs to protect their child as best as they could from all potential dangers. One caregiver explained that attaining HPV vaccination would protect against HPV transmission during sexual activity, including potentially nonconsensual activity. The caregiver from Metro Atlanta elaborated, "And that we were also motivated that it might not be um that if sexually, if some sexual encounter happened… that it could be rape, so just knowing that that could possibly prevent something [HPV infection] based from another person." (FG8). Caregivers expressed a fear of uncontrollable things that may happen to their adolescents and a desire to mitigate the damage as much as possible. A caregiver from South Georgia shared, "But you know the reality is that, you know if I can prevent her even if she chooses to you know engage in unprotected sex you know that if I can keep her from that [HPV infection] until her head comes on straight, you know." (FG9). In all FGDs, most caregivers expressed a desire to protect their adolescent as the strongest commonly held sentiment towards HPV vaccination of their adolescents. HPV vaccine

uptake, as decided by the caregiver, provides protection against the virus which could be introduced through non-consensual means.

MERCK© Commercial

The MERCK© commercial was found to be a motivator for some caregivers who felt that it was a "wake-up call" to vaccinate their adolescents. A caregiver from Southeast Georgia shared, "More information on them [newer commercials] than the previous ones. And more um mind triggering because you have the kids showing back in life to where if you would have when I was 6 versus I'm 20 and I ain't going to be here much longer because I now I got cancer." (FG16). Although scare tactics were deemed not particularly useful among some caregivers, others were encouraged to investigate the vaccine and other HPV-related information. These caregivers reported that the "Did You Know?" commercial was a motivator to conduct their own HPV research and ultimately choose to vaccinate their adolescents. A caregiver from Southeast Georgia said, "I think those commercials have done a lot to educate the public… done a lot to help and education…. The commercials make you go ask, they'll make you ask the questions." (FG13). Another caregiver said, "The commercials are always good motivators… To get it." (FG13). Some caregivers also identified the "Did You Know?" commercial as the cause for them choosing to vaccinate their male adolescent(s), after not knowing that the vaccination is now recommended for male adolescents. One caregiver from Southeast Georgia shared, "Cause you don't hear people talk about it, open as much about boys, well never, until I saw that commercial, I was like… a boy?" (FG13).

Trust in Healthcare Provider

Most often, trust in healthcare providers was reported by caregivers as being correlated with long-standing patient and community relations and good communication skills. Without trust in providers, many caregivers reported rejecting or being wary of the HPV vaccine. A caregiver from East Georgia elaborated, "you have to have faith in your physician, if they're recommending something for your child you have to trust that it's in your child's best interest." (FG18). For many caregivers, trust in provider recommendation was dependent on the longevity of their patient–provider relationship. A caregiver in Southeast Georgia said, "Well me personally all my daughters have had the same pediatrician for the last 24 years, I make sure that the person, the doctor I chose I wanna stick with. So that way they know everything, the history, that they're familiar with my babies… you have to actually grow to know each other" (FG16). The reputation of doctors in a community was also imperative to a caregivers' trust level in their healthcare provider. Some caregivers discussed talking about their providers with friends and community members; "Um doctors. Well same thing to me, I mean, I sure talk to a lot more friends than I talk to my doctor once a year, I talk to my friends every day." (FG18). Long-standing personal and community relationships with providers were reported as equally important and intertwined to motivate uptake.

This developed trust created greater reported acceptance of healthcare provider recommendations to vaccine uptake. A caregiver in Southeast Georgia recalled, "my doctor said 'you know um, they need to take this vaccine,'… he had to explain to me what it was for and I was like, 'ok, you know, you know what's best.'" (FG13). Patient-

Provider communication was also described as being integral in the development of trust. A caregiver in East Georgia elaborated, “trusting my doctor is [dependent on] 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.” (FG18).

3.5 Discussion

Introduction

The analysis of the motivators and barriers affecting caregiver’s decision to vaccinate their adolescent against HPV found that trust in the healthcare provider eased many of the reported barriers. Caregivers’ had an intrinsic need to protect their adolescent, motivating vaccination, however, became hesitant when encountering information about adverse events, contradicting sources, and aggressive provider recommendations. Additionally, representation in commercials and marketing impacted perceptions of who the vaccine was for. All motivators and barriers found are interconnected and many act as nuances impacting caregiver perceptions of HPV vaccination and can be used to inform efforts to improve HPV vaccine confidence and buy-in.

