AN EXAMINATION OF BARRIERS TO CERVICAL CANCER SCREENING AND PARTICIPANTS' PERCEIVED SOLUTIONS: A MIXED-METHODS STUDY UTILIZING THE HEALTH BELIEF MODEL

by

KAYIN TANISHA ROBINSON

(Under the Direction of Carolyn Lauckner)

ABSTRACT

Cervical cancer is currently a significant public health concern. In 2014, approximately 12,578 American women were diagnosed, and 4,115 women died of cervical cancer. A Pap smear is an effective test used to examine cervical cells for abnormality in the detection and prevention of cervical cancer. The reported percentages of women who have received a Pap smear based on the national guidelines are as follows; 81.4% of women between the age of 21 and 44 years of age, 81% of women between the ages of 45 and 65 years of age, and 49.9% of women 65 years of age and over. According to this statistic, many women are receiving a Pap smear but there are still a significant number of women not adhering to the recommended Pap smear guidelines. This dissertation examined Pap smear barriers among women and their perceived solutions to these barriers. A cross-sectional mixed-methods design was utilized consisting of a questionnaire and focus groups. The study was divided into Phase 1 and Phase 2. Phase 1 consisted of quantitative data and utilized the Health Belief Model to adapt a Pap smear screening questionnaire to identify barriers among women. Phase 2

comprised of focus groups to explore participants' suggested solutions to Pap smear nonadherence among women. Participants reported various barriers to Pap smear adherence and perceived barriers were the only Health Belief Model construct that predicted adherence in a logistic regression model. Participants also reported various solutions for both healthcare professionals who aid in administering Pap smears and women who are hesitant in getting a Pap smear. Some themes for the proposed solutions include education, convenience, provider outreach, provider-patient communication/rapport, distractions(s), policy/trainings/regulations, social support, body image, and patient autonomy. The results and findings suggest that perceived barriers deter participants from obtaining a Pap smear. Therefore, healthcare professionals should focus on examining and implementing some of the solutions proposed by women in this study to eliminate associated barriers. However, more research is needed to better understand the barriers among various populations, and to further explore the effects of the participants' perceived solutions to Pap smear adherence.

INDEX WORDS: Mixed methods; Cervical cancer; Pap smear barriers; Pap smear barrier solutions; Health Belief Model.

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DEDICATION

This dissertation is dedicated to my entire family, who has provided me with relentless support throughout my academic journey. To my parents, thank you for instilling a strong passion for learning in me. You've done so much to help me reach the peak of my education and your contribution to my success does not go unnoticed. To my brothers, Kito and Kwasi, thank you for your encouragement and kind words as I completed my program. To my furry best friend Prince, thank you for your warm kisses and amazing companionship that I will always cherish. And to all of my friends, thank you for being my biggest fan. I am blessed to have an amazing support system that have provided support, guidance, love, and lots of prayers throughout my journey.

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CHAPTER 1: INTRODUCTION

1.1 Statement of the problem

Pap smear exams are a routine screening tool used to detect abnormal cells of the cervix.[1,2] If left untreated these abnormal cells may become cancerous, leading to cervical cancer.[3] It is recommended that women receive their first Pap smear exam at age 21, and every three to five years thereafter depending on age up to age 65.[4-6] Although Pap smear exams are fast, simple, and highly effective in detecting potentially cancerous cells, [7] many women are not adhering to routine Pap smear screenings. Even with the efficiency and effectiveness of this screening test, the National Center for Health Statistics estimates that only 81.4% of women between the age of 21 and 44 years of age have received a Pap smear.[8] One reason may be that the process of getting a Pap smear is considered invasive and uncomfortable to some women,[1] among other socio-cultural, institutional, and personal barriers. The following section will discuss cervical cancer in detail, cervical cancer predictors and screening behaviors, the relationship between HPV and cervical cancer, and will put forth specific research aims for the proposed study examining predictors of Pap smears among graduate students.

1.2 Definition

Cervical cancer is cancer of the cervix;[3] the result of abnormal growth of cervical cells becoming malignant.[3] The progression of the cervical cells developing into cancerous cells is usually asymptomatic[9,10] but some women may experience vaginal bleeding, pelvic pain, or pain during sexual intercourse later in the process.[11,12] In

advanced cervical cancer, symptoms may include loss of appetite, weight loss, fatigue, pelvic pain, back pain, leg pain, swollen legs, heavy vaginal bleeding, and bone fractures.[13] In most cases the development of cervical cancer typically takes 10 to 20 years,[14] and in severe cases cervical cancer can be fatal.[15]

1.3 Significance

Cervical cancer is currently a significant public health concern. According to the U.S. Cancer Statistics Working Group, in 2014, approximately 12,578 women were diagnosed and 4,115 women died of cervical cancer.[16] As a result of its high prevalence and mortality rates, Healthy People 2020 devoted two of its objectives to cervical cancer. The objectives are to 1) reduce the death rate from cancer of the uterine cervix, and 2) reduce invasive uterine cervical cancer.[17] National efforts are focused on increasing cervical cancer screening and improving cervical cancer treatment options. While cervical cancer screening is effective in detecting and preventing cervical cancer, the overall direct medical cost is burdensome on the economy. It is estimated that $6.6 billion dollars are spent on cervical cancer screening and follow-up each year.[18] The estimated cost for routine cervical cancer screening was $103 per case and the estimated annual cost for cervical cancer treatment was $38,800.[18]

Not only does cervical cancer have a negative impact on the economy, it can also be harmful to individuals. Cervical cancer can lead to poor quality of life, infertility, and ultimately, death.[19,20] For example, being diagnosed with cervical cancer can include bodily pain and discomfort due to the cancer itself and/or treatment.[11-13] The emotional distress may include feeling tense, weak, irritable or depressed.[21] Social distress may include interference in relationships with family and friends, interruptions in social

activities, or financial difficulties.[21] Cervical cancer can cause poor sexual drive or lack of sexual activity among diagnosed women when compared to their "healthy" counterparts.[21] Since cervical cancer affects the reproductive organs, some procedures and/or treatment options can either prevent pregnancy or cause pregnancy to be difficult. For example, if the uterus is removed as in a hysterectomy, then pregnancy is impossible since there is no place for the embryo to implant or develop.[19] In other cases, such as following radiation therapy, pregnancy may be difficult due to radiation therapy that may cause the ovaries to stop working.[19] In advanced stages of cervical cancer, the cancer has spread to other body parts and may be extremely difficult to treat, so it may unfortunately lead to death.[20] Fortunately, prevention and treatment options for cervical cancer are available and effective.

1.4 Epidemiology

Cervical cancer is the fourth most common cancer in women worldwide.[14] Although there is a higher prevalence of cervical cancer in developing countries, there is still a need to decrease the rate of cervical cancer in the United States.[14] Pap smear screening (discussed later) and regular gynecologist appointments have contributed significantly to the decline of cervical cancer. However, for young women, the incidence of cervical cancer has increased. This shift in trend may be the result of increased rate of Human Papillomavirus (HPV) among young women, further explained in section 1.5.[22]

Trends

Overall, cancer rates have steadily declined over the past decade.[15] The Annual Report to the Nation on the Status of Cancer helped determine cancer incidence, mortality, and trends in the United States using some of the most trusted national cancer databases and organizations. Overall, cancer rates for both male and female are 454.0 per

100,000 people and have declined 2.1% from 2008 to 2012.[15] When we look at women alone, cancer rates are 412.6 per 100,000 women and have decreased 0.8% from 2008 to 2012.[15] Although overall cancer incidence among women has declined slightly, cervical cancer has decreased 1.3% from 2008 to 2012 for all racial and ethnic groups.[15] Once separated by ethnicity, Whites, Blacks, Asian Pacific Islanders, Hispanics, and Non-Hispanics have had decreased cervical cancer incidence by 1.1%, 2.3%, 3.0%, 3.9%, and 1.1% respectively from 2003 to 2012.[15] American Indian/Alaska Natives were the only racial group that remained the same during this period.[15]

