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The Church as an Agent of Change: A Case Study of HPV Vaccine Perceptions and HPV Prevention Strategies in an African Methodist Episcopal Church in Georgia

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Abstract

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Background and Objectives
Since 2006, a vaccine to prevent human papillomavirus (HPV) infections and associated cancers has been recommended for use in the US; however, vaccine uptake has consistently remained suboptimal. Many sociodemographic factors have been evaluated with regard to HPV vaccine uptake. However, relative to other factors such as race, ethnicity, poverty status, and education, there has been less focus on the role of religion and religiosity related to the HPV vaccination.

Methods
The aim of the study was to gather knowledge, perceptions, and beliefs related to HPV and the HPV vaccination among church leaders and members at an African Methodist Episcopal (AME) in metro Atlanta, Georgia. Seven semi-structured focus group discussions (FGDs) were conducted with a variety of participants who were members of the AME church (e.g., religious leaders, health ministry, parents and adolescents). Utilizing a deductive approach based in grounded theory, a codebook was developed based on apparent themes present throughout the FGDs to guide thematic analysis. A Social Ecological Model (SEM) was created to visualize the AME church's pre-existing membership-level hierarchy to identify future leverage points for strengthened communication and health promotion strategies.

Results
Two social norm-based barriers were identified in the FGDs: 1) high levels of mistrust in the healthcare system and 2) the expectation of abstinence among adolescents. A spectrum of attitudinal norms related to HPV vaccine were present among all participants. Lastly, recommendations for future HPV prevention programs were provided by the AME church leaders and members in which they highlighted enhanced receptiveness to transparent information received from a pre-established trustworthy source. The SEM was aligned with a Behavior Change Communication (BCC) framework to identify intervention points for church leaders to leverage social engagement strategies, in turn producing health positive social influence.

Conclusions
With the pre-established trust between the church leaders and the congregation, the implementation of a church-based intervention has the potential to transform perceptions of the HPV vaccine and increase HPV vaccination coverage rates. These findings can be leveraged in future evaluations of HPV vaccine promotion strategies in other faith communities to ensure the avenue of providing health communication messages in a familiar and trusting setting is utilized.

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CHAPTER I: INTRODUCTION

Overview

Data reveals that one in five, or 80 million Americans are currently affected by human papillomavirus (HPV).[1] Multiple strains of this virus are responsible for a number of diseases. Based on 2015 annual data, 9 high-risk HPV types are associated with nearly 33,737 cancers in the United States with 20,260 cases among women and 13,477 cases among men.[2] Persistent HPV infections may lead to anogenital cancers over time.[3,4] Racial disparities continue to perpetuate health issues such as HPV-associated cancers.[5] From 2011-2015, the overall rate of HPV-associated cancers was 12.0/100,000 in the US.[6] Similarly, the rate of HPV-associated cancers among African Americans alone was 11.6/100,000 in the US.[6] African American women are diagnosed with cervical cancer 30% more frequently and are twice as likely to have a death related to their cervical cancer diagnosis compared to white women.[5] The national annual diagnosis rate for HPV-associated oropharynx cancer among men (4.8%) is lower compared to the diagnosis rate for HPV-related oropharynx cancer among African American men (6.6%).[6]

To date, there is no routine screening for HPV-associated cancers other than cervical cancer.[7] Since 2006, a vaccine to prevent HPV infections and related cancers has been recommended for use in the US; however, vaccination uptake has consistently remained suboptimal.[8] HPV vaccination can prevent infection with the 9 high-risk HPV types linked to HPV-associated cancers.[9] In 2017, the overall national HPV-vaccination up-to-date coverage was 48.6% among adolescents (13-17 years of age).[8] Among African American adolescents (13-17 years of age) the up-to-date coverage was 50.2%.[8] Previous research indicates that HPV-associated cancer statistics among African Americans are particularly concerning, addressing the need for higher HPV vaccination up-to-date coverage among this population.[2,10,11]

Previous literature has shown that religion is a social determinant of health, partly due to the influence of social norms within congregations.[12] Within the United States, attendance of religious services is highest among African Americans, with 47% of adults reporting they attend church services at least once a week.[13] Research shows that African American women have strong religious beliefs upon which often they base health decisions.[14-16] With the state of Georgia being in the "Bible Belt" with a high percentage of religious populations, and African Americans specifically reporting high religiosity, a church-based HPV prevention strategy may be effective.[13,17] Emory University's Interfaith Health Program and the CDC's *Influenza Initiative* demonstrates how a church-based intervention through capacity building and mobilization of church-based networks linked with public health may be effective.[18] From 2009-2016, the program collaborated with religious leaders and faith-based organizations to improve influenza vaccination outreach and uptake and administered 171,747 influenza vaccines across 24 states.[18] Like the *Influenza Initiative*, tailored church-based HPV vaccination promotion strategies could be implemented to increase HPV vaccination coverage and alleviate these racial health disparities. The church is a trusted space that cultivates a safe and supportive environment for congregation members.[18,19] A shared vision among congregational leaders and public health professionals is central to leveraging capacities and resources to collaboratively build an HPV prevention church-based intervention.[18] Partnering with religious communities may increase uptake of the HPV vaccine and change the current landscape of HPV vaccination coverage among religious communities in Georgia.

Problem Statement

African Americans are disproportionately affected by HPV-related cancers in the United States.[10] Despite HPV vaccination promotion strategies implemented over the years, HPV

vaccination uptake continues to remain suboptimal in both the US and Georgia.[20] In 2017, the completed HPV vaccination series coverage rate was 45.7% among adolescents (ages 13-17) in Georgia with a similar coverage rate of 46.5% among African American adolescents (ages 13-17) in Georgia.[8] Little is known about HPV prevention efforts to educate parents among African American religious communities in a church-based setting. There is a need for qualitative research to inform the development and implementation of HPV prevention strategies among religious communities. With insight and guidance from religious communities and church members we can work together to decrease the HPV vaccination coverage gap among congregations, ultimately working to decrease the disproportionate effect of HPV and HPV-related cancers among African Americans.

Purpose Statement

In alignment with the scope of the study, we collaborated with a mega African Methodist Episcopal (AME) church located in the greater Metropolitan area of Atlanta, Georgia. There were three primary objectives for this qualitative study: (1) to analyze the effectiveness of current HPV prevention efforts by assessing participants' knowledge and attitudes towards the HPV virus and vaccination series; (2) to explore how receptive these particular AME congregation members are to current HPV prevention strategies; and (3) to solicit recommendations on how to create future HPV prevention strategies that would resonate with the congregation. These objectives may help inform underlying motivators and barriers to HPV vaccine uptake among the AME community and how public health can partner with a church to address these barriers while leveraging motivators to increase HPV vaccine uptake.

Research Questions

The scope of the research is two-fold; the following questions are of interest:

1) What are HPV vaccine barriers and attitudes towards the vaccination series in AME religious communities?
2) In what ways can future HPV prevention efforts be more effective and receptive among AME communities?

Significance Statement

It is crucial to understand if current HPV prevention strategies are effective in providing parents and adolescents within sufficient information for them to make an informed decision about the HPV vaccine. In states with high religiosity (high personal church involvement), such as Georgia, exploring the roots of receptivity and hesitancy towards the HPV vaccination among AME religious communities will allow us to cultivate tailored HPV prevention church-based strategies. Understanding contextual reactions to current HPV prevention strategies may lead to better HPV vaccination promotion among AME religious communities and ultimately in achieving high HPV vaccination coverage in states with high religiosity.