General Vaccine Confidence

Although general confidence in vaccines exists amongst participants of this study, a longstanding relationship between regularly administered adolescent vaccinations (i.e. Tdap, meningococcal, etc.) and vaccine mandates proved to be an underlying motivator as has been shown in previous research (R. A. Bednarczyk, King, Lahijani, & Omer, 2019). General confidence in GDPH mandated vaccinations seems not to apply to the non-mandated, although recommended by the state, HPV vaccination due to its

perceived “newness” as well as the negative connotation and connection participants have with the HPV vaccine as sex-permitting or encouraging for adolescents (Georgia Department of Public Health, 2019). Each of these seemed to create a barrier between HPV vaccination and its inclusion under the umbrella of generally trusted, or mandated, vaccinations.

Barriers to HPV Vaccination Uptake in Adolescents

An Overload of HPV-Related Information

In line with what caregivers shared during FGDs, information about HPV and HPV vaccination is plentiful and available on various platforms. The internet, in particular, provides access to a wide variety of websites and groups promoting one side or another. It is likely that some caregivers hold a bias that guides them towards a particular set of information which aligns and supports their beliefs; not necessarily aligning with what may be factual. Biased preferences towards certain sources of information may be guided by preconceived beliefs or because the caregiver has found a resource or organization they resonate with.

Caregivers following persuasive but not reliable sources may weaken caregivers’ ability to decide regarding HPV vaccine uptake or put them in a standstill. This is a result of there being an overwhelming amount of marketed information which may cloud caregiver judgement from fact. If caregivers struggle to differentiate between factual and non-factual sources, it complicates public health initiatives to improve uptake. Being more receptive to non-factual sources was linked to a limited trust level in provider recommendations and finding more representative sources based on caregivers’ race, religion, and/or general beliefs.

The lack of representation of African Americans in the MERCK© commercial "Did You Know?" led to further questions of data on how HPV affects various racial groups of people. African Americans are frequently unrepresented in research studies, often stemming from a lack of trust that has been generationally passed down regarding the Tuskegee Syphilis Study. The lack of representation connects with a lack of perceived risk as caregivers see mostly Caucasian children represented in these commercials.

HPV vaccination uptake faces increasing barriers as caregiver concerns and questions go unanswered. A caregiver in the study reported being concerned with the ingredients of the vaccine and if it upheld with their religious beliefs (i.e. whether or not it was Kosher). Although this was not discussed frequently in the study, literature backs this barrier to vaccine uptake, particularly amongst immigrant populations (Grabenstein, 2013; Ko et al., 2018; Pelcic et al., 2016). Certain religious practices strictly prohibit vaccinations, and any form of medical treatment, due to the belief that any illness is the work of God (i.e. fatalism) (Ko et al., 2018; Vanderpool et al., 2015). Religious beliefs to HPV vaccine uptake have not yet been addressed thoroughly in current vaccine marketing strategy, leaving caregivers with a significant gap of information that could improve HPV vaccine coverage (Grabenstein, 2013). This once again ties to the lack of information on the HPV vaccine being widely shared and understood.

Factual information regarding HPV vaccine will need to be better streamlined, address different sub-groups (i.e. racial and religious), ensure transparency of the benefits and adverse events of vaccination, and introduced earlier in adolescents'

primary care appointments. Earlier presentation (i.e. at or before the CDC recommended ages 9-10) of HPV information may allow providers more time to address caregiver concerns and build a longer timeline of HPV discussion amongst providers in general if caregivers are to switch providers (Centers for Disease Control and Prevention, 2018d). Many caregivers reported not receiving HPV vaccination recommendations from their provider until their adolescent was around 13 or 14 years old, well into pubescent years in which may promote negative connotations of the vaccine as sex-permitting. By providing HPV vaccination information and recommendations alongside childhood vaccines, caregivers may be able to focus on the HPV vaccination as a health benefit and providers may have more time to encourage uptake.

Fear of Perceived Side Effects of HPV Vaccination

The results of this study showed that most caregivers were concerned of the possible side effects and adverse reactions that may occur if they vaccinate their adolescent against HPV. This was due, in large part, to the vaccine's perceived "newness" and the caregiver not having information on the vaccination. This was further exacerbated amongst individuals reporting higher levels of distrust towards the healthcare system.

Some caregivers relied on community knowledge and anecdotal information to bridge the gap between medical information and trusted sources. Ultimately, this led to participants placing anecdotal information of HPV vaccination side effects and adverse reactions over what has been researched (Centers for Disease Control and Prevention, 2013; Schiller, Castellsague, & Garland, 2012; Van Damme et al., 2015). Anecdotal

stories reported in the study included extreme adverse effects, such as paralysis, that concerned caregivers as to what "hidden issues" their adolescent may have and create complications when vaccinated. The fear of "hidden issues," allergies, diabetes, unknown immunocompromised state, and other possible issues in adolescents further intensified concerns of what iatrogenic adverse effects may result from HPV vaccination.