Examining cancer-related death rates in the United States, the mortality rate for all cancers including both male and female is 171.2 per 100,000 people and has decreased 1.5% from 2008 to 2012.[15] Looking at women alone, the mortality rate for all cancers is 145.4 per 100,000 has decreased 1.4% from 2008 to 2012.[15] Although cervical cancer has been ranked as the 13th most common cancer in the United States, its ranking for mortality is number 14.[15] In other words, cervical cancer is slightly more prevalent compared to other type of cancers but is not always fatal. The overall mortality rate for cervical cancer in all racial ethnic groups is 2.3 per 100,000 women and has decreased 0.9% from 2008 to 2012.[15] Once separated by ethnicity, Whites, Blacks, Asian Pacific Islanders, Hispanics, and Non-Hispanics have had mortality rates decrease by 0.6%, 2.2%, 3.1%, 2.3%, and 0.8% respectively from 2003 to 2012.[15] Thus, American Indian/Alaska Natives were the only racial group whose mortality rate remained the same during this period.[15] Overall, cancer**,** cervical cancer incidence, and cervical cancer mortality have steadily declined over the past few years.

The CDC has also plotted the incidence and mortality rate for cervical cancer in the United States.[23] Figure 1.1 illustrates apparent clusters in some regions. The most noteworthy region is the lower half of the Southern central portion of the United States including Texas, Oklahoma, Arkansas, Louisiana, Mississippi, and Alabama.[23] The southern central region had the highest incidence rate in the United States followed by the middle central states including South Dakota, Nebraska, Kansas, Missouri, and Illinois etc.)[23] The state of Georgia has a high cervical cancer incidence rate of 7.6 to 8.7 per 100,000 women. Figure 1.2 demonstrates a similar trend for cervical cancer mortality rates in the United States.[23] The mortality rate for cervical cancer in the state of Georgia is indicated between 1.9 to 2.2 per 100,000 women.

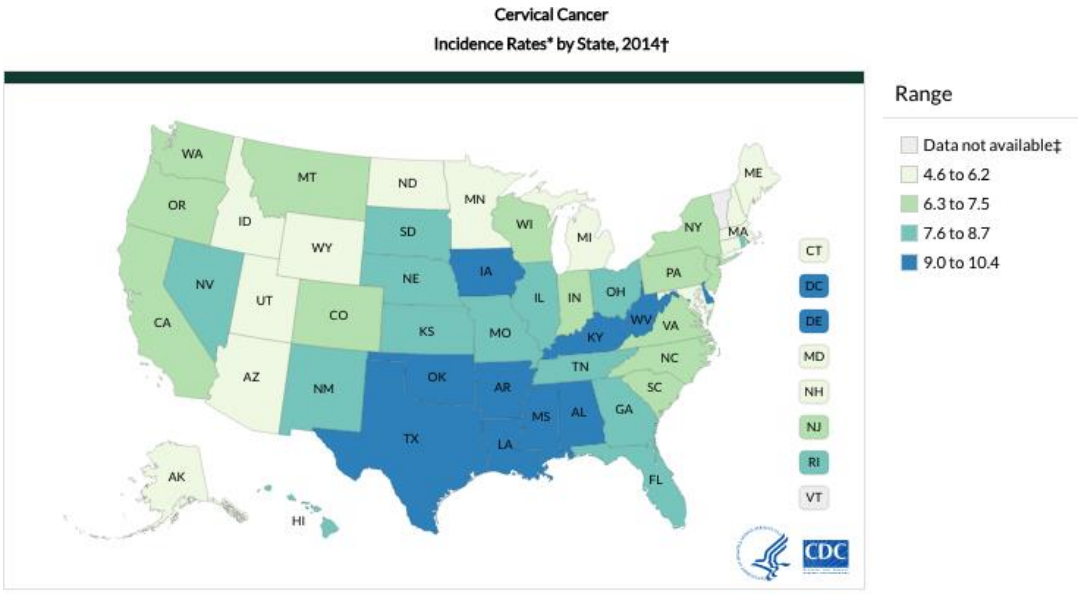


Figure 1.1 Cervical Cancer Incidence Rates by State, 2014[23]

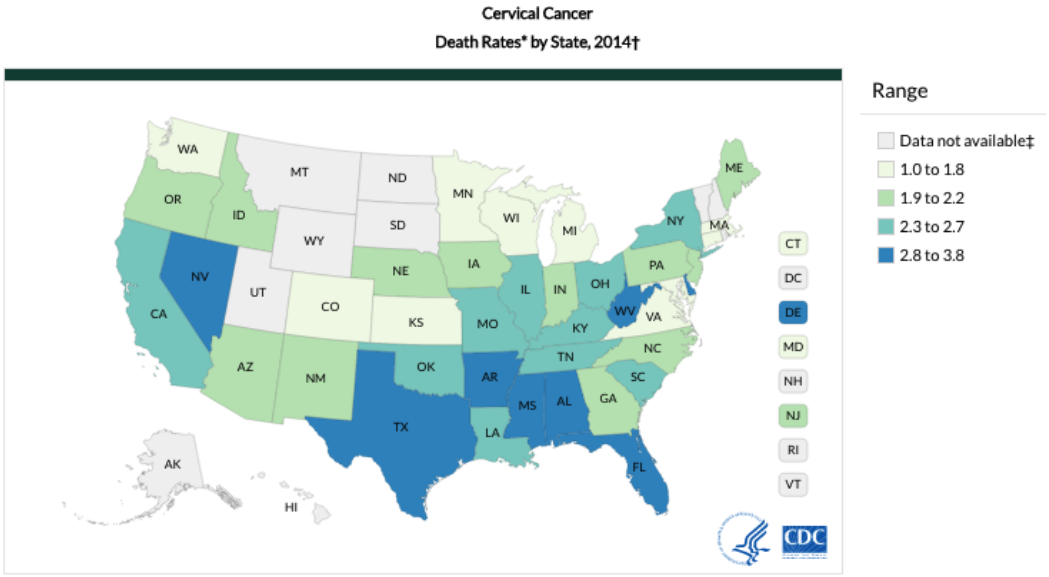


Figure 1.2 Cervical Cancer Death Rates by State, 2014[23]

1.5 Risk factors

HPV

There are several common risk factors known to increase or cause the development of cervical cancer. The primary cause of cervical cancer is HPV. HPV is a skin-to-skin infection caused by the DNA virus, *human papillomarvirus*. The most common mode of transmission for HPV is through vaginal or anal skin-to-skin contact.[24] *Human papillomarvirus* is part of the papillomavirus family, which has over 200 different genotypes.[25] Out of the 200 different genotypes, approximately 40 are transmitted sexually via anogenital contact.[25,26] While most genotypes are asymptomatic and resolve spontaneously, others may cause benign or malignant lesions.[25] The most common genotypes are 6, 11, 16, 18 and 31.[25] Genotypes 6 and 11 are usually benign and considered less harmful, whereas genotypes 16 and 18 are usually malignant and considered more severe.[25] In fact, studies have shown that 75% of all cervical cancers occur as a result of HPV16 and HPV18 infections.[27] In addition, HPV infections can

cause genital lesions on the penis, vulvar, vagina or anus. If left untreated, lesions may increase the risk of cancer of the cervix, vulva, vagina, penis, anus, mouth, or throat.[28,29] Occasionally, a mother can infect her baby during her pregnancy but HPV cannot spread through fomites such as toilets or articles of clothing.[30] HPV only affects humans and a person can be infected with more than one type of HPV.[31] While HPV itself is not fatal, contracting cervical cancer can be fatal.