Definition of Terms

As a disclosure, any attempt to define these terms will undeniably fail due to the complex nature of these terms having vastly different meanings to individuals and the varying ways these definitions are practiced in one's life. For study purposes, *faith* is defined as a strong belief in a higher power and religious doctrines as a foundational meaning for an individual's life.[21] The phrase *the intersection of faith and health* is commonly used to mean the point where faith and

health influence one another or an opportune access point to curate positive influence on one another.[12]

Religion is defined as an institution of particular set of beliefs, doctrines and worship with postulated supreme beings.[22] Throughout this and other studies religion is considered to be a social determinant of health.[12] *Religious denominations* are subgroups of a certain religion that hold slightly different beliefs than the overarching religion.[23] For example, this study focuses on a local congregation of the AME religious denomination. A person who identifies as *religious* means someone who believes in a certain religion and is involved with living out these beliefs and worship.[23,24] Lastly, *religiosity* is defined on a spectrum of how *religious* an individual is based on involvement with the church such as the frequency of church attendance and abiding to the doctrines of an ascribed religion.[23,24]

List of Acronyms

ACIP	Advisory Committee on Immunization Practices
AME	African Methodist Episcopal
BCC	Behavior Change Communication
CDC	Centers for Disease Control and Prevention
CBPM	Community-based Participatory Marketing
CBPR	Community-based Participatory Research
EIRB	Emory University Institutional Review Board
FBO	Faith-Based Organization
FDA	The U.S. Food Drug and Administration
FGD	Focus Group Discussion
HIV	Human Immunodeficiency Virus

HPV	Human Papillomavirus
IDDI	Intervention Development, Dissemination, and Implementation
MSM	Men who have sex with men
NIS	National Immunization Survey
OB-GYN	Obstetrician-Gynecologist
qHPV	Quadrivalent HPV vaccine
SEM	Social Ecological Model

CHAPTER II: BACKGROUND

Overview of the Literature

Before cultivating health promotion strategies in a church-based setting, we must examine the role of religion as a factor in the uptake of the HPV vaccination. Review of the literature includes both quantitative and qualitative studies with the exclusion of systematic reviews. Seventy-two sources were reviewed to inform the basis of this research study. The first half of the literature review provides a general review of HPV and associated cancers, the vaccine, and current HPV prevention strategies. Search terms included [HPV] and [HPV vaccin*]. The second half of the literature reviews showcases research studies that were selected because they examined the scope of religion as an influencing factor in the HPV vaccine decision-making process among religious communities and African American communities. Search terms included [HPV AND relig*] and [HPV OR papillomavirus AND African American* AND relig*].

Human Papillomavirus

It is estimated that 80 million Americans are currently affected by HPV, with 14 million people becoming newly infected each year.[1] HPV consists of over 150 different strains of viruses.[25] The primary modes of transmission are vaginal or anal penetrative sexual intercourse, or oral sex with someone infected with the virus.[26] However, HPV is an epithelial virus, meaning that it can be spread through non-sexual and non-penetrative sexual contact with someone infected with the virus.[26]

Most HPV infections are cleared by the immune system and do not cause cancer.[4] In fact, 90% of newly acquired HPV infections are cleared by the immune system within 2 years.[3,27]

However, when the infection does not clear the persistent infection of high-risk HPV types this can lead to certain cancers over time.[27] Persistent HPV infections cause virtually all cervical cancer, about 90% of anal cancers, 60% of oropharyngeal cancers, and nearly 40% of vaginal, vulvar, and penile cancers.[28] At least 12 strains of HPV are known to be associated with cancer.[29] Human papillomavirus strains are typically categorized as low-risk and high-risk.[27,30] Annually these high-risk strains lead to 33,700 HPV-associated cancer diagnoses in both sexes in the United States.[2] It is estimated that high risk types HPV 16 and 18 lead to 70% of cervical cancer cases alone.[31] Low-risk strains may lead to papillomas (warts) of the genitals, anus, cervix, or vagina.[4]

HPV-related cancers disproportionately affect African Americans.[10] The American Cancer Society reports the incidence rate of cervical cancer in non-Hispanic Black women as 10.0/100,000 compared to 7.1/100,000 in non-Hispanic White women (Rate Ratio: 1.41).[10] Additionally, women are more than twice as likely to die from cervical cancer – the cervical cancer mortality rate for non-Hispanic Black women is 4.1%, compared to 2% in non-Hispanic White women.[10,11] African American women also have a higher rate of HPV-related vaginal cancer diagnoses than any other race; African American men have a higher diagnosis rate of HPV-related penile cancer compared to white men in the US.[6] These HPV-associated cancer statistics of African Americans are concerning and highlight the need for better cancer screenings and HPV vaccine promotion among this population.[2,10,11]

HPV Cancer Screenings

Screenings do not exist for all HPV-associated cancers.[7] Routine cervical cancer screening (pap tests) can detect abnormal cells if present on the cervix. Abnormal cells can become normal over time and not cause cervical cancer. However, a follow up screening is

important to determine if the abnormal cells need to be removed before cervical cancer develops.[7] There are currently no routine cancer screenings for anal, penile, or oropharyngeal cancers which are all often attributed to HPV.[7] Since there are no routine screenings available for these cancers, regular checkups are still necessary. In addition to regular checkups, it is important to be vaccinated to prevent most HPV-associated cancers and other diseases (e.g. genital papillomas) caused by the virus.[7]

Human Papillomavirus Vaccination Series

In 2006, the quadrivalent HPV (qHPV) vaccine was introduced in the United States.[32] The qHPV vaccine protects against certain HPV types including high-risk viruses (16 and 18) and low-risk viruses (6 and 11).[32] The U.S. Food Drug and Administration (FDA) first approved the vaccine series for girls and women ages 9 to 26 years old with recommended vaccination start age being 11 or 12 year of age.[32] The vaccination consists of a three-dose series over a period of six months.[33] In 2010, the FDA approved the extended target population to include young men and boys to receive the qHPV vaccine.[32] Additionally in 2010, a bivalent vaccination that protects against HPV types 16 and 18 became available in the United States.[32]

In 2014, the FDA approved the HPV 9-valent vaccine.[34] The development of the new 9-valent vaccine expanded protection to 9 human papillomaviruses including types 6, 11, 16, 18, 31, 33, 45, 52, and 58.[34] Vaccination helps to protect against these 9 high-risk HPV types that are associated with about 33,737 cancers in the United States each year with about 20,260 cases among women and 13,477 cases among men.[2]

The Centers for Disease Control and Prevention (CDC) now recommends that all girls and boys ages 11 and 12 years should receive the HPV vaccine series (able to initiate as early as 9 years old).[33] It is recommended that young women receive the vaccine series until 26 years of

age while young men are eligible until the age of 21 years old.[33] Young men who have immunocompromising conditions (such as HIV), men who have sex with men (MSM), or who are transgender have an extended recommended age guideline of 26 years of age.[33] In 2016, the CDC and the Advisory Committee on Immunization Practices (ACIP) revised the dosing schedule of the 9-valent HPV vaccine from the 3-dose schedule to a newly recommended 2-dose schedule at least six months apart for adolescents aged 9 to 14 years.[35] Adolescents who start the series later (≥15 years) will still need to follow the 3-dose schedule to ensure virus protection.[35] The change in recommendation was based on data from clinical trials demonstrating the 2-dose schedule in those aged 9 to 14 years had a similar or better immune response than the response in those aged 15 to 26 years who received the 3-dose series.[35]

From 2015-2016, the National Immunization Survey-Teen (NIS-Teen) data shows HPV vaccine coverage (≥ 3 doses) was 34.9% (CI: 33.7-36.1) among adolescents aged 13-17 years.[36] With the ACIP's new recommendation resulting in a dose policy change, assessment of HPV vaccination initiation and completion of the 2-dose schedule before 15 years of age is necessary.[37] Analysis results show that only 15.7% of adolescents (aged 13-17 years) had completed the HPV vaccination series before their 13th birthday and 34.8% were up to date by their 15th birthday, demonstrating that a percentage of adolescents are being vaccinated after the age markers of 13 and 15.[37]

HPV vaccine coverage (≥1 dose) has seen a 6.4% average annual increase among African American female adolescents (aged 13-17 years).[38] National-level coverage data of at least one dose of Tdap, MCV4, and HPV shows similar trends but the HPV vaccine has slightly lower uptake among African American female adolescents compared to the Tdap and MCV4.[38] Perceived newness of the HPV vaccine is often noted as a barrier, however the HPV vaccine

became available the same time as the Tdap and MCV4 yet still has lower coverage rates.[38] Research has consistently presented findings of suboptimal vaccinations rates and African Americans being disproportionately affected by HPV-related cancers, this demonstrates a need to develop innovative HPV prevention strategies to promote the HPV vaccine.