Many caregivers expressed an interest in knowing more about post-market research findings on adverse events, despite marketed information already existing as to why adolescents should get vaccinated against HPV. Additionally, many caregivers of diverse ethnic and cultural backgrounds reported an interest in seeing HPV and HPV vaccine related information stratified by sub-groups. These fears of unknown side effects can be mitigated with a more holistic approach to addressing perceived risk. Without the rapid public access to these pieces of information, reliance on caregiver trust in provider recommendations is imperative to HPV vaccine acceptance and uptake.

Most caregivers reported a strong determination to protect their child, which usually meant vaccinating although they may not have all the information desired. Despite this determination, concerns of potential side effects and adverse reactions persist as a barrier. Caregivers vaccinating although not fully informed may be more prone to vacillating on this decision as vaccine safety concerns or issues arise in the media or their community (Gust et al., 2005). Thus, fear of HPV vaccination surpasses fears of HPV infection, stemming from several root beliefs aforementioned. Most commonly, a distrust in the healthcare system and provider recommendations pushes caregivers to believe in outside sources, exacerbating hesitation towards uptake.

Caregivers that remain hesitant to take a firm stance on HPV vaccination may be described as being torn between the fears that they will vaccinate, resulting in a potential side effect or adverse event and fears that they will not vaccinate and their adolescent gets infected or a HPV-related disease (i.e. sins of commission versus sins of omission) (Asch et al., 1994; Hayward, Asch, Hogan, Hofer, & Kerr, 2005). Omission bias has been reported as an influencer on decisions not to vaccinate, showing that caregivers were more fearful of the vaccine itself than potential diseases (Asch et al., 1994). The MERCK© commercial was reported to use the angle of the sins of omission to persuade caregivers to vaccinate their adolescent. Many caregivers reported being unsure of the risks and benefits to vaccinating their adolescent, despite reported statistics, thus fearing both sins of commission and sins of omission.

Adolescent's Physical Sex

There was a disparity in perceived risk between female and male adolescents reported amongst caregivers. HPV vaccine was heavily marketed towards females, even after males were included in vaccine recommendations. This bias has feminized the vaccine, placing the burden on adolescent females and promoting a misconception that HPV only impacts females. Caregivers may find limited or underestimated statistics on HPV infections in males, thus potentially perpetuating the misunderstanding that males are not at risk or at as high of a risk as females. While males are not tested for HPV, they are still at risk and may not be aware of an HPV infection unless it persists and develops into genital warts or an HPV-related cancer within themselves or a partner. It is just as important for males as it is for females to be vaccinated against HPV in efforts to protect themselves and all current and/or future partners against HPV infection.

National HPV vaccine coverage estimates have been increasingly closing the gap in vaccine initiation and coverage between male and female adolescents [Initiation: 62.6% (m) and 68.6% (f); Coverage: 44.3% (m) and 53.1%(f)] (Walker et al., 2018). This is reflective in Georgia state-specific HPV vaccine coverage estimates, although coverage remains generally low [Initiation: 52.6% (m) and 65.5% (f); Coverage: 19.4% (m) and 21.7% (f)] (Machado, Thomas, Drenzek, & Lovett, 2018). Despite these coverage rates, disparities in perceptions of who needs to be vaccinated persist.

The disparity between the physical sexes may be further exacerbated by the lack of knowledge of what HPV-related cancers males are at risk of. Penile (1,269 cases per year), anal (2,197 cases per year), and oropharyngeal (14,814 cases per year) cancers are all HPV-related cancers males are at risk for (Centers for Disease Control and Prevention, 2018a). Males are most commonly at risk for oropharyngeal cancer, making up 81.3% of cases (Centers for Disease Control and Prevention, 2018a). HPV vaccines are not licensed for prevention of oropharyngeal cancers, presenting a marketing and messaging problem, further allowing for the feminization of the vaccine. Although it may be biologically inferred that HPV vaccination may prevent oropharyngeal cancers linked to HPV, there is no clinical trial data to back this assumption (Guo, Eisele, & Fakhry, 2016; National Cancer Institute, 2017).

Even after the inclusion of male adolescents in vaccination, it wasn't until years later that the MERCK© commercials began to represent males in their "Did You Know?" advertisements (Merck Sharp & Dohme Corp, 2016). For some caregivers, being involved in the focus group discussion was the first time they realized that HPV could impact their male adolescents as well.