Risky sexual behavior

Risky sexual behavior is the primary risk factor for both HPV and cervical cancer, since risky sexual behavior increases the risk of HPV, which simultaneously increases a women's risk for cervical cancer.[24,32] Risky sexual behavior can be defined as any behavior that will increase an individual's risk of contracting a sexually transmitted infection or becoming pregnant.[33] Some examples of risky sexual behavior may be lack of condom use, drinking alcohol, or having multiple partners. It is suggested that "risky behaviors" begin in high school and peak in college. The CDC reports that 41% of US high school students have had sexual intercourse and, of these high school students, 43% did not use a condom during their last sexual encounter, 14% were not using any method of birth control, and 21% drank alcohol.[34,35] A recent study also found that 33% of college-aged students had two to five sexual partners, 15.5% had six to ten partners, and 16.6% had 11 or more sexual partners.[36] When asked about condom use, 50.9% reported having unprotected vaginal intercourse, and 12.4% of females had an unplanned pregnancy.[36] It was also reported that 58.1% of the students surveyed admitted to consuming alcohol prior to or during sex.[36] An additional risk factor is early onset of sexual intercourse, due to a longer exposure period. The earlier an individual begins

sexual intercourse, the longer their sexual experience period, which makes individuals in their early 20s most at risk.[37] While these risky sexual behaviors occur across genders, HPV disproportionately affects women more than men due to the sensitivity and vulnerability of the vagina.[38,39]

Family history

A family history of cervical cancer may also increase individuals' risk for cervical cancer up to three times.[20] Some researchers believe cervical cancer can be inherited from family members.[20]

Other risk factors

There are several other risk factors for cervical cancer, including a weakened immune system, smoking, multiple pregnancies, long-term use of oral contraceptives, and sexually transmitted infections. A weakened immune system can make it difficult to fight infection,[28,38] and smoking increases exposure to harmful cancerous substances if inhaled.[20,40] Multiple full-term pregnancies can also increase a woman's risk for cervical cancer.[20,41] Although the reason is not clear, it is suggested that hormonal changes during pregnancy may increase a women's risk for HPV infection and cancer development.[32] It is also suggested that pregnant women may have a weaker immune system during pregnancy, causing them to be more susceptible to HPV infection or cancer development.[32] In addition, women who take oral contraceptives for five to nine years are three times more likely to develop cervical cancer.[41] The link between oral contraceptives and cervical cancer is unknown. However, since oral contraceptives protect against pregnancy but have no protection against HPV, oral contraceptive users may have a false sense of security. Finally, sexually transmitted infections (STI) such as HIV or chlamydia

may also increase an individual's risk for cervical cancer because they can weaken a woman's immune system, making it difficult for the body to naturally protect against cancerous cells.[20]

Populations most at risk

Since 90% of all cervical cancer is attributable to HPV, women who are currently infected with HPV are at highest risk for cervical cancer.[42] In addition, because HPV is transmissible through sexual contact, women who practice risky sexual behaviors such as not using protection, having multiple sex partners, and consuming alcohol prior to or during sex may be at an increased risk for HPV, which may lead to cervical cancer.[33] Other populations at higher risk for cervical cancer include women between the ages of 35 and 44.[43] While it is still possible for women outside of this age group to develop cervical cancer, the majority of women diagnosed are middle aged women. Lastly, minorities such as Black, Hispanic, and American Indian women are most at risk for developing cervical cancer for unknown reasons.[44]

1.6 Protective factors

Unfortunately, since the cause of cervical cancer is not completely known or understood, there are no preventative factors to completely eliminate a women's risk for cervical cancer.[3] Nonetheless, discussed below are some practices that may reduce a women's risk for HPV, which can later develop into cervical cancer.

Abstinence

Since cervical cancer has been linked to genetics, individuals with no sexual experience are still at risk for cervical cancer.[20] However, since HPV is the primary risk factor for cervical cancer and HPV is primarily transmissible through sexual activity,

anyone who is sexually active is at risk for HPV infections. The only way to completely refrain from HPV exposure is to practice abstinence.[45] Abstinence means sustaining from any sexual activity such as anal, vaginal, or oral routes, penetration, or participating in genital skin-to-skin contact. Although sexual intercourse is the most common mode of transmission for HPV, it may also be transmissible through non-penetrative sexual activity.[46] Some data suggests that abstinence programs are not effective in deterring adolescents from engaging in sexual activity.[47] In fact, studies show that adolescents in abstinence programs engage in sexual activity at a similar rate and age when compared to adolescents who did not receive an abstinence program.[47] Thus, while abstinence is effective for reducing HPV exposure and cervical cancer risk, it may not be a realistic option for protecting against the disease.

Safe sex practices

As previously stated, practicing "risky sexual behavior," such as not using protection during sexual activity, will increase a person's risk for contracting HPV. Therefore, practicing "safer sex," defined as minimizing one's risk of contracting a STI such as consistently and properly using condoms, has been effective in preventing an HPV infection.[46,48] While condoms are 98% effective in preventing pregnancy, the same is not true for HPV. For example, a condom whether male or female, only convers a portion of the genitals, whereas HPV can also be transmissible through areas not covered by the condom such as the anus, scrotum or vulva.[45] A study in the New England Journal of Medicine found that consistent condom use can prevent HPV infection up to 70%.[49] Research suggests a high rate of HPV among young adult women because of lack of condom use and HPV awareness.[50,51]

Refraining from multiple sexual partners is another "safe sex" practice for reducing the risk of getting a sexually transmitted infection or HPV.[41] However, while it is logical that multiple sex partners may increase individuals' risk of HPV, this does not mean a person with one sexual partner cannot be infected. HPV, like human immunodeficiency virus, can be transmitted to another individual as a result of one sexual encounter with an infected person.

Barriers to safer sex

A recent study reported that more than half (51%) of participants who engaged in vaginal intercourse either did not use a condom or used it inappropriately.[52] Participants who used condoms incorrectly or not at all reported that condoms "spoil" the mood and are a "turn off", suggesting that condoms are not comfortable.[52] Interestingly, those who dislike condoms but use them correctly and consistently benefitted from condom use.[52] As an intervention to promote maximum condom use it was suggested to "sexualize condom" use in the media to make condoms more pleasurable to attract sexually active individuals.[52]

In a study conducted on African American college students, self-efficacy was one of the biggest barriers to safer sex.[48] The study demonstrated or recommended more educational programs teaching students how to properly use a condom as well as building the credibility of condom use by using African American role models to change behavior.[48] Another study examined African American college students and their perceived barriers towards safer sex.[53] African American males reported that their top three reasons for not practicing safer sex were trust in their partner, living for the moment, and negative views about condoms.[53] Females reported their top three reasons

were negative views about condoms, feeling invincible, and trust in their partner.[53] Additional barriers to safer sex practices included lack of self-control, peer pressure, unavailability of condoms, the practice of pulling out before ejaculating, decisions to get pregnant, a lack of knowledge regarding the consequences, a lack of self-respect, excitement that leads to forgetting to use protection, condom cost, religious beliefs, allergies to latex, and alcohol or drug consumption.[53,54]

Vaccinations

One of the greatest accomplishments in HPV research was the development and clinical effectiveness of prophylactic vaccines to prevent HPV infection. The two most commonly used and Federal Drug Administration (FDA) approved vaccines are Gardasil and Cervarix, approved in 2006 and 2009 respectively. Both vaccines protect against the most severe HPV genotypes, 16 and 18, and against the lesser HPV genotypes, 6 and 11.[55] Before Gardasil and Cervarix are fully effective, multiple doses are required. Nonetheless, both vaccines are highly effective and immunogenic when successfully administered.[56] In addition, when an infected woman is vaccinated, the vaccine will not cause harm and can aid in protecting the body against other HPV genotypes.[57-59] Although preventive vaccines are highly effective, there is still a need for therapeutic HPV vaccinations.