Human Papillomavirus Vaccination Promotion Strategies

HPV vaccination promotion was initially provided within healthcare facilities such as offices of a pediatrician, primary care provider, or an obstetrician-gynecologist (OB-GYN). HPV vaccine educational pamphlets and fact sheets are typically available at the office and given to parents with adolescents approaching the recommended vaccination age of 11 years old. A strategy healthcare providers use to effectively promote the HPV vaccine is recommending it the same way and on the same day they would recommended other adolescent vaccinates.[39] Public health officials have contributed to HPV vaccine promotion with education campaigns. These campaigns increase HPV awareness while promoting the HPV vaccine series. Websites have been used to disseminate information to the public by governmental agencies, cancer associations, or other public health organizations which mainly provide statistics on HPV-associated cancers and HPV vaccine coverage. These education campaigns emphasize the importance of the HPV vaccine as cancer prevention.[39] As of late, the media has also become a vehicle for HPV vaccine promotion strategies.

In 2016, Merck & CO., Inc. produced a new HPV vaccine promotion commercial titled "It's Personal: What Will You Say?" (J. Forstner, personal communication, January 15, 2019). Many may know this commercial as the young girl or boy infected with HPV asking, "Did you know? Mom? Dad?".[40] This commercial is controversial as there are mixed reactions from parental figures and the larger community.[41] To date, little is known about the effectiveness of

the commercial. However, news sources such as *The Washington Post* have considered the marketing strategy of Merck & CO., Inc. as a shaming tactic to make parents fear doing right by their child.[41] It is critical that qualitative research be conducted to explore the perceptions of parental figures to understand if the commercial works to achieve desired results.

A research team explored African American parents' perceptions of the HPV vaccination from a marketing perspective.[42] The findings indicate personal testimonies are more effective at conveying HPV prevention messages than statistics.[42] The CDC's educational materials used in the study did not provoke stimuli to engage the participants to receive the intended message.[42] Additionally, results show that the parents' perceived susceptibility of their child contracting HPV correlated with their receptivity of the HPV prevention message.[42] For example, those with high-perceived susceptibility benefited more from a gain-framed message while a loss-framed message was more effective for parents with low-perceived susceptibility of HPV.[42] In light of this research, there are mixed reactions to the marketing strategy of Merck & CO., Inc.'s Gardasil® commercial and further analysis is needed to determine the effectiveness.

To better serve African American communities, there needs to be an understanding of knowledge, perceptions, roots of hesitancy, and common barriers to the HPV vaccine. A study utilized a Community Based Participatory Marketing (CBPM) model to examine how to develop a culturally competent social marketing intervention to promote HPV vaccination uptake among African Americans.[19] The CBPM model integrates community-based participatory research (CBPR) with theories and methods of social marketing.[19] Findings from the study revealed that the church is an influencer on decisions made by African American mothers.[19] Further, when asked for recommendations for HPV vaccination promotion design it was discussed that receiving the message from a trusted source, such as the church, is important and effective.[19]

Thus, we can see the potential for a church-based intervention that promotes HPV prevention through health ministries to be successful within AME religious communities.

Barriers to the HPV Vaccination among African Americans

Previous research studies have examined barriers that exist towards uptake of the HPV vaccine from the perspective of parental figures across racial and ethnic groups.[19,43] Common barriers include lack of knowledge, lack of insurance coverage, perceived susceptibility, fear of earlier sexual debut, concerns of perceived side effects, and child's fear of needles.[19,43] Barriers unique to African American religious communities are namely, the reluctance to discuss sex and lack of trust in the healthcare system.[5,44-46] Further exploration is of vital importance to understand how to help alleviate these barriers to the HPV vaccine within African American religious communities.[44,45]

The topic of sex is often considered taboo in a church setting.[44] Thus, sexual health is often not discussed within a church, especially sexual health as it relates to adolescents. From a religious perspective, discussing sexual health with adolescents may be seen as contradictory to the socially accepted message of *abstinence until marriage*.[44] With the church being one of the main trusted sources of health education for many African Americans, this may leave individuals who find this to be their main source without comprehensive adolescent sexual health education.[47]

A barrier that significantly affects some African Americans is the lack of trust in the healthcare system caused by racial injustice and historic events. Previous research has described the lack of trust to be mainly attributed to the Tuskegee Syphilis Study of 1932.[19,45] This study, conducted for 4 decades by the U.S. Public Health Service, observed untreated syphilis among African American men in Alabama, which was later deemed ethically unjustified due to

withholding information from patients and failing to provide the standard of care once treatment became available.[45] Research proves there is a needed relationship between trust in the healthcare system and the government when it comes to vaccination acceptability.[45] Thus, understanding trust as a determinant of vaccine uptake is necessary prior to constructing HPV vaccine promotion strategies for African Americans.

To further understand the impact of the Tuskegee Syphilis Study, several studies have examined the correlation of various racial populations and their levels of trust in the healthcare system. Results show that African American respondents were significantly less likely to trust doctors than their Caucasian counterparts.[48] Additionally, studies show African Americans have greater trust in informal sources of health information – church, religious leaders, family, friends – compared to Caucasians.[49] Other studies have found African Americans are more likely to question the goals of healthcare actors, creating significantly lower levels of trust in the healthcare system compared to Caucasians.[50] The Tuskegee Syphilis Study has consequently added to the lack of trust in the healthcare system and lowered utilization of healthcare services, further perpetuating racial disparities.

Another study measured antivaccination attitudes among adults in 24 countries and found conspiratorial thinking as a determinant of vaccine hesitancy.[37,51] Participants with high levels of vaccination hesitancy had the common trait of high levels of conspiratorial beliefs.[51] The most common conspiracy believed was the healthcare system (e.g. Big Pharma, healthcare providers) just wants to make a profit and fails to explain the potential dangers of vaccinations.[51] Further research is needed to understand conspiratorial beliefs, if any, circulating among AME religious communities.[52] In turn, the research will inform how HPV vaccination promotion strategies can

be more receptive within these communities to decrease the disproportionate effect of HPV-associated cancers among African Americans.

Influence of Religion on Health Behaviors

Religion is a social determinant of health with the magnitude of influence it holds on health behaviors worldwide.[12] The relationship of faith and health is intrinsically complex in that while it may act as a protective factor in many instances, other times it may not.[12] In the past and the present, many religious institutions have been reluctant to discuss the topic of sex.[53] In many instances, the subject of sexual health is not discussed within a church setting.[12,53,54] To add to the complexity of the issue, with the religious tenet of *abstinence until marriage* and HPV being sexually transmitted, religiosity may act as a heightened barrier for the HPV vaccination compared to other childhood vaccinations.[44] This may be due to a belief held among parents that the HPV vaccination signals to their child they condone premarital sex.[55] In Canada, Roman Catholic Bishops highly disagreed with the HPV vaccination series being added to the school vaccination program stating, "a school-based approach to vaccination sends a message that early sexual intercourse is allowed, as long as one uses 'protection'".[56] The influential role of religion seen through implementation issues in previous school-based HPV prevention efforts help construct a platform to shape our understanding of religion and HPV vaccination uptake. An understanding of how religion may influence the HPV vaccine decision-making process is crucial when developing church-based public health interventions.

Holt and McClure (2006) conducted a study to examine the relationship between religious beliefs and health behaviors among African American church members.[57] Participants were sampled from predominately African American churches of various denominations such as Baptist, Catholic, African Methodist Episcopal, Christian Methodist Episcopal, and Church of

God in Christ. This study provides an understanding of the intersection of faith and health from themes that emerged from the interviews. The most prominent theme was the idea of having overwhelming support provided in times of illness by *the church family.*[57] Other main themes include *acknowledging the body as a temple of God* and *surrendering problems & difficult decisions to God*.[57] The themes presented demonstrate the grounds for how these religious parents think about the decision-making process of the HPV vaccination for their adolescent child. These themes act as internal guiding frameworks for these participants and provide us with insightful framework principles to acknowledge and incorporate when developing church-based public health interventions.