Prioritization of HPV Vaccination

Reports show higher initial uptakes for HPV vaccine series initiation than HPV vaccine completion among adolescents (Walker et al., 2018; Widdice et al., 2018). This results from a number of different causes, however a common sentiment among caregivers was the difficulty associated with scheduling various vaccination appointments and follow-ups. As noted in the results section, caregivers reported their responsibility to ensure their children attend various after-school or extracurricular activities alongside balancing their own personal and business lives. This scheduling and management of responsibilities was said to create significant issue for getting the adolescent fully vaccinated against HPV due to the necessity of 2-3 doses per adolescent.

Caregivers intend to protect their adolescent; however, a lack of perceived risk to their adolescent may reduce their prioritization of HPV vaccination. Caregivers are constantly fed with external information on what they should be doing for their adolescent and it is ultimately their judgement call. As many caregivers reported, the belief related to HPV infection was that it is only transmitted through sexual activity, however nearly all caregivers reported that their adolescents were not, and would not be, having sex any time soon, thus risk of HPV infection was perceived as low. If they do not perceive the HPV vaccination as important during the regularly recommended ages (i.e. 11-12 years old), other routine vaccinations and health needs may take precedence. Early HPV vaccination is important to its efficacy as the immune system is most receptive earlier in adolescence and has been consistently proven to not increase sexual activity amongst adolescents (R. Bednarczyk, Davis, Ault, Orenstein, & Omer, 2012; Robert A. Bednarczyk, 2015; Smith, Kaufman, Strumpf, & Levesque, 2015).

Additionally, results found that distance to a trusted provider and scheduling an appointment with said trusted providers posed as a challenge. If there isn't a strong enough feeling that their adolescent is at risk and there are more pressing matters, HPV vaccination is not prioritized.

Unable to Develop Trusting Relationship with Healthcare Provider

Previous research has shown that a strong healthcare provider recommendation for HPV vaccination is critical to vaccination uptake (Brewer & Fazekas, 2007; Brown et al., 2017; Reiter et al., 2009). In our study, an inability to develop a trusting patient-provider relationship was regularly and thematically reported throughout FGDs. This inability to develop a strong relationship with a provider was reportedly caused by a number of issues. Caregivers reported perceiving some providers as aggressive, especially during vaccination appointments. Caregivers also reported that their provider was rash or that the appointment felt rushed and that they weren't able to ask questions or have their concerns heard. Some participants also reported that some providers lack a positive reputation in the community and that a general distrust in the healthcare system itself created issues in developing a strong relationship.

Providers were reported as rash and aggressive in their recommendations by some caregivers, which may stem from a movement towards presumptive communication and the "announcement" approach for HPV vaccine recommendations (Brewer et al., 2017). The "announcement" approach was not received well by caregivers, contradicting past qualitative studies reporting a positive reaction and increase in HPV vaccine uptake (Dempsey, Pyrzanowski, Campagna, Lockhart, & O'Leary, 2019; Malo, Hall, Brewer, Lathren, & Gilkey, 2018; Reno et al., 2018). Some

caregivers responded that these methods strayed them away from developing any trust with that provider. While caregivers recognize the important role of providers, many strongly believed that it was ultimately their decision and aggressive methods may be perceived as providers trying to take control of their choice without any genuine regard for what is in the adolescent's best interest. This may be tied with general lack of trust expressed in the healthcare system, which is guided by the commonly held belief that profit is prioritized over patients. Caregivers were often concerned by the HPV vaccination and healthcare providers intrinsic support of it, which may seem like the provider works with and in favor of pharmaceutical companies. Sentiments that the whole healthcare system is money driven exacerbates distrust in the system and causes concerned caregivers to question their provider's intentions if significant trust has not been previously developed.

Caregivers and providers must believe HPV vaccination is important in order for vaccine recommendations to work. There are several opportunities to target and explain the importance of HPV vaccination to adolescents and their caregivers. One mentioned was school health education lessons. Results showed that current health education courses in schools lacked in breadth of information provided to adolescents and caregivers. HPV-related information is not promoted as seriously by schools nor healthcare providers according to some caregivers, compromising caregiver perception of the adolescent's risk. School health education courses may be biased by the state's religious-political beliefs that subvert some aspects of life, thus skewing course lessons towards the promotion of abstinence until marriage rather than a comprehensive education covering the realities of adolescent risk to HPV. The lack of prior HPV

education exacerbates the perception that HPV vaccination is "new" and misconceptions that because they were not as aggressively informed about it as other STIs throughout their life it is not as immediate of a threat.