Types of vaccinations

Gardasil is the gold standard for HPV preventative vaccination because it protects against twice as many HPV genotype as Cervarix. There are two types of Gardasil: the original Gardasil, and Gardasil 9. The original Gardasil was approved by the FDA in 2006 and Gardasil 9 was approved in 2014 as a new and improved vaccination to the

original Gardasil.[58,59] The original Gardasil and Gardasil 9 was manufactured similar and contain some of the same components.[59] To differentiate their protection, the original Gardasil only protects against HPV 6, 11, 16, and 18 while Gardasil 9 protects against 6, 11, 16, 18, 31, 33, 45, 52, and 58.[58,59] The FDA recommends both the original Gardasil and Gardasil 9 for females 9 through 26 years of age for the prevention against cervical, vulvar, vaginal and anal cancer, genital warts and several other lesions.[58,59] However, neither Gardasil (the original or Gardasil 9) has proven effective in women over 26 years of age.[58,59] Both Gardasil vaccines are recommended for males ages 9 through 26 years of age for the prevention of genital warts, anal cancer and several other lesions.[58,59] For the original Gardasil the vaccine should be administered on a three-dose schedule: 0, 2, and 6 months.[58] For Gardasil 9 there are two possible vaccine dose regimen.[59] If the patient is between the ages of 9 and 14 then they can either have a two- or three-dose regimen.[59] The two-dose regimen has the following schedule: 0, and 6 -12 months. The three-dose regimen is at 0, 2, and 6 months but if the patient is between the ages of 15 and 26 they will also get a 3-dose regimen at 0, 2, and 6 months.

Side effects of the vaccine may deter some individuals from completing the course. Some of the most common adverse side effects for both Gardasil vaccines are syncope, headache, fever, seizures, pyrexia, nausea, dizziness, fatigue, injection site pain, swelling, erythema, pruritus and bruising.[58,59] Despite these side effects, both Gardasil vaccines has a high efficacy rate across all clinical studies.[58,59] However, both Gardasil vaccines is most effective if the patient completes all three doses at the following schedule: 0, 2 months, and 6 months.[58] Nonetheless, if the individual did not complete the

three-dose cycle, there is still some evidence for protection against the specified HPV genotypes.[60-62]

Cervarix is approved for females between the ages of 9 and 25 for the protection against cervical cancer and pre-cancer lesions caused by HPV 16 and 18.[57] The injection is also administered in three doses: 0, 1, and 6 months. Reports from a study has shown that one or two doses of Cervarix can be effective in long-term HPV 16 and 18 protection.[62-64] Some of the most common adverse side effects are headaches, fatigue, syncope, muscle aches, nausea, vomiting, diarrhea, stomach pain, and pain, redness, and swelling at the site of the injection.[57] Despite these side effects, Cervarix has a consistently high efficacy score of 92.8 and 94.9% efficacy in preventing cervical cancer and precancerous cells caused by HPV 16 and 18 conducted in studies among females between 15 and 25 years of age.[57] It is also worth noting that Cervarix protects against cervical cancer and not recommended for males.

Despite the success of these vaccines, cervical cancer screening is still optimal because vaccinations are not treatments for HPV, STIs or any external lesions but rather protect against specific genotypes.[57-59]

Controversy of HPV vaccinations

The main controversies for HPV vaccinations are related to the age of vaccination and long-term efficacy and safety.[65] Although nine is the minimum age required to receive a HPV vaccination, the Advisory Committee on Immunization Practices highly recommends vaccination of 11-12 year olds.[66] The younger age group is preferred because a study showed that more than a quarter of 14 and 15 year old females are sexually active or have previously engaged in sexual intercourse.[66] While some believe

adolescents are still too young to be vaccinated against a sexually transmitted infection, others argue that 11 and 12 years of age is an appropriate age for pre-exposure prior to them becoming sexually active. The HPV vaccination is most efficacious if a HPV-negative female is vaccinated prior to HPV exposure.[42]

Another controversy is the vaccination of minors accompanied by the fear that the vaccination for immunity against cervical cancer will increase sexual promiscuity among young women.[67] Parents are hesitant to vaccinate their children because they believe their child is not sexually active but fail to understand that vaccination is to prevent the disease and must be administered prior to the individual becoming sexually active. Others argue immunity from a sexually transmitted infection does not promote sexual activity but rather "parental monitoring", peers, and age of sexual partner promotes sexual activity.[67] Another point of controversy is one's religious beliefs. If parents believe that HPV vaccination is against their religious beliefs then it would be unethical for HPV vaccines to be mandated.[65] To date, only three states (Virginia, Rhode Island, and Washington, D.C.) mandate HPV vaccination among adolescent females.[68] Despite the fact that most people oppose HPV mandates, research shows that mandates have increased immunizations and access to vaccinations among some underserved populations.[69]

Despite the fact that women between the ages of 27 and 45 years of age could still benefit from vaccination if they have not been previously infected with HPV,[70] the FDA does not recommend vaccination of women over the age of 25 due to lower efficacy and the high cost of the vaccine and screening. It has been reported that vaccinating older women would be too costly.[71] However, women 26 years of age or older can still get

vaccinated, but the vaccination cost will not be covered by insurance since the drug had not been FDA approved for this age group.[72]

Another concern is the long-term efficacy and safety of the vaccination. Although the HPV vaccination has been known to be extremely effective, scientists are still uncertain on the length of time the HPV vaccine will protect against HPV. For example, the longest clinical trial has only been for five years.[73] Furthermore, it is unknown whether the vaccination will continue to protect against HPV infections for a lifetime or if a booster injection will be necessary. In addition, concerns remain about the safety of the HPV vaccine and reported adverse reactions.[74] Although these vaccines are FDA approved and deemed safe, there have been a few unforeseen incidents.[74] In 2009, several studies reported serious adverse side effects from Gardasil such as autoimmune diseases, blindness and paralysis.[75-78]Although the side effects were extremely rare, the administration of HPV vaccinations warranted parental and health professional concerns.

1.7 Cervical cancer screening

Pap smear

A Pap smear is a test used to examine cervical cells for abnormality in the detection or prevention of cervical cancer.[2,79] A Pap smear test is the only cervical cancer screening procedure recognized by all three major cancer organizations; the American Cancer Society (ACS), the U.S. Preventative Services Task Force (USPSTF), and the American College of Obstetricians and Gynecologists (ACOG).[4-6] The Pap smear detects early or progressive stages of cancerous cells in the cervix. During a Pap smear, the health provider directs the female to undress from the waist down. The patient is placed in a recumbent position with her knees bent. The provider uses a speculum to prop open the vagina walls.[2,79] A spatula is then inserted inside the vagina in order to collect a small

sample of the cells from the cervix.[2,79] The sample of cervical cells removed from the cervix of the patient is sent to the lab for evaluation.[79] If the lab results are abnormal, the patient will be highly recommended for follow-up with the provider. A positive Pap smear does not mean that the woman has cervical cancer but rather indicates the presence of abnormal cells of the cervix and is recommended for further testing.[2,79]