Religion as a factor of HPV vaccination uptake

The majority of Americans identify as religious, making religion a sociocultural factor in the United States.[58] The sociocultural role of religion factors into health decisions, such as uptake of the HPV vaccine.[58] A study by Shelton et al., utilized a survey to examine the influence of religion on the HPV vaccine decision-making process among White, Black, and Hispanic parents.[58] Variables such as religious denomination and frequency of attendance at religious service were included to explore the association between religiosity and vaccine-related beliefs and decisions.[58] Results show that parents who frequently attend church were more likely to have decided not to vaccinate their daughter rather than remain undecided (OR = 3.05, 95% CI = 1.41, 6.58).[58] Two additional studies found comparable results of parents with higher rates of church attendance having greater vaccine hesitancy with less intent on having their adolescent child vaccinated against HPV.[59,60]

The variability of religious denominations should also be considered when assessing the influence of religion on HPV vaccination uptake. When parents were asked for an appropriate

age to start the HPV vaccine series for their child it is noted that Christian parents wanted their daughter to be vaccinated but preferred a later age of 19+ years.[58] Protestant parents preferred no vaccination at all while most Catholic parents in the study had already vaccinated their daughters ages 9-17 years old.[58] Notably, another quantitative study had comparable results of Catholic parents having a high acceptance level of the HPV vaccine (87.7%).[61]

Are Religion and Religiosity factors of HPV Vaccination Uptake among African Americans?

While most research points to the lack of trust in the healthcare system and low vaccine acceptance among African Americans, it is important to note these findings are not consistent. A qualitative study sought to understand influential factors on the HPV vaccine decision process of parents of adolescents ages 9 to 17 and found results contrary to the norm.[62] Participants within the study reported that the recommendation of their child's pediatrician influenced their decision due to a long-term trusting relationship.[62] The nuance derived from these interviews demonstrates that a long-term trusting relationship allows a recommendation of the HPV vaccination series to be better received, considered, and initiated. Additionally, most of these participants did not see HPV vaccination as sex permitting. One parent stated, "the shot is not a hormone shot; it will not make them want to have sex".[62] Further, it was common understanding that adolescents may engage in sexual activity with or without the HPV vaccine and that it is an issue of parent-child communication, not linked to the HPV vaccine.[62] Most importantly, these parents saw the HPV vaccine as protective, unlike birth control, which they did see as sex permitting.

Participants of the study continued to discuss their devout religiosity as it relates to decision-making and uptake of the HPV vaccine. Many participants indicated that religious

leaders and doctrines do not hold influence on their decision-making.[62] However, participants did emphasize they have prayed for guidance on making a decision about the HPV vaccine for their child.[62] A participant stated, "…I always trust God first. I always pray for guidance and protection. And if it's something He put on this earth to help His people, then yes…I want that to be given to my daughter".[62] The nuance provided from this study is important to recognize when analyzing religion as an influencing factor of HPV vaccine uptake.

In 2016, a questionnaire-based survey was conducted among African Americans who attended a Baptist church in Houston, Texas to understand how HPV awareness, knowledge, and attitudes correlate with sociodemographic characteristics among church-going African Americans.[63] From the sample in this study, 68.2% (N=210) of the participants were aware of HPV.[63] Additionally, 58.6% of the participants knew there is a link between HPV and cervical cancer. However, only 11.3% knew there is a link between HPV with mouth and throat cancers while only 4% knew of HPV-related penile and anal cancers.[63] Respondents of a younger age and higher-level education were associated with having more HPV knowledge ($p < .001$).[63] An analysis on vaccination attitudes by knowledge resulted in a positive association between vaccine uptake for both sexes based on knowledge of the number of HPV-related cancers ($p=0.012$).[63] From these results, the study concluded that knowledge of the multitude of HPV-related cancers is an important contributing factor in the parent's decision-making process of the HPV vaccine. Therefore, HPV education and prevention should not mainly focus on cervical cancer but all HPV-related cancers.

A similar study was conducted to assess HPV awareness, knowledge, and attitudes among Methodist African American women.[64] These women were sampled from a large Methodist church in Houston, Texas into a large longitudinal cohort study (N=1501).[64] The main

finding from the study was that education level had a significant association with HPV knowledge, especially in knowing HPV is linked to cervical cancer.[64] The study suggests that older African American women with less education, higher religiosity, and/or without familial history of cancer may benefit from HPV education programs in a tailored church-based setting. A church-based intervention in an African American religious community is promising given the high rates of religiosity in African American culture and the prominence of active health ministries within these religious communities.[63]

Study Relevance

With the concept of religion as a social determinant of health being newly explored, there has been limited research conducted on religion as a factor of HPV vaccine uptake. The qHPV vaccine has been recommended for all boys and young men since 2011; however, little research has been conducted with both boys and girls and parents of these adolescents in the study population.[33] Further, with Merck & CO., Inc. Gardasil® HPV vaccine promotion commercial being aired for the past two years, there is a need for an analysis of the effectiveness of the commercial.

With HPV knowledge being reportedly low among African Americans and cervical cancer levels being highest among African Americans communities, there is a need for a targeted intervention to promote the HPV vaccination series among African American communities.[5,11] A qualitative research study that allows shared personal experiences directly from African Americans would provide the valuable and rich data needed to inform prevention strategies. Qualitative research can help inform underlying contributing factors of the decision making process of the HPV vaccination such as racial undertones, religiosity, religious institutions being a source of health information, and the hesitancy of discussing sex in the church. Understanding

the factors that contribute to the decision-making processes directly from African American religious communities may allow for a tailored health intervention that is receptive among the community to be created.

CHAPTER III: MANUSCRIPT

Background

Although there are screenings for certain HPV-associated cancers, annually there are 33,700 new HPV-associated cancer diagnoses in the United States.[2] African Americans are disproportionately affected by HPV-associated cancers, the annual rate of HPV-associated cancers among African Americans alone is 11.6/100,000 in the US.[6] Similarly, the annual rate of HPV-associated cancers among all races and ethnicities is 12.0/100,000 in the US.[6] African American women are diagnosed with cervical cancer 30% more frequently and are twice as likely to have a death related to their cervical cancer diagnosis compared to Caucasian women.[5] Since 2006, a vaccine to prevent HPV infections and related cancers has been recommended for use in the US, although vaccination uptake has been consistently suboptimal.[8] In 2017, the national HPV-vaccination up-to-date coverage was 48.6% among adolescents (13-17 years of age).[8] The national HPV-vaccination up-to-date coverage was 50.2% among African American adolescents (13-17 years of age).[8] HPV-associated cancer statistics among African Americans are particularly concerning, addressing the need for an increase in HPV vaccination coverage among this population.[2,10,11]

Many sociodemographic factors have been evaluated with regard to HPV vaccine uptake.[19,43] However, there has not been much focus on the role of religion and religiosity. The factor of religion is particularly prominent for African American populations, with 47% of adults reporting they attend church services at least once a week.[13] Additionally, 75% of African American adults report religion as 'very important' in life, the highest among any racial and ethnic group.[13] With religion being of high importance and high religiosity being present among African Americans, a church-based HPV prevention strategy may be effective.[17,45]

As part of a broader environmental scan related to HPV vaccine uptake in the state of Georgia, we conducted seven focus group discussions (FGDs) among key populations in an African Methodist Episcopal (AME) church to gain perspectives on the relationship between religion and the HPV vaccine. These findings can help support future research efforts to develop culturally appropriate HPV vaccine promotion tools and strategies for use in a church setting. Successfully reaching African American religious communities may decrease the HPV coverage gap and change the current landscape of HPV vaccination coverage.

Methodology

The research team conducted seven semi-structured FGDs with participants from an AME church in metro Atlanta, Georgia. The aim of the study was to gather knowledge, perceptions, and beliefs related to human papillomavirus and the vaccination series among AME leaders and members. To ensure quality data collection, all focus groups were facilitated by a trained qualitative researcher while a note taker captured all non-verbal reactions and key points made by participants. The semi-structured focus group guides were reviewed for behavioral science research methods quality by the Intervention Development, Dissemination, and Implementation (IDDI) Shared Resource at Winship Cancer Institute of Emory University. These FGDs were part of a broader environmental scan of HPV vaccine uptake in the state of Georgia, approved by the Emory University Institutional Review Board (EIRB).