In the results, we found that most caregivers perceived HPV vaccination as a "new" vaccination pushed by healthcare providers. The CDC guideline states that while HPV vaccination is recommended to be administered starting at the age of 11 years old, healthcare providers are recommended to begin discussing HPV vaccination with caregivers when their adolescents reach age 9 (Centers for Disease Control and Prevention, 2018d; Khatib, 2015). Caregivers do not receive this information until their adolescents was 13 or older, thus posing questions fueling suspicions towards the healthcare system (i.e. why they haven't been informed sooner and why vaccinate so late outside of the proximity of regularly administered adolescent vaccines).

These questions of the vaccine parallels with the Tuskegee Syphilis experiment and the lack of information targeted at African American population. Some African American participants noted that the "Did You Know?" commercials were dominated by Caucasian children, giving little motivation to vaccinate their own when promoted visually as such. The lack of representation posed the question as to who the vaccination is for and if not for them, why would they adhere to provider recommendations. The implications and continued effects of the Tuskegee Syphilis experiment have strayed many African Americans from "new" medical treatments and prevention methods as a whole, creating a generational fear that they will be used as lab rats for a study. The historical harm the healthcare system has inflicted on African American communities and lack of representation in mass-population health promoting measures have

impacted African American caregiver hesitation towards provider recommendations, trying to understand if the vaccine truly applies to them. The perceived "newness" of the vaccine further promotes perceptions that they are being used as lab rats, as shown historically.

Motivators to HPV Vaccination Uptake in Adolescents

Protection for Adolescent

The findings showed that caregivers were motivated by the fear of the sins of omission, expressing a common sentiment that they'd rather be safe than sorry as it related to HPV vaccination. In many cases this meant putting their trust in their healthcare provider, particularly when they may not feel as though they themselves have all the information. Many caregivers were generally motivated by an intrinsic parental need to protect their adolescent and further driven by concerns against unvaccinated adolescents that could hurt their adolescent.

Abstinence until marriage was expressed as a virtue that adolescents practiced by few caregivers and wishful thinking by many caregivers. Yet, many caregivers acknowledged the high teen pregnancy and STI rates in their region as an indication that adolescents, possibly their own, were not adhering to abstinence nor safe sex practices. Thus, many caregivers recognized that faith in abstinence alone would not protect their adolescent and that HPV vaccination protects adolescents against others that have not been vaccinated. Thus, above all else, caregivers' health decisions towards uptake are motivated by a preference to vaccinate for protection of the adolescent.

Caregivers have limited control over what happens to their adolescent and HPV transmission is a non-exclusive infection. Married couples can transmit HPV to one another. Additionally, there is the bitter reality that some may be coerced into nonconsensual sexual activity that may also infect them with HPV. Thus, caregivers may be, although still unsure, willing to vaccinate their adolescents out of fears regarding events outside of their control and guidance. However, based on the barriers presented, they may be persuaded out of it by fears of harming their adolescent in an effort to protect them just because they themselves did not do the full research. This may imply that caregivers need to have external fears mitigated in order for uptake to improve.

Caregivers recognized that they cannot shield their adolescent from all the risks in the world and therefore strongly considered preventative measures. Ultimately, caregivers reported higher concern that if they do nothing, something preventable may severely harm their adolescent later in life. This motivator emerged from a greater fear of the sins of omission than the sins of commission. The decision-making process, in large part, is pushed by an aggressive parental need to protect their adolescent.

MERCK© Commercial

Many caregivers reported being shocked, few feeling offended, by the "Did You Know?" commercial yet motivated by the information provided. The shock value of the commercial grabbed the attention of the target audience, pulling on emotional strings. Few caregivers found the commercial offensive and reported feeling attacked and guilted for their health-decisions regarding their adolescent. Playing up the sins of omission, whether it be HPV vaccine uptake in general, or between the physical sexes of the adolescents, caregivers saw the potential severity of not vaccinating their adolescent

through the commercial. This may be more relevant to caregivers that are initially unaware of HPV or HPV vaccination or some element of the infections. For example, caregivers unaware of the effect of HPV on boys saw the "Did You Know?" commercial impacting a boy and his lifespan after not being vaccinated as educational and motivating to vaccinate their male adolescents. Representation plays an imperative role in commercials and public advocacy initiatives. There is a connection between caregivers seeing themselves or their adolescents represented and their perceived risk as the imagery creates a visual representation of what could happen to them, decreasing the abstractness of information (Ball, Liang, & Lee, 2009; Kline, 2006; Krakow & Rogers, 2016; Marlow, Wardle, Forster, & Waller, 2009; Primack, Bui, & Fertman, 2007). African American caregivers reported that if they had known HPV vaccination protects their adolescent as well as those represented in the MERCK© commercial, they would be motivated to vaccinate.