The USPSTF, ACS, and ACOG recommends that all women get a Pap smear every three years.[4-6] However, the ACS and ACOG prefer women between the ages of 30-65 to get a Pap smear combined with an HPV test (explained below) every five years.[4,6] Prior to 2012 the old Pap smear practice was to screen women less than 21 years of age if sexually active, however this guideline is no longer practiced, since most abnormal cell growth will resolve on its own and treatment will do more harm than good.[5,80] In addition, yearly routine screenings are not recommended by the ACS or ACOG. Women between the ages of 20 and 65 who have NOT had a history of abnormal Pap smears are recommended to be screened every five years.[5] Also, women who have had a hysterectomy are not required to receive a Pap smear since the uterus has been removed.[5]

The high effectiveness and low adherence of Pap smear screening are reasons why two of the Healthy People 2020 goals addressed 1) increasing the proportion of women who receive cervical cancer screening based on the most recent guidelines and 2) increasing the proportion of women who were counseled by their providers about Pap smears.[17] Currently, approximately 85% of women received a cervical cancer screening based on the most recent guidelines, although the target is 93%.[17] In addition,

approximately 60% of females were counseled by their health care providers about Pap smears but the target is 66%.[17]

Pap smear screenings are known to have high reliability and validity. A study conducted in 2011 evaluated the effectiveness of Pap smear screenings and reported 83% sensitivity, 98% specificity, 97.9% positive predictive value, and 80% negative predictive value.[7] These results explain the effectiveness of the Pap smear test in identifying women who do have HPV or are at risk for cervical cancer and correctly identifying women who are HPV negative and not at risk for cervical cancer. Despite the effectiveness of the test, false positives and false negatives are still possible.

Liquid-based cytology (LBC)

The process of a LBC test is similar to that of a Pap smear but once the cells of the cervix are collected, they are mixed with a special liquid before the specimen is sent to a lab for processing and screening.[45] The advantage of LBC is that it is time efficient and requires fewer rescreening due to inadequate or insufficient samples.[45] The disadvantage of LBC is that it is more expensive than the conventional Pap smear screening, and insufficient data is available regarding its effectiveness.[45] LBC is not recommended by the USPSTF but is recognized by the ACS and the ACOG.[4,6] In addition, some organizations use the term Pap smear and LBC interchangeably despite them being different tests. The ACS and the ACOG recommends women to get a Pap smear/LBC test (same as Pap smear) every three years.[4,6]

HPV testing

The process of HPV testing is similar to a Pap smear but the swab used to collect the cells of the cervix tests for the HPV virus rather than changes in the cells of the

cervix.[45] The advantage of HPV testing is that a negative test means no HPV and it has a high specificity in women over 35 years of age.[45] A disadvantage is that it has a low specificity on young adult women, and is costly.[45] The ACS and the ACOG recommends that women 30 years and older get a Pap smear and HPV test every five years until the age of 65 or get a Pap smear every three years until the age of 65.[4,6]

1.8 Cervical cancer diagnosis

The first step in a cervical cancer diagnosis is the presence of an abnormal Pap smear. Once the assigned health provider has confirmed a positive Pap smear, several diagnostic options are available to test for cervical cancer. Prior to offering these tests, the provider will inquire about the patient's sexual activity and symptoms. If the provider has not already done so, a pelvic exam will be performed before the diagnostic test. The three diagnostic tests are a colposcopy, endocervical scraping, and cone biopsies.[81]

A colposcopy is similar to a Pap smear in the sense that the patient is positioned in similar manner for the exam; the healthcare provider uses a speculum to visualize the cervix, and a colposcopy to examine the cervix. If the physician notices anything abnormal on the cervix, a biopsy (tissue removal) will be performed and sent to a lab for further examination.[81] In cases where the cervix cannot be examined via the colposcope, an endocervical scraping may be performed.[81] During an endocervical scraping, a curette, which is a long narrow instrument, is inserted into the cervix and used to scrape the inside of the canal for a tissue sample.[81] A cone biopsy is the removal of a cone-shaped piece of tissue from the cervix, using one of the following methods: loop electrosurgical procedure or cold knife cone biopsy.[81] For a loop electrosurgical procedure, the tissue is removed using a heated electrical wire.[81] In a cold knife cone biopsy, a surgical scalpel or

laser is used to remove the tissue.[81] In some cases, if the cancerous site is small or if it is detected that the tissue is precancerous, the biopsy may be effective in removing all the abnormal tissue at the site and function as the treatment.[81]

All biopsies are reported based on the cervical intraepithelial neoplasia (CIN) depending on the level of abnormal cells.[81] CIN1 means there is limited abnormal tissue growth, CIN2 means there is a moderate amount of abnormal tissue and CIN3 means there is a lot of abnormal tissue.[81] In cases where cancer is present, further testing is needed to determine the extent and pervasiveness of the cancer. In a cystoscopy or proctoscopy, a tube is inserted in either the bladder or rectum, respectively to determine if the cancer has spread to these structures.[81] In other cases, a chest x-ray, computer tomography, magnetic resonance imaging, intravenous urography, or positron emission tomography may detect the spread of cancer in other areas.[81]

1.9 Cervical cancer stages (prognosis)

Once a woman is diagnosed with cervical cancer, treatment options are usually determined by the cancer's stage. There are two types of systems used to determine the stage or progression of cervical cancer: the International Federation of Gynecology and Obstetrics (FIGO) staging system and the American Joint Committee on Cancer (AJCC) TNM staging system.[11] The FIGO staging system is usually used when examining women's reproductive organs while the AJCC TNM staging system is used to classify the cancer.[11] Cancer can be classified based on three factors: the extent of the main tumor (T), the spread of the tumor to lymph nodes (N), or metastasis, the spread of the tumor to other distant parts of the body (M).[11] When examining the extent of the main tumor, there are four possible stages: Tis, T1, T2, T3, and T4. Tis is the detection of cancerous cells

only on the surface of the cervix.[11] T1 is the detection of cancerous cells on the surface of the cervix and also spread to deeper tissue of the cervix.[11] T2 is the cancerous spread to the upper part of the vagina, and T3 is the spread of the cancer to the lower part of the vagina or the walls of the pelvis.[11] T4 represents the spread of cancer to the bladder, rectum, and outside of the pelvis.[11] The progression of the stages indicates the pervasiveness of the cancer.

Another factor for classifying cervical cancer is if the cancer has spread to the lymph nodes. There are three categories for determining if a cancer has spread to nearby lymph nodes. NX is used if the lymph nodes cannot be examined.[11] N0 is used if the cancer has not spread to nearby lymph nodes and N1 is used if the cancer has spread to nearby lymph nodes.[11] The classifications to determine the spread of cancer to other parts of the body are M0, indicating no spread, and M1, when the cancer has spread to other organs such as the lungs or the chest.[11]

1.10 Treatment

Treatment for cervical cancer is dependent upon the prognosis of the cancer.[20] It is also possible for a woman to undergo multiple treatments depending on her stage of cancer. The most common types of treatment for cervical cancer are surgery, radiation therapy, chemotherapy, and targeted therapy.[20] Surgery is often used for women who are in the early stages of cancer. When surgery is used as the treatment for cancer, the cancerous tissue or cells are either cut and removed or lazered to destroy the cancerous tissue.[20] The most common types of surgery for cervical cancer are cryosurgery, laser surgery, conization, simple (total) hysterectomy, radical hysterectomy, trachelectomy,

pelvic exenteration, pelvic lymph node dissection, and para-aortic lymph node sampling.[20]

Radiation therapy refers to the use of radioactive particles to kill cancerous cells.[20] The benefit of radiation therapy is that it can be used to treat cervical cancer cells that have spread to other parts of the body.[20] The most common types of radiation therapy are external bean radiation and brachytherapy.[20] Chemotherapy refers to the use of anti-cancer drugs used inside the body to help kill or destroy cancerous cells.[20] Chemotherapy is the most aggressive treatment option for cervical cancer. Although it can be highly effective, chemotherapy can have major side effects such as nausea, vomiting, loss of appetite, loss of hair, mouth sores, fatigue, menstrual side effects, neuropathy, and increased risk of leukemia in its users.[20]

1.11 Significance of the study

The National Center for Health Statistics has reported the most recent Pap smear adherence among women in the United States [8] The overall percentage of lifetime Pap smear use among women 18 years and older was 72.9% in 2015.