With the permission of each participant, digital audio recorders were used to capture all information discussed during the FGDs. The audio recordings were then used to create verbatim transcripts used for data analysis. After transcription the research team stored project transcripts on password protected, HIPAA compliant servers. To ensure quality data, free from error, a three-step check and re-check system was employed by the research team, involving a double

review of transcripts by research team members. After one team member completed a transcription a second team member would review and propose edits as needed. A third team member would then review the transcript and accept or decline edits when appropriate while making any additional edits as needed. This multi-reviewer system verified that the focus groups were transcribed verbatim and all shared data from FGDs were captured for analysis. Recordings were deleted after finalization of transcripts to ensure confidentiality and privacy for participants.

Recruitment

The research team used the assistance of a congregation member to recruit participants from the AME church. The member was an individual who is actively involved in the church and has close relationships with many members. The gatekeeper was provided with the eligibility criteria for participants and an EIRB approved recruitment flyer template to use for advertisement. The gatekeeper distributed recruitment flyers to potential eligible participants and included information in the weekly church bulletin. The gatekeeper managed all participant recruitment and invited interested individuals to focus groups on specified dates.

Eligibility Criteria

The sampling frame consisted of English-speaking leaders and members of the AME church. Religious leaders were included based on their role within the AME church as lead pastor, associate pastor, youth pastor, Bible study and Sunday school leaders, as well as retired pastors. Members from the Health Ministry represented leaders, facilitators/educators, and general members. Congregation members of the AME church included parents/guardians of adolescents, young adults (18-26 years of age) and adolescents (9-17 years of age). Parents and guardians were only included if they were the primary caregiver for at least one adolescent

between the ages of 9 to 17 years old. The seven focus groups consisted of samples of participants based on varying roles at the AME church (**Table 1**).

Table 1. Participants Role at the AME church classified by FGD number

Participant Type	FGD #
Parents & Guardians of Adolescents	FG6
Parents & Guardians of Adolescents	FG8
Parents & Guardians of Adolescents	FG17
Parents & Adolescents	FG20
Health Ministry	FG21
Religious Leaders	FG22
Adolescents & Young Adults	FG23

Informed Consent

Informed consent and assent forms were created by the research team and approved by EIRB for use in the study. Participants were provided informed consent or assent forms and asked to review the document and ask any clarifying questions upon arrival to a FGD. All participants were to provide written informed consent or assent before partaking in the FGDs. When participants arrived after a FGD had already began, the facilitator would stop questioning and pause the recorder in order to review the informed consent and acquire consent for recording the focus group. After participants had provided informed consent the facilitator would turn the recorder back on and continue questioning in the focus group.

Focus Group Facilitation

All FGDs were conducted in a private room at an offsite church affiliated building. The facilitator began each FGD with an introduction of the study and allowed ample time for participants to ask clarifying questions. Each participant was given a fictitious first name to use

during discussion to protect anonymity in the digital recording and hand written notes. During the FGDs, no answers were given to participants as to not to bias their responses. Upon competition of the FGDs, the facilitator stayed after to clarify any misunderstandings participants presented throughout the discussions and to address any HPV related questions asked by participants. As a token of our appreciation, participants were offered a $30 gift card. The offering was EIRB approved and the research team found this to be an adequate amount for the participants' time and effort without creating any potential selection bias on the study.

The semi-structured focus group guides consisted of open-ended questions in six conceptual domains: (1) General health, (2) Vaccinations/Immunizations, (3) Human Papillomavirus knowledge and beliefs of both the virus and vaccine, (4) HPV barriers and motivators, (5) Sources of HPV related information, and (6) Development strategies for a potential HPV-focused informational website. We sought to gather the participants' experiences and community norms by asking open-ended questions pertaining to these six conceptual domains.

Activities were conducted in select FGDs to gain a further understanding of motivators and barriers of the HPV vaccination series among participants. For the Parents/Guardians of Adolescents FGDs, the activity further engaged participants by having them discuss motivators and barriers and rank them from most to least important of a factor in the decision-making process for uptake of the HPV vaccine. Religious leaders engaged in a different activity of holding up cards provided to take position (agree, disagree, neutral) on statements read aloud by the facilitator. The statements were generally related to perceptions of doctors, vaccines, and social norms of the AME church. Neither the Health Ministry FGD nor the Adolescent and Young Adult FGD participated in additional activities.

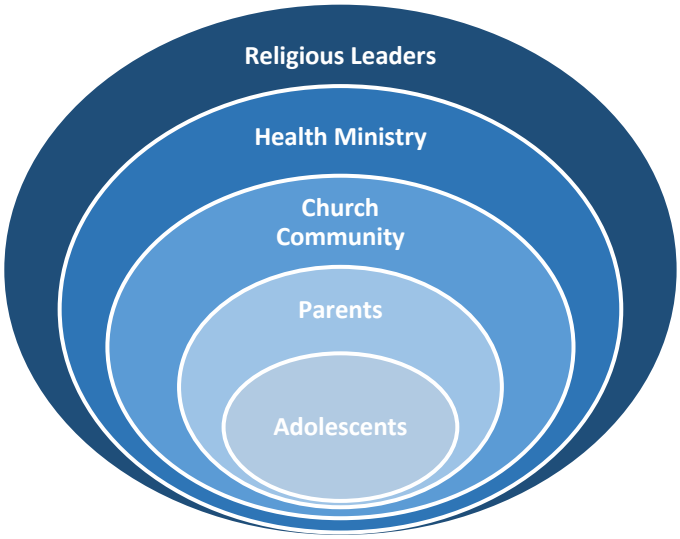
Analysis

All transcriptions were entered into MAXQDA 2018 (*VERBI GmbH, Berlin, Germany)*, qualitative software package, for analysis. Data analysis were in alignment with study objectives and focused on describing how current HPV prevention strategies affect participants' knowledge and attitudes towards the vaccination series. Further analysis was done to gain an understanding of the decision-making factors that affected uptake of the vaccine series. The researcher reviewed all transcripts and notated the creation process for categories and sub-categories of key issues to assist the development of codes and sub-codes for thematic analysis. Utilizing a deductive approach based in grounded theory, a codebook was developed based on apparent themes present throughout the FGDs. The codebook provided a definition for each theme, code, and sub-code while providing inclusion and exclusion criteria for each. The codebook was used as an aid to code all collected data appropriately. The researcher continually referenced the codebook during coding and sought to achieve code saturation throughout all transcripts. The software MAXQDA 2018 was used to facilitate analysis as it allows for sets of themes with embedded codes to easily retrieve coded segments for comparison across focus groups. Further, the software allows for the comparison of a code across variables (e.g. participant type, age, race) to develop an understanding of the nuance that contributes to the complex nature of the issue.

A Social Ecological Model (SEM) was created to further understand the interactive effects of behavior through multifaceted relationships within the AME church (**Fig. 1**). Further, it aids in visualizing the AME church's membership-level hierarchy to identify future leverage points for strengthened communication and health promotion strategies within the AME church. These aligned leverage points make up the Behavior Change Communication (BCC) framework

that show how the church may be an actor in promoting positive health outcomes among their congregation.

Figure 1. Social Ecological Model of the AME church



*Adapted from UNICEF. (n.d.). Module 1: What are the Social Ecological Model (SEM), Communication for Development (C4D)?

Results

The results are based on analysis of seven FGDs conducted between April 2018 to July 2018, with forty-nine (N=49) total participants. Participants ranged in age and sex with thirty-four adult female (n=34) participants, three adult male (n=3) participants, three young adult female (n=3) participants, six adolescent female (n=6) participants and two adolescent male (n=2) participants. Themes and patterns arose throughout the data with twenty-nine (N=29) codes of interest present. Twenty-one (72%) codes used in analysis were deductive, resulting directly from the semi-structured FGD questions. The remaining eight (28%) codes were inductive and were introduced independently by participants. The results focus on the following:

1) Social norm-based barriers to the HPV vaccine
2) Attitudes towards the HPV vaccine

3) Strategies for future HPV prevention programs

Social Norm-based Barriers to the HPV vaccine

Many of the barriers to vaccine uptake described by participants in this group (e.g. lack of health insurance, perceived side effects) have been detailed in previous research.[19,43] However, two barriers described in literature and the FGDs that stand apart from others are (1) the high levels of mistrust in the healthcare system and (2) the expectation of abstinence among adolescents.[5,44-46] These two barriers are spurred by social norms that may be addressed through the BCC framework leverage points within the SEM of the AME church.