Trust in Healthcare Provider

The trust between caregiver and provider motivates caregivers to follow their provider's recommendation regarding vaccine uptake (Dilley, Peral, Straughn Jr., & Scarinci, 2018; Gamble, Klosky, Parra, & Randolph, 2010; Nan et al., 2018). With trust comes an understanding that their provider has the adolescents' best interest at heart. This is particularly important as it combats the expressed belief that the healthcare system just wants a profit. This trust was expressed by caregivers as being developed over a long-standing relationship built with their healthcare provider; at times developed generationally. Some caregivers described their decision-making process with trusted healthcare providers as smooth, being supported by a transparent and at times

very brief conversation on why vaccine uptake was needed. With increased trust and longevity of patient-provider relationship, caregivers may feel more at ease and more willing to follow provider recommendations with less concerns of side effects because of an increased trust that the provider knows and has taken a holistic look at their adolescent's health and knows what would be most beneficial. Concerns of "hidden issues" in their adolescents are eased by the belief that this is not just a rash and general recommendation, but rather a catered recommendation to that specific adolescent given the information known. The prioritization of HPV vaccination is thus simplified as much of the decision-making process is placed on the provider's recommendation, easing some of the workload of caregivers.

3.6 Limitations

As with any research, limitations were identified within our own research project. Due to a lack of prior research studies completed that identify Georgia caregivers' perceptions and attitudes towards the HPV vaccine series, there wasn't contextual support. Recruitment methods utilized by the research study may have allowed for increased selection bias as recruitment was completed through the assistance of regional cancer and immunization coalitions who recruited through their respective networks. For future research, greater participant diversity would be sought to increase understanding of barriers and motivators amongst more diverse populations. Future research studies would also need to attempt to increase participation of male participants as our recruitment efforts resulted in a majority of female caregiver participants. Greater understanding of the many motivators and barriers amongst caregivers could be reached by conducting research in multiple other languages (e.g.

Spanish, Korean, etc.) in order to include considerably more diverse populations. Due to the nature of qualitative research, our findings are not generalizable to other states, however the research and findings do provide sound footing for other states to conduct similar research project to identify specific motivators and barriers to HPV vaccination among caregivers in each respective state.

3.7 Conclusions

Caregivers' trust in healthcare providers and the healthcare system were the overarching factor interacting with both motivators and barriers, impacting caregiver's health decision making process. Distrust in healthcare providers and the healthcare system creates a barrier and limitation to provider recommendations and HPV vaccine messaging, leaving caregivers to search for other sources of information. In this search, non-factual, anti-vaccination, or anecdotal sources exacerbate a distrust in provider recommendations and distrust towards the true risk-benefit of vaccine uptake. A trusting and communicative patient-provider relationship mitigates many of these barriers, allowing caregivers to place more value in provider recommendations, thus improving caregiver acceptance and uptake of HPV vaccination. This alone does not ensure caregiver buy-in to HPV vaccination, requiring barriers to continue to be addressed while improving trust levels in providers and their recommendations. Along with mitigating barriers, trust reinforces motivators. Information and caregiver knowledge have been proven to play an interacting role with trust levels particularly amongst caregivers hesitant towards uptake. The consistency and uniformity of factual HPV and HPV vaccine related information may promote trust in healthcare providers, reinforcing provider recommendations.

There should be an emphasis of HPV vaccination as a cancer-preventative measure to remove some of the stigma associated with HPV and promote understanding that while HPV may clear up on its own, it may cause the development of HPV-associated cancers. These recommendations should be introduced by healthcare providers in earlier (e.g. at or before age 9) primary care visits to prepare caregivers and address their concerns long before the recommended age to vaccinate, building a repertoire over time. Areas to further target improved understanding of HPV vaccine importance include school health education courses, public service announcements, and informative pamphlets in concise layman's language for both caregivers and adolescents. Inclusion of various underrepresented groups in Georgia (i.e. males, African Americans, religious communities) need to be addressed in public health initiatives to improve uptake and further researched to promote the inclusivity of HPV vaccination. As post-licensure research continues, transparency of HPV vaccination benefits and adverse effects should be provided in layman's terms for caregivers, allowing them to feel confident in making their own decision based on updated facts. It is particularly important to share stratified data on HPV vaccination efficacy and safety amongst sub-populations in Georgia.