The reported percentages of women who have received a Pap smear within three years by age are as follows; 81.4% of women between the age of 21 and 44 years of age, 81% of women between the ages of 45 and 65 years of age, and 49.9% of women 65 years of age and over.[8] According to this statistic, 21 to 44 year old women are just as likely to receive a Pap smear as women who are between the ages of 45 and 64. Since the recommendation to receive a Pap smear is for women between the ages of 21 and 64, it is expected that Pap smear use among elderly women would be lower.[5]

The reported percentages of women who have received a Pap smear within three years by race are as follows; 73.9% of Whites, 77.9% of Blacks or African Americans, 65.5% of American Indians or Alaska Natives, and 67% of Asians.[8] It is interesting to note that Blacks and African Americans have the highest Pap smear use, which is beneficial since Blacks are at a higher risk for cervical cancer.[44]

The reported percentages of women who received a Pap smear within three years by level of education are listed as follows; 61.7% of women with no high school diploma or GED, 67.9% of women who have a high school degree or GED, and 82.9% of women with some college or more education.[8] It is apparent that the more education a woman has, the higher her likelihood of being up-to-date with cervical cancer screening.

As was discussed, many women are receiving a Pap smear from their physician or gynecologist but there are still a significant number of women not adhering to the recommended Pap smear guidelines. Pap smears are fast, simple, easy, and an effective way to detect potential precancerous cells and prevent the development of cervical cancer. Examining the barriers and brainstorming solutions in overcoming these barriers will drastically improve Pap smear adherence among women.

1.12 Study purpose and research questions

The purpose of this project is to examine the application of the Health Belief Model (HBM) to Pap smear adherence by examining the predictive utility of perceived benefits, perceived susceptibility, perceived severity, self-efficacy, cues to action, and perceived barriers in order to identify solutions to Pap smear non-adherence and increase cervical cancer screening among eligible women. This study will inform health care

professionals of possible solutions to help minimize and/or eliminate barriers for women who are hesitant to comply with present or future Pap smear recommendations.

Short-term goal

A primary goal of this project is to 1) add to the pre-existing Health Belief Model Scale for Cervical Cancer and Pap Smear Test in order to identify a complete list of barriers that prevent women from obtaining a Pap smear and 2) to conduct focus groups to explore participants' perceived solutions to overcome and/or eliminate these barriers.

Long-term goal

The long-term goal of the proposed study is to aid Healthy People 2020 in increasing the proportion of women who receive a cervical cancer screening based on the most recent guidelines released in 2008. Currently, 84.5% of females aged 21 to 65 years received cervical cancer screening.[17] While the ultimate goal is to reach 100%, the current target is that 93% of women in this age range will receive recommended screening.[17] In the long-term, this study will provide important insight to help address Healthy People 2020 goal of 93% of women receiving cervical cancer screening.

Research Aims

1) Modify existing measures to develop a new HBM scale for Pap smear adherence.

- Research Question 1: Do the HBM subscales (perceived barriers to Pap smear adherence, perceived benefits of Pap smears, perceived susceptibility and perceived severity of cervical cancer, cues to action for Pap smears, and/or Pap smear self-efficacy), have adequate internal reliability?
- Research Question 2: Does the modified barriers scale adequately capture the barriers reported by women?

2) Test the predictive utility of the HBM for predicting Pap smear adherence.

- Hypothesis 1: Perceived barriers will have a negative relationship with Pap smear adherence, such that as a person's level of perceived barriers increases, their likelihood of adherence will decrease.
- Hypothesis 2: Perceived benefits will have a positive relationship with Pap smear adherence, such that as perceived benefits increase, their likelihood of adherence will also increase.
- Hypothesis 3: Perceived susceptibility will have a positive relationship with Pap smear adherence, such that as a person's threat level increases, their likelihood of adherence will also increase.
- Hypothesis 4: Perceived severity will have a positive relationship with Pap smear adherence, such that as a person's threat level increases, their likelihood of adherence will also increase.
- Hypothesis 5: Cues to action will have a positive relationship with Pap smear adherence, such that as a person's cues to action increase, their likelihood of adherence will also increase.
- Hypothesis 6: Pap smear self-efficacy will have a positive relationship with Pap smear adherence, such that as a person's self-efficacy increases, their likelihood of adherence will also increase.

3) Explore participants' proposed solutions for reducing barriers to Pap smear adherence.

- Research Question 3: Using an interactive focus group discussion, what solutions do women propose for increasing Pap smear adherence?

CHAPTER 2: REVIEW OF LITERATURE

2.1 Overview of Pap smear adherence

As discussed in chapter 1, Pap smears are highly effective in detecting and preventing cervical cancer, however, many women are not up-to-date with their Pap smears. Women need to be educated, barriers need to be addressed, and encouragement needs to be heard from providers to increase the number of females getting a Pap smear. When women are aware of the need for a Pap smear and are encouraged to be tested, with the absence of barriers, the rate of Pap smears should increase. The National Center for Health Statistics has reported approximately 80% of women are currently up-to-date with their Pap smear.[8]

In sections 2.2 and 2.3, the predictors and barriers to Pap smear screenings will be discussed. Predictors are defined as factors that would increase a woman's likelihood of getting a Pap smear, and barriers are defined as factors hindering women from receiving a Pap smear. In section 2.4, solutions and interventions implemented to increase the rate of Pap smear adherence among women will be discussed.

2.2 Predictors of cervical cancer screening

Previous literature has found multiple variables that increase a woman's likelihood of receiving cervical cancer screening. Some of the most common positively-associated predictors are higher education,[82-84] higher financial status,[84-86] cervical cancer and HPV knowledge,[87-91] and health insurance coverage.[84-86,92,93] As one's socioeconomic status improves, individuals who have increased knowledge, health insurance, and secure

finances are more likely to embrace screening. Inconsistencies exist regarding the impact of the age of women on cervical cancer screening. Some researchers argue older women are more likely to get a Pap smear while others argue younger women are more likely to get a Pap smear.[82,87,88,91,94] These inconsistencies in findings could be a result of variation in age group among study populations. Studies with immigrant populations suggest that cervical cancer screening likelihood increases with longer United States residency or higher levels of acculturation.[87,88,90,92,94-96] Being married also increases the likelihood of women being screened for cervical cancer, especially among certain racial and ethnic groups.[82,84,87-89,94,95] Lastly, research has suggested that women's current health practices may be predictors of cervical cancer screening. Women who maintain a healthy body weight are more likely to be screened for cervical cancer than women who are either over- or underweight. [82,93] In addition, women who are up-to-date with breast cancer screening are also likely to have received cervical cancer screening.[84,91]

2.3 Barriers to cervical cancer screening

Sociocultural barriers

In the United States, barriers to Pap smear screening can be categorized within three groups: socio-cultural, institutional, and personal barriers (see Table 2.1). Sociocultural barriers consist of social beliefs, expectations, and norms of what is considered acceptable for that culture. Among research studies, some of the common factors related to Pap smear screening are social influence, cultural beliefs, and healthcare expense, especially for women who did not have health insurance.[83,94,97-103] Women indicate that friends and family influence their decision to receive a Pap smear, whether the experiences are positive or negative.[98,100,101,104,105] Further, in the African American

community, a woman's mother, in addition to her health care provider, plays a crucial role in her decision to receive a Pap smear.[105] Other studies have found that if the participants friends or family did not receive Pap smear exams, they were unlikely to do so as well.[98]