1) Mistrust in the healthcare system. A religious leader shared, "in the African American community in general there is a suspicion of doctors, medical, vaccinations, all of that" (FG22). In line with this thought, only 1 out 5 religious leaders involved in a FGD thought doctors are trustworthy sources (FG22). A parent shared more about suspicions of vaccinations by stating, "I have a five year old, and I have not given him all the vaccinations…I'm against vaccinations. Because I think it's just like a test, you're a guinea pig…So basically what I've done with him is I've given him just the vaccinations that will get him into schools" (FG20). It was common that mistrust in the healthcare system was attributed to the unethical events against African Americans, like the Tuskegee Syphilis Study. A participant shared, "they used them [African Americans] as test cases, and…pretend to treat them and not really treating them and seeing how bad it can actually get and things of that nature. And um, so yes that made me very wary especially when something first comes out…It makes me have a second thought because when they have done stuff like that in the past it was not totally honest" (FG8).

When discussing other communal barriers from seeking medical care, participants referenced other historic events such as the 1960 eugenics program in North Carolina. A

participant shared, "…the African American people have been test dummies. They have given us, like thousands of us, um things to sterilize us and say 'oh, this is a vaccine'…these women, they couldn't reproduce. And it's not something they signed up for…we were the guinea pigs…" (FG22). This participant also shared how historical events have contributed to communal mistrust in the healthcare system. She shared, "I know people in my circle, we don't want to go to the doctor. We don't want any kind of medication, no prescription. What are you giving me? No vaccinations, no my child will not be getting no more vaccinations" (FG22).

However, mistrust in the healthcare system was not completely attributed to historic events and racial undertones. The idea that 'healthcare just wants a profit' was common across FGDs. A participant stated, "And right now there is a suspicion of uh 'Do I really need this? Or…is this some other type of ploy? Or maybe this is just a money making thing, there's people trying to make money'" (FG22). This concept extended to how accepting participants are of current HPV vaccine promotion strategies such as the Merck & CO., Inc. Gardasil® commercial titled "It's Personal: What Will You Say?" (J. Forstner, personal communication, January 15, 2019). A participant shared the concern of conflict of interest, "I don't want to see it from the company that's making money off of it" (FG6). A participant made the claim, "That's advertising. They out there making money, if you get it, somebody is getting paid! Pharmaceutical companies are getting paid a lot of money. And doctors are getting paid every time they administer that vaccination too!" (FG22). A highlighted recommendation was for information to be provided from a "neutral party that will get all sides…based on research. Just lay out the facts…These are the facts, this is the research, we have this much data, and this is what it shows" (FG8).

Participants discussed how HPV prevention strategies through the medium of a commercial are ineffective at alleviating preconceived mistrust in the healthcare system. A participant shared, "Because it's in the media it doesn't do anything for my suspicions that I had…because I have the same suspicions about the media! That hasn't made it a more personal way in order to get me this information or to talk to me about it" (FG22). Participants all agreed that the commercial employs scare tactics but had different opinions on the commercial's effectiveness. Majority of participants felt the "commercials are scaring people more than anything" (FG21) and shared that "scare tactics don't work" (FG22). A parent added, "It seems to put it back on us like, mom did you know? Well no, I didn't know" (FG21). The participant emphasized that more information is needed "so mom could know, dad could know…Because we get blamed for everything" (FG21). Some participants believed the commercial is effective because it "is a good way to make people aware and…prompt them…to take the child in to at least inquire about it" (FG20).

It is worthwhile to note that all participants in the FGDs had seen the commercial yet had very low knowledge and understanding of the HPV virus and of the HPV vaccine. Throughout each of the focus groups, several participants shared information related to the HPV virus and the HPV vaccination that was not factually correct, yet the participants believed it to be so. For example, a participant stated, "Unless you're sexually intimate in some sort you can't really catch it [HPV], so should you have to be vaccinated?" (FG6). This indicates that the commercial has been ineffective in providing enough correct HPV education and the goal of the vaccination. A participant emphasized, "I just don't think there is enough information other than seeing the commercials and it's like more of a scare tactic. And I'd just, I'd like to have more information" (FG8).

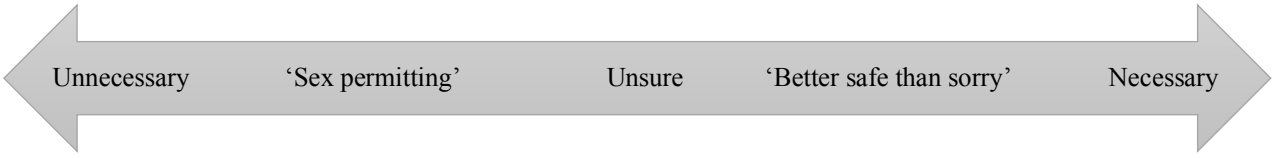
2) Expectation of abstinence among adolescents. A common barrier to HPV vaccine uptake among the AME church members was a social expectation that adolescents remain abstinent until marriage. A participant shared, "I explained to them [participant's children], if you choose to live that type of life, if you choose at 18…that you're going to be promiscuous…then go ahead and get it [the HPV vaccine]! It's on you now. But I wouldn't consent to it" (FG22).

Due to this social norm, participants shared that adolescent sexual health is not typically discussed in a church setting. A young adult participant shared, "especially in the Christian community, its real taboo to talk about HIV, sex, and everything like that. And it can be a hard topic to talk about with your parents" (FG21). Misinformation about both the virus and the vaccine were present in FGDs. Participants had the misconception that "sexually active kids" (FG8) are those who are at risk of contracting HPV and who should receive the vaccine series. As abstinence is expected among adolescents, parents viewed the vaccination as troublesome.

Attitudes towards the HPV Vaccine

A spectrum of attitudes (**Fig. 2**) towards the HPV vaccination ranging from unnecessary to necessary became apparent across all FGDs.

Figure 2. HPV Vaccination Attitudinal Spectrum



Some participants saw the HPV vaccine as completely unnecessary. A participant stated, "Why put your child through anything that unnecessary?" (FG17). Another participant added, "Yeah, if you're not sure it's gonna work" (FG17). Participants on this side of the spectrum had various opinions on vaccinations, from believing all vaccinations are unnecessary to believing only

recommended vaccinations for things such as HPV and influenza are unnecessary. Participant's views ranged from, "I'm highly against vaccinations" (FG20) to "my son is up-to-date on all his vaccines, but he doesn't do the flu vaccine or even the HPV [vaccine]" (FG6).

Some participants shared the attitude that the HPV vaccine is a 'sex permitting' signal to their adolescent child. A participant made the claim that the HPV vaccine "gives them permission" (FG8) to have sex. This is troublesome due to the socially accepted message of abstinence until marriage. A participant feared the signal it would send to her child, she shared, "I didn't tell him what it was for I just told him it was a regular vaccine that he had to take because he turned 11" (FG8). The participants shared that influential attitudes in their social network of what is socially accepted has in turn created stigma towards the HPV vaccine.

Some participants were unsure of what to think of the HPV vaccine, sometimes even after having their child vaccinated. A participant stated, "so, my daughter was vaccinated but I don't know how I feel about that. Just…I'm conflicted. Yeah, vaccines, I don't know I really feel like they're just testing our bodies" (FG6). Many participants discussed that they remain unsure because they do not have "enough knowledge to make a decision" (FG17), emphasizing the need for additional HPV information and education.

Conversely, some participants were more receptive to the HPV vaccine and shared a 'better safe than sorry' viewpoint, mainly due to the perceived motivators outweighing the perceived barriers. When ranking personal motivators for HPV vaccination, parents indicated that the strongest motivator was to provide protection from their child developing an HPV-related cancer (FG6/FG8/FG17/FG20). A parent shared, "I was scared giving the vaccinations but I was more scared not to" (FG17). Another parent commented, "I just finally gave in with [daughter's name] because I was wanting to rather be safe than sorry for her" (FG6).