It is important that future public health initiatives ease aggressive tactics and develop trust within communities to improve uptake. If caregiver trust is not placed in healthcare providers, provider recommendations will fail to other sources of information. This may develop a double burden in developing trust in providers and combating false information presented. Redirecting caregivers' trust to provider recommendations may mitigate most barriers presented in this study's findings. By

addressing the various factors and nuances posing as a challenge to building caregiver trust in healthcare providers, public health initiatives may be able to mitigate barriers presented in this study and potentially improve HPV vaccine uptake in adolescents.

4.0 PUBLIC HEALTH IMPLICATIONS

Public health still has work to do to improve caregiver perceptions towards HPV vaccine uptake amongst adolescents, and thus increase adolescent HPV vaccine uptake. Caregivers are key to improving adolescent health and their understanding of who HPV vaccination is designed for may eliminate some vaccine hesitation. One potential method to do so is to update guidelines to ensure that providers begin to inform caregivers of HPV vaccination around the same time as other vaccines administered earlier in adolescence. This way caregivers may have more time to reach acceptance and ease any concerns well before the ideal age of uptake, thus increasing the coverage and efficacy of HPV vaccination. Developing trust between caregivers and providers is imperative systematically to healthcare. HPV vaccination has been heavily stigmatized and requires a concerted effort to mitigate stigma and increase perceived risk.

By addressing the barriers and utilizing the motivators presented in this study, we may be able to increase caregivers trust in the HPV vaccine, the vaccination system, and the healthcare providers who give the vaccines. This is particularly important to establish amongst marginalized groups (i.e. African Americans and immigrants), thus making it imperative that future public health interventions work to address gaps in transparency and historically inflicted distrust in the healthcare system. With so many competing sources of information, trust in the healthcare system allows for a streamline of factual information to occur directly from provider to patient.

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APPENDIX

Appendix I: eIRB

TO: Robert Bednarczyk, PhD
Principal Investigator
*SPH: Global Health

DATE: November 15, 2017

RE: **Expedited Approval**
IRB00100271
Environmental Scan of HPV Vaccination in the State of Georgia

Thank you for submitting a new application for this protocol. This research is eligible for expedited review under 45 CFR.46.110 and/or 21 CFR 56.110 because it poses minimal risk and fits regulatory category F7 as set forth in the Federal Register. The Emory IRB reviewed it by expedited process on 11/13/2017 and granted approval effective from **11/13/2017** through **11/12/2018**. Thereafter, continuation of human subjects research activities requires the submission of a renewal application, which must be reviewed and approved by the IRB prior to the expiration date noted above.

The Emory IRB hereby grants a waiver of documentation of consent for online provision of consent.

The following documents are approved for use or otherwise acknowledged:

- Study Protocol, version date October 23, 2017
- NCI Grant Application 3P30CA138292-09S2
- HPV Environmental Scan Qualtrics survey instrument, undated
- Qualtrics Recruitment Script

Any reportable events (e.g., unanticipated problems involving risk to subjects or others, noncompliance, breaches of confidentiality, HIPAA violations, protocol deviations) must be reported to the IRB according to our Policies & Procedures at www.irb.emory.edu, immediately, promptly, or periodically. Be sure to check the reporting guidance and contact us if you have questions. Terms and conditions of sponsors, if any, also apply to reporting.

Before implementing any change to this protocol (including but not limited to sample size, informed consent, study design, you must submit an amendment request and secure IRB approval.

In future correspondence about this matter, please refer to the IRB file ID, name of the Principal Investigator, and study title. Thank you.

Sincerely,

Samuel Roberts
Senior Research Protocol Analyst
This letter has been digitally signed

Emory University
1599 Clifton Road, 5th Floor - Atlanta, Georgia 30322
Tel: 404.712.0720 - Fax: 404.727.1358 - Email: irb@emory.edu - Web: http://www.irb.emory.edu/
An equal opportunity, affirmative action university

Appendix II: Consent Form

Emory University

Consent to be a Research Subject

Title: Environmental Scan for HPV Vaccination in the State of Georgia – Focus Group Discussions

Principal Investigator: Robert A. Bednarczyk, PhD
Hubert Department of Global Health
Rollins School of Public Health, Emory University

Funding Source: National Cancer Institute (grant 3P30CA138292-09S2)

If you are the legal guardian of a child who is being asked to participate, the term "you" used in this consent refers to your child.

Introduction

You are being asked to be in a research study. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. You can skip any questions that you do not wish to answer.**

Before making your decision:

- Please carefully read this form or have it read to you.
- Please ask questions about anything that is not clear.

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. By signing this form you will not give up any legal rights.