Among Mexican women, husbands often serve as an additional barrier, preventing women from receiving Pap smears.[100] However, when a health care professional reinforces Pap smear exams, women are more likely to adhere.[94,105] One study found that once women engage in regular Pap smear exams, the influence from others are no longer significant because the habit is already formed.[94] Social influences from the media however, are also a concern. One study mentioned the media as a barrier, stating that when women heard from the news that the Pap smear test is not accurate ,it also prevented women from getting tested.[98] In addition, financial expenses such as copays was also a concern for women.[83,98,99,101]

All studies that mentioned culture as a barrier consisted of participants that were Mexican, Hispanic, Muslim or Vietnamese.[100-103,106] These cultures valued modesty and sexual topics were prohibited from discussion.[100,101,103] In addition, some Mexican women had a misconception that Pap smear exams also test for sexually transmitted infections, which deterred most women from getting screened for fear of being stigmatized for premarital sex or for questioning their husband's fidelity.[100] Also, some Hispanics thought it was worthless to see a healthcare provider or receive a Pap smear exam unless they were sick or displaying symptoms.[101] Finally, it is important to note that acculturation was associated with being more likely to have had a Pap smear exam.[102]

Institutional barriers

Institutional barriers, suggested by other research studies, consist of healthcare access, provider characteristics, and health insurance. Some of the most common barriers in this category include the use of male physicians,[101,105,107] lack of physician/provider recommendation,[97,98,101] lack of health insurance,[97,100,107,108] and scheduling conflicts.[98,104] The sex of the physician was a concern because women did not feel comfortable being exposed to or examined by a male physician,[98,101,103,105] and the experience was described by some women as embarrassing.[105] Another concern was that healthcare professionals are not counseling or recommending that women receive a Pap smear,[97,98,101] so most women may not view Pap smear screening as a priority or even be aware of the necessity of the exam.

Some women, especially immigrants, who desire to receive a Pap smear are unable to do so because they do not have health insurance,[97,100,107,108] Consequently, if a person does not have health insurance they are also less likely to have a doctor[97] or utilize a healthcare facility,[107] which is in itself another deterrent. Therefore, many immigrants who desire testing may not do so because of access. Another concern of immigrants was language barriers.[101,104,109] It is often difficult for the non- English speaking individuals to understand their providers or health literature.[101,109] It has been suggested that non-natives prefer to have health information given to them in their first language, despite being bilingual.[104]

Healthcare access is another barrier, such as proximity to healthcare facilities and a lack of transportation, especially in rural communities.[94,101,104,110] Another study also examined the diversity of physicians that are willing or equipped to perform Pap smear

exams on disabled or handicapped women.[110] The availability of childcare is another important barrier. For example, due to the nature of the exam, childcare is needed but is often unavailable and/or unaffordable for women.[104] In addition, scheduling is also a problem. Women are frustrated about the scheduling process, including time constraints, inconvenient appointments, and long waiting periods.[98,104]

Personal barriers

The final group of barriers identified by research refers to personal barriers, including Pap smear knowledge, emotions, and pain. The most common personal barriers were based on emotions. Emotional barriers were fear of pain,[83,94,97,99] diagnosis[104,108] and embarrassment[94,97,99] or feeling vulnerable.[105] One study found that pain was the top reason why African American women did not receive a Pap smear. Other reasons for women in general were disbelief they were susceptible to cervical cancer,[105] either because they did not have a family history, they perceived themselves as being healthy[98] or they were not sexually active.

Many women also did not have adequate knowledge about cervical cancer and Pap smears.[97,101,105] In fact, some women were unaware that Pap smear screens are primarily for detecting cervical cancer and not STIs,[100] which led to the fear of spousal infidelity.[100,101] Also, some women were unaware that cervical cancer screening can prevent cancer progression[104] and as a result believed not knowing their status was beneficial.[98] It is suggested that women who are distressed will be less likely to engage in Pap smear screening for fear of being doomed.[111] Some women had a previous experience with a Pap smear that was not pleasant due to the pain.[99,105] Others had traumatic experiences unrelated to Pap smears, such as a sexual, physical or medical

experience, that may have discouraged them from ever receiving a Pap smear.[98,105,112] Finally, some women do not trust the accuracy of the test[99] or physicians' intentions,[101] and women with two or more children[113] were less likely to have had a Pap smear.

Table 2.1 Definition of Pap smear barriers

Types of barriers	Definition	Examples
Sociocultural barriers	Consist of social beliefs, expectations, and norms of what is considered acceptable for that culture	Social influence Cultural beliefs Healthcare expense
Institutional barriers	Consist of healthcare access, healthcare expenses, policies, and practices that may prevent or hinder women from adhering to a Pap smear.	Healthcare access Provider characteristics Health insurance
Personal barriers	Anything on a personal level including Pap smear knowledge, emotions and thoughts that may make women feel uneasy, anxious and/or embarrassed about receiving a Pap smear exam	Pap smear knowledge Emotions Pain Susceptibility Traumatic experience

2.4 Solutions/interventions to increase cervical cancer screening

Pap smear non-adherence is a huge public health concern in light of the incidence of and consequences associated with cervical cancer. Many health professionals and researchers have investigated methods of improving Pap smear adherence among women. The most common intervention methods comprise of telephone calls, invitation letters, educational activities, outreach through community health workers, and partnerships. Below is a brief description/overview for each type of intervention.

Telephone calls & text messages

Telephone calls have historically been used as an effective tool within the clinical setting to get patients to be seen by a healthcare provider and to comply with medical advice.[114,115] Even more recently, text messages have been found to be an effective method as well.[116] When a patient receives a call or text from their provider or clinic it usually serves to "reinforce" or to remind patients to schedule an appointment and to adhere to health professionals' recommendations. In Pap smear interventions, telephone calls and text messages have been shown to increase women's Pap smear adherence.[117] In one study, automated phone calls were developed to encourage women, family, and or friends to schedule an appointment to get a Pap smear. However, only about a third of participants opted-in to receive automated or text messages, and within that group, many cell phone numbers and landlines were blocked.[117] Despite the difficulties documented in this study, reminders via telephone messages have been successful in other research efforts.

In studies outside of the U.S., telephone calls to remind women to schedule an appointment to get their Pap smear have also been effective.[118,119] In Sweden, a study was conducted that compared the rate of Pap smear adherence among women who received a reminder call about their Pap smear compared to women who did not receive a reminder call.[118] The study showed that telephone calls increased Pap smear adherence among women that were overdue for a Pap smear, and the process was very cost-efficient.[118]

Another study compared the effectiveness of a three stage intervention for Pap smear screening.[119] The first stage was the distribution of an educational brochure, the second stage was a telephone call/interview, and the third stage was a face-to face

interview.[119] Out of the three interventions, the telephone interview was found to be the most effective.[119] Telephone reminders were also the most effective intervention in another Sweden-based study.[120] Together, these studies suggest speaking to someone about the importance of getting a Pap smear and reminding them of screening recommendations may help reduce or eliminate some Pap smear barriers among women.[119]

Invitation letter

Invitation letters work similar to telephone calls and text messages. The purpose is to remind the patient that they are due for a Pap smear and prepare them to schedule an appointment. Overall, studies conducted in countries outside of the U.S. have demonstrated that invitation letters have increased Pap smear adherence among women despite whether they included additional information.[120,121] A study conducted in Sweden compared reminder letters to modified invitation letters, which included additional information about Pap smears.[120] There was no difference in Pap smear adherence among women who received regular invitation letters compared with women who received modified invitation letters.[120] It may be important to explore the information printed on the letter, such as a physician's signature, personalization, readability, and simplicity of the letter, to determine which elements are important in preventing additional barriers.