Finally, other participants felt that the HPV vaccine was necessary and needed as a method of preventive health. A participant adamantly stated, “You just need it, part of turning 12” (FG8). One participant held deep regrets of not having her daughter vaccinated after her daughter faced the scare of an abnormal pap smear and precancerous cells. She shared, “I should have said yes. Because she faced something that she did not have to face if I had not been so close-minded” (FG22). Participants on this end of the attitudinal spectrum expressed a general sense of confidence in the HPV vaccine. A participant stated, “I trusted the vaccine um just as much as I trusted the chicken pox vaccine” (FG8).

Strategies for Future HPV Prevention Programs

During FGDs participants shared a desire to break down the taboo nature of discussing sex in the church and the communal mistrust held towards the healthcare system. During the Health Ministry FGD, when asked if they specifically discuss adolescent health, participants stated “not as much as we should” (FG21), recognizing a need to mobilize efforts to improve adolescent health education in the church. Of the religious leaders, 3 out of 5 believed church members support vaccinations of children/adolescents (FG22). Religious leaders discussed their willingness to the facilitate the intersection of faith and health, stating “From a…pastoral standpoint…one of the things that we have to be able to do is we have to be open, transparent…and willing to even…talk about these things… especially if we have that platform where we are actually speaking to be open” (FG22). Another religious leader further states, “We have to be able to be open to the intersection of medicine and faith” (FG22).

Religious leaders discussed their readiness to move forward from suspicions of the healthcare system and stigma against the HPV vaccine to advocate for better health in the church community. A religious leader shared, “I’m trying to move from um the suspicion to being open,

I'm doing it because I don't want my children to grow up having that same suspicion of doctors" (FG22). Another leader further iterates, "You know, everybody goes back to the Tuskegee experiment, there are things that have happened but I believe there are suspicions that I hold onto um really blindly and that is one of them as it relates to vaccinations" (FG22). In hope for the next generation to transition away from suspicions of the healthcare system, 4 out of 5 religious leaders thought adolescents (ages 9-17) should receive important information about vaccine preventable diseases to make educated decisions (FG22).

Participants highlighted the positive influence of pre-established trust in church-based interventions by stating, "Even though you have a doctor it depends on the relationship you have with that doctor as opposed to someone that you know at church that you can relate to, the trust value" (FG21). Health ministry members discussed how church members will ask them questions like, "do you have more information about this new shot, that they came out, it was on the news, CDC said…what do you think?" (FG21). Further adding, "they feel comfortable that they can come and ask a familiar face. When they know you're in the health ministry they tend to come to you all the time…" (FG21). There was the common phenomenon present among the FGDs that "it plays a part in how receptive you are to the education if it's coming from someone that you're familiar with" (FG21). The pre-established trust between the church leaders and congregation members aligns with literature demonstrating that church-based interventions have potential to be effective in promoting health behaviors.[18,19]

The value of transparency was an emergent theme among participant's recommendations for future strategies to be more effective. Adolescent participants discussed their appreciation of transparent sexual health education by stating, "she's [Outsourced Health Educator] very real…She didn't like dance around, she was just like this is what happens…" (FG23).

Adolescent participants discussed their receptivity to prevention education rather than abstinence-only education by stating, “That’s like the worst thing when people are like ‘Don’t have sex! What’s the best way to prevent STD’s? DON’T HAVE SEX!’” (FG23). Additionally, parents shared how they value transparency from their child’s pediatrician. A participant shared, “there is a very open, honest, candid dialogue that takes place and for me that makes me respect her [pediatrician] more because she is not trying to, you know, sugar coat anything” (FG22). The thread of transparency continued to be discussed among recommended strategies to effectively provide HPV education. Participants shared “I need stats. I want real studies. I actually like to see the test studies, I even want to see the demographics of the studies” (FG17). Participants added, “True testimonials! Not someone just someone…like in the commercials…they’re all actors” (FG8). Across all FGDs there was discussion that participants would be most receptive to hearing testimonies and seeing statistics from populations who share similar characteristics as their social network (e.g. race/ethnicity, religiosity).

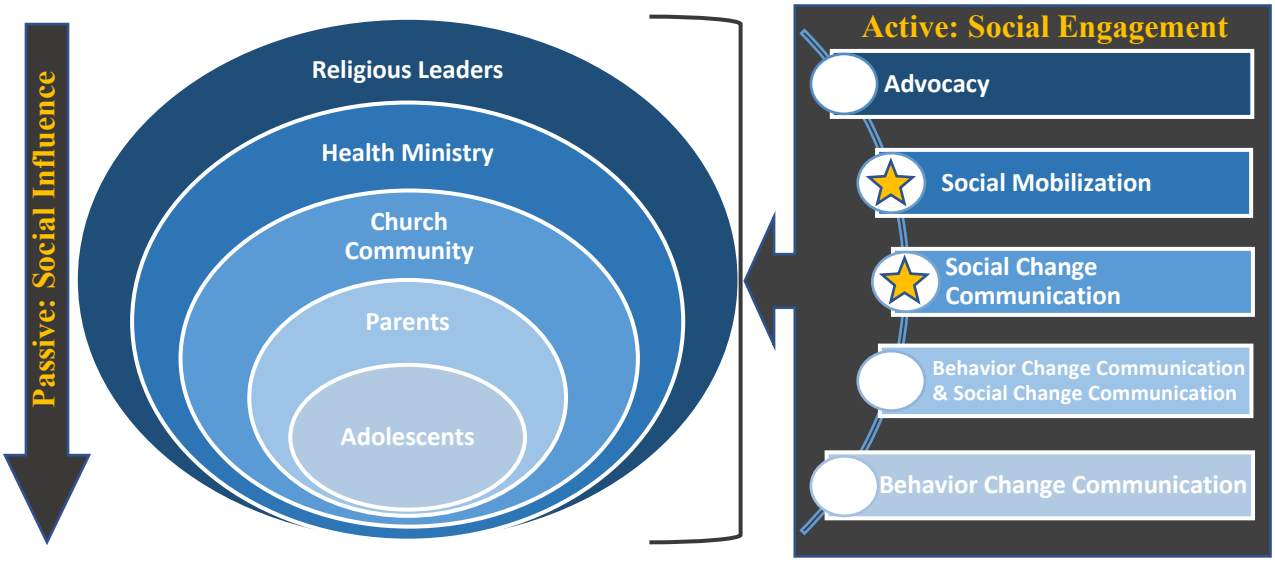
Discussion

This study identified three key themes in the results informing how the church can be an agent of social and behavior change. We will discuss how to shift social normative barriers and HPV vaccine attitudes and how to leverage the natural organizational SEM structure of the AME church for future HPV prevention programming utilizing the BCC framework. Particularly, we will look at how the AME church can utilize the BCC’s *social mobilization* and *social change communication* intervention points in concert with the passive strategy of *social influence* and the active strategy of *social engagement* to produce behavior change communication (**Fig. 3**).

The BCC process is interactive, providing a synergistic effect when used to develop tailored messages disseminated from religious leaders and the health ministry to the church

community, parents, and adolescents to motivate individual and community level behavior change.[65] The multi-level use of the BCC intervention points interacting with the corresponding SEM level stimulates individual preventive actions while fostering a supportive community by shifting social, cultural, or institutional norms to sustain long-term behavior change.[65] The strategic use of the BCC approach aligned with the SEM organizational levels may help stimulate community dialogue to raise HPV awareness, increase HPV knowledge, promote positive sexual health education, reduce HPV vaccine-related stigma, and promote services for HPV prevention.[65]

Figure 3. Social Ecological Model of the AME church aligned with BCC Intervention Points with Active and Passive Strategies for HPV Prevention Efforts



*Adapted from UNICEF. (n.d.). Module 1: What are the Social Ecological Model (SEM), Communication for Development (C4D)?