Study Overview

The purpose of this study is to collect in-depth information on beliefs, perceptions, and opinions about HPV, HPV Vaccine, and HPV-related cancers in the state of Georgia. We will use this information to develop future tools, interventions, targeted messaging, and health programs related to preventing HPV infection and HPV-related cancers. We plan to conduct focus group discussions with various populations throughout Georgia. We intend to conduct focus group discussions with leaders in HPV education, vaccine promotion, and research. We also intend to conduct focus group discussions with community leaders, parents, medical professionals, religious leaders, and various other individuals throughout the state of Georgia. We will conduct focus group discussion in all regions of Georgia.

Procedures

If you agree to participate in this research study, we will invite you to join a focus group discussion at a set time and location which are convenient to all focus group participants. The focus group will discuss

HPV-related issues and we encourage your participation and inclusion of your opinions/views. The focus group will last no more than 2 hours. The focus group will be audio-recorded and manually transcribed. After transcriptions are verified to be complete and accurate, we will delete the audio files, and interview transcripts will use a study number rather than your name.

Risks and Discomforts

The risks to you for being in this study are minimal. There is always a small chance that confidentiality will be breached. We will make every effort to guarantee that all conversations are kept secure and confidential. We will conduct the focus group in a private location and all study-related materials will be stored on password-protected computers only the study team can access. If there is a loss of confidentiality, we will work with Emory officials to inform all participants and we will take steps to correct the situation. Additionally, some of the research questions about your personal experiences and opinions may make you uncomfortable. You can refuse to answer any questions.

Benefits

The study is not designed to benefit you directly. The reason we are doing this study is to learn more about community views and perceptions of HPV-related cancers and the HPV vaccine series. The study results may be used to help others in the future through development of health related programs HPV vaccine messaging strategies.

Compensation

You will get a gift card(s) in the total of $30 for your involvement in the focus group discussion.

Confidentiality

Certain offices and people other than the researchers may look at study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include the Office for Human Research Protections, the Emory Institutional Review Board, and the Emory Office of Research Compliance. Study funders may also look at your study records. Emory will keep any research records we create private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

Voluntary Participation and Withdrawal from the Study

You have the right to leave a study at any time without penalty. If you choose to withdraw from the study, you can request that your information is not used.

Contact Information

Contact Dr. Robert Bednarczyk at 404-727-9713 or rbednar@emory.edu:

- If you have any questions about this study or your part in it, or
- If you have questions, concerns or complaints about the research

Contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu:

- If you have questions about your rights as a research participant.
- If you have questions, concerns or complains about the research.

Version date 2/15/2018

- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at http://www.surveymonkey.com/s/6ZDMW75

Consent

Please, print your name and sign below if you agree to be in this study. By signing this consent form, you will not give up any of your legal rights. We will give you a copy of the signed consent, to keep.

_____
Name of Subject

_____
Signature of Subject Date
Time

_____
_____
Signature of Person Conducting Informed Consent Discussion Date
Time

_____
_____
Signature of Legally Authorized Representative Date
Time

_____
Authority of Legally Authorized Representative or Relationship to Subject

Appendix III: Focus Group Discussion

Parents of Adolescents (Age 9-17)

Key:
Red Italics – Do not read aloud.

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

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

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

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

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

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

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

Ground Rules:

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

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

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

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

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

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

Warm Up:

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

Section 1: General Health

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

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

Probe: Has anyone else experienced things like this?

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

Section 2: Human Papillomavirus

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

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

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

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

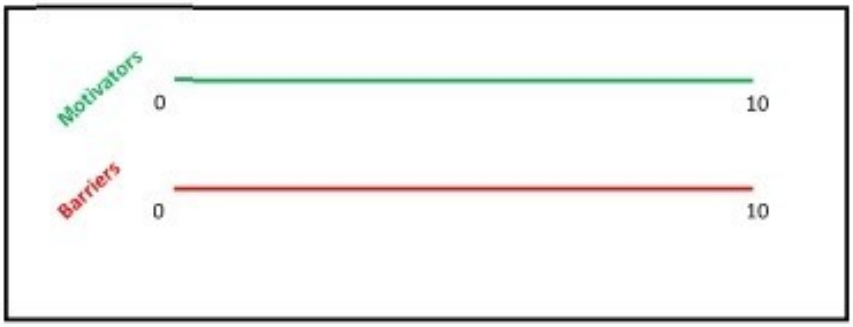
Probe: Health Care Provider, community leader, religious leader, other, etc.

Activity: Ranking HPV Vaccine Barriers and Motivators

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

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

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



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

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

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

Section 3: Web Portal Development

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

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

Closing:

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