Shifting Social Normative Barriers and HPV Vaccine Attitudes

Social norms are attitudes of accepted behaviors based on perceived standards of what others in the community are adhering to and the consequences of not conforming to what others in their community perceive as acceptable.[65] Social norms and stigma are both generally deeply

ingrained into a community, and thus difficult to change. A shift in normative behaviors requires shifting the paradigm of what individuals in the community believe to be acceptable utilizing the BCC framework.[65]

Social Mobilization. From the results, we see that the social expectation of abstinence among adolescents and high communal mistrust of the healthcare system are present throughout the AME church FGDs. The AME church participants from the top two organizational levels (religious leaders & health ministry) expressed the need to overcome these social norms that double as barriers to the HPV vaccine to reduce racial disparities to HPV-associated cancers in their community. S*ocial mobilization* is an action-oriented intervention point and focuses on the health ministry organizing to create a positive health environment.[65] This would entail leaders changing the social, cultural, and institutional norm of discussing sex in church from taboo to establishing an environment where adolescent sexual health topics are open for discussion. In turn, allowing HPV prevention education to be guided into dialogue by *social mobilization* of the health ministry at the AME church.

Social Change Communication. The church community in the SEM has the ability to leverage the *social change communication* intervention point. This intervention point focuses on empowered communities becoming agents to change social norms.[65] *Social change communication* is participatory and is meant to eliminate disadvantageous social norms and behaviors on a large scale.[65] S*ocial change communication* could be used to shift the HPV vaccine attitudinal norms such as the vaccine being seen as 'sex permitting' within this community. Working towards *social change communication*, it is important to provide consistent evidence that HPV vaccine uptake is not associated with earlier sexual debut or increased promiscuity.[66-69] As well as emphasizing that the HPV vaccine prevents cancer-causing

infections and stressing the importance of the recommended age group (11 & 12 years of age) to protect the adolescent long before they are exposed to the virus.[33] The cancer prevention message of the HPV vaccination is key, just as we wouldn't wait to apply sunscreen after being in the sun for hours or buckling a seatbelt once arriving to the destination, we should not wait until after onset of sexual activity to attempt to prevent HPV.[70]

The *social change communication* intervention point would also work well with the attitudinal norm of parental acceptance towards school mandated vaccinations but not recommended vaccinations as demonstrated through some participants on the 'unnecessary' side of the HPV vaccination attitudinal spectrum. Parental decision-making on childhood and adolescent vaccinations often boils down to *is it required for school? If not, then we'll pass.* Schools follow state-level requirements and as only a few states require school mandates of the HPV vaccine, it may sometimes be viewed as optional and unnecessary by parents.[71] However, it is important to emphasize that state's enforce minimum standard requirements on schools, but acceptance of all recommended vaccines ensures comprehensive prevention towards all vaccine preventable diseases, HPV included.[71] The AME church and the health ministry fostering the *social change communication* environment through *social mobilization* allows individuals to receive transparent information in a church setting and may allow parents to more thoroughly consider the HPV vaccine series. Providing HPV prevention education that instils *social change communication* within the church community, parents, and adolescents may ultimately allow *behavior change communication* and an increase in uptake of the HPV vaccine.

Future Programming

A church-based HPV prevention intervention has not yet been attempted at the AME church. The passive strategy of *social influence* and active strategy of *social engagement* can be

used for future programming efforts. As seen in the FGDs, the religious leaders of the AME church *advocated* for the importance of interventions allowing for the intersections of faith and health and a church-based intervention to even be conceivable.

Passive Strategy. *Social influence* is the passive proposed church-based intervention strategy as it does not require deliberate or conscious attempts to change behavior.[72] This is due to human nature of people seeking normative guidance based on what is accepted in their social network and conforming and reinforcing these attitudes and behaviors. Religious leaders *advocating* to shift the previously defined social norms that act as barriers and the health ministry *mobilizing* to shift *social influence* within the AME church to create *social change communication* is a powerful strategy that may impact the health of the congregation and the larger social network. We may see *social influence* unfold organically as the active *social engagement* strategies are implemented.

Active Strategy. The active strategy for a church-based intervention to impact congregational health is through *social engagement*.[61] The most effective way to achieve social change communication is through community leaders creating tailored messages that are socially and culturally appropriate to the community. This strategy is more straightforward and requires the church and the health ministry to encourage discussions to motivate new social norms and behaviors.[65] For example, Emory University's Interfaith Health Program *The Influenza Initiative* demonstrates how capacity building and mobilization of faith-based organizations (FBOs) linked with public health has improved influenza vaccination outreach and uptake.[18] Ten specified FBOs were site locations for community outreach events and the FBOs tailored influenza prevention messages towards their communities, with only six sites choosing to directly provide vaccinations.[18] The capacity building and community outreach of FBOs resulted in 171,747

influenza vaccines administered over a seven year period.[18] The *Influenza Initiative* could possibly be used as a guide for engaging religious groups to engage in vaccination initiatives such as the HPV vaccine. Engaging the AME church community to discuss how HPV-related cancers disproportionally affect African Americans will demonstrate the AME church network's health values and therefore may reconstruct social norms. The HPV health topic discussion not only creates a space for this conversation but may stimulate perpetual discussions.

Concurrent Strategies. As demonstrated in the FGDs, participants shared they value the pre-established trust developed within their social network at the AME church to the extent that it enhances their receptiveness to information. Therefore, it is likely that congregation members may be receptive to the *social engagement* strategy. Not only may it positively affect receptiveness to information, but HPV education will be disseminated to all the AME congregation members potentially allowing a paradigm shift (*social change communication*) and enablement of health positive *social influence*. Ultimately, the BCC intervention points aligned with the AME church SEM may be used to stimulate health positive social norms in the social network through *advocacy, social mobilization, social change communication*, and ultimately *behavior change communication*.

Limitations

Although the study findings are from one church in one geographic area, the sample was from a large congregation and included a diverse representation of church members and leaders. As this was only based in one congregational denomination of one racial group, the findings are not widely generalizable but have resulted in the development of a framework to guide new health intervention efforts in church settings. Further, it is recommended that preliminary community-based research is done on the community of interest to incorporate cultural

sensitivity and differing social normative barriers and attitudes into the model. One author conducted the analysis, however, research team members collaborated at every stage, with the FGD facilitator confirming key thematic findings. Lastly, a common concern of FGDs is social desirability; however, the facilitator assured participants there is no right or wrong answer to the questions asked and encouraged discussion of all topics and ideas expressed by participants to gather diverse perspectives.

Conclusions

Changing the current HPV vaccination coverage landscape may require tailored communication strategies to reach communities with suboptimal coverage. Pre-established trust from the organizational SEM already present within the AME church with utilization of the BCC intervention points will likely allow these strategies to be effective. The church-based intervention facilitating strategies such as *social engagement* and *social influence* may be the most effective way to achieve this for the AME church and possibly other AME communities. Further work should be done to implement the HPV prevention church-based intervention at the AME church utilizing these strategies to first evaluate the effectiveness and determine if this framework would be suitable for other religious communities. Successful implementation of a church-based intervention could help reduce the HPV vaccine coverage gap for African Americans in the AME church member network. Ultimately, these coordinated church-based strategies may reduce the disproportionate effect of HPV-related cancers on congregation members with possible extension to other AME social networks.

CHAPTER IV: PUBLIC HEALTH IMPLICATIONS

HPV vaccination is the best way to protect individuals from HPV-associated cancers and genital papillomas. The vaccine may be overlooked by African Americans who have high levels of mistrust in the healthcare system due to historic unethical medical treatment. Likewise, the vaccine may be overlooked by congregations due to the socially accepted norm of abstinence until marriage and misperceptions of the HPV vaccine. With the pre-established trust between the church leaders and the congregation, the implementation of a church-based intervention has the potential to transform perceptions of the HPV vaccine and increase HPV vaccination coverage rates. Alignment of the SEM with the BCC framework utilizing the social influence and social engagement strategies to create social communication change and ultimately behavior change may be successful within church settings. Successful implementation of a church-based intervention would mean the church members being receptive to the BCC strategies, in turn increasing the uptake of the HPV vaccine among adolescents and reducing HPV infection and HPV-associated cancers among the AME church members. On a larger scale, if other AME churches and historic African American churches adopted similar approaches there is potential to change the current landscape of HPV vaccine coverage by reducing the HPV coverage gap and therefore reducing the disproportionate HPV-associated cancer rates among African Americans.

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