Invitation letters and post cards are often costlier compared to telephones due to the postal stamp and envelope cost. Studies in the U.S. that compared telephone reminders with invitational letters found that telephone reminders were more effective.[122,123] Yet, in countries outside of the U.S., letters and post cards may be more appropriate if women do not have access to a telephone.[124] For example, in one study

done in Alsace, a region on the eastern border of France, more than half of the participants did not have a telephone. However, both telephone and mail reminders were found to be equally effective.[124] The disadvantage of telephone reminders in this study was that it was costlier compared to the mail reminders because an independent company was hired and trained to do the telephone outreach.[124] In summary, a decision to use telephone versus mail reminders should be based on whether the women have access to a working telephone, and if independent companies will be used, which may increase the cost of phone call reminders.

Educational activities

Some interventions have utilized educational activities to increase women's knowledge of the importance of cervical cancer and to encourage screening. The intervention strategies used in previous research were typically completed in person, but the educational activities varied. For example, some studies consisted of focus groups,[125,126] educational workshops,[125-129] participant interaction with a physician,[127] and information on how to access affordable screening services.[127] One study found that educational activities were maximized when used in conjunction with lay leaders (see next paragraph for more detail).[130] Other studies targeted minorities and designed educational intervention programs specific to culture.[126-128] Culturally-tailored programs have been found to be most effective in changing cervical cancer screening behaviors among minorities.[127,128,131,132] Many of these programs focused on identifying a free or reduced cost clinic, as that was a challenge reported by many minority groups.[127] In one study, the majority of Chinese women were uninsured and needed assistance in identifying a clinic.[127] An intervention was designed to educate these women on the

importance of Pap smear adherence, allow them to interact with a Chinese physician, and assist them in locating a free or reduced cost clinic.[127] This study demonstrated that education alone may not be sufficient, but interventions should consider including physician interaction and patient navigation.

Lay leaders/ community health workers

Lay leaders or community health workers (CHW) have served as health navigators for decades. CHW are often used to visit the homes of patients and educate them on the risks of cervical cancer and the importance of Pap smear adherence. The defining component of CHW or lay leaders is that they are a part of the community and possess similar qualities as the patient, so they tend to make the patient feel more comfortable than physicians or other healthcare professionals. Research has shown that the inclusion of CHW is a useful strategy in increasing Pap smear adherence among women.[133-135] In Brazil, CHW in collaboration with a Pap smear mobile unit were very effective in increasing Pap smear adherence among women.[136] In another study, the intervention consisted of a CHW visiting the home of Vietnamese American women and requesting that they watch an educational cervical cancer and Pap smear video together.[134] It found that home visits may only be effective if they had previously had a Pap smear.[134] In summary, CHW are effective in reaching patients that are typically hard to reach due to lack of trust in physicians.

Partnerships

Partnerships are often used to develop a relationship with a population. In some populations, there may be a barrier or stigma against health professionals but the development of a relationship with the population/patients may reduce those social

barriers. Some studies have established a relationship with faith-based organizations as a technique to connect with the community and to develop a rapport.[95,137] The findings of the studies showed reduced social barriers and increased Pap smear adherence among women.[95,137]

Overall, research has shown that conducting reminder calls or text messages, disseminating invitation letters, providing educational activities or material, utilizing CHW, and developing partnerships can be effective in improving Pap smear adherence among women. However, combining these strategies could be most effective in improving Pap smear adherence among women. For example, one study showed that telephone calls, face to face visits with CHW, and disseminating postcards were most effective compared to the control group or utilizing a single intervention method.[135] In addition, in another study it was suggested the intervention of choice should be based on the anticipated barrier and size of the targeted population.[119] For example, this study suggested providing educational material may be effective for a large or small group of women with little to no knowledge of cervical cancer, while face to face visits conducted by CHW may be most effective for a small group of women with significant barriers.[119] Thus, it is essential to determine the most important Pap smear barriers for specific populations.

2.5 Gaps in the literature

Although Pap smear non-adherence has been extensively studied, existing scales examining Pap smear barriers among women fail to utilize all of the current constructs of the Health Belief Model (HBM). In regard to interventions used to improve Pap smear adherence there were no interventions identified that focused on addressing barriers

related to the emotional distress of getting a Pap smear. Emotional distress may include embarrassment, fear of pain, and fear of the unknown due to previous traumatic experiences. The proposed study will conduct a survey and detailed focus group to identify and explore possible solutions for women experiencing emotional discomfort in receiving a Pap smear.

THEORY: HEALTH BELIEF MODEL (HBM)

The Health Belief Model (HBM) will be used to inform the proposed research. A description of the HBM and how it applies to cervical cancer screening is explained below.

2.6 HBM overview

The HBM was developed by Godfrey Hochbaum and Irwin Rosenstock in the 1950's.[138] The aim of the HBM is to explain and predict people's health-related behaviors. The HBM consists of six constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy, as defined in Table 2.2.[138]

Perceived susceptibility is a key construct of the HBM. Perceived susceptibility is defined as the individual's perceived likelihood of developing a disease or condition.[138] In order for a person to act or change their health-related behavior they must believe that they are susceptible to or at risk for the disease or condition.

Perceived severity is the degree of seriousness in which the individual believes the health condition is detrimental to them.[138] Perceived severity can be addressed by simply informing the individual of the potential risk if action is not taken.[138] Research has

shown that the more visible the severity of the health condition is, the higher the likelihood the individual would change their behavior.[139,140]

Perceived benefit is the ability of the advised action to reduce the risk or seriousness of the impact.[138] A person may believe they are susceptible to a disease or perceive the disease as severe but may not engage in behavior change due to their perception of the benefits. An important component of this construct is that in order for the individual to engage in behavior change they must believe there are real benefits and their action will reduce or eliminate their risk of developing the disease.[138] It is also important to note that perceived benefits are usually hypothetical.[139] In order for a person to respond they must believe that the recommended health behavior will result in a positive health outcome.[139] To increase the individuals' perceived benefit, health education is necessary to educate the individual and make them aware of how to reduce their risk as well as the treatment options that are available.[138] It is important also that the health advantages are explained in order to affect the behavior change.[138]

Perceived barriers are considered the negative consequences of engaging in a health-related behavior change.[138] Some researchers would even say that perceived barriers have the biggest influence on behavior change.[141] The key to this construct is that the individual must perceive the benefits as outweighing the barriers in order to be successful towards behavior change.[138] Perceived barriers, even if they are not grounded in reality, are legitimate barriers and should be considered and discussed with the individual through education and assistance (financial, monetary, or psychological).[138]

Cues to action are defined as the triggers that may motivate an individual towards behavior change.[138] Cues to action may be recommendations, events or people that

influence a person to take action. Other cues to action may include how-to-information, reminders, or media influence.[138]

Self-efficacy is the individual's confidence in their own ability to take action.[138] In most cases an individual will not engage in a behavior change unless they believe they are capable. Self-efficacy can be improved by providing training and guidance in performing recommended actions, using progressive goal setting, giving verbal reinforcement, demonstrating desired behaviors, and reducing anxiety.[138]

Table 2.2 Constructs and Definitions for Proposed Study

CONSTRUCT	DEFINITION
Perceived Seriousness	The degree of seriousness in which the individual believes the health condition is detrimental to them. [138]
Perceived Susceptibility	The individual's perceived likelihood of developing a disease or condition.[138]
Perceived Benefits	The ability of the advised action to reduce the risk or seriousness of the impact.[138]
Perceived Barriers	Considered the negative consequences of engaging in a health-related behavior change.[138]
Self-efficacy	The individual's confidence in their ability to take action.[138]
Cues to Action	The triggers that may motivate an individual towards behavior change.[138]

2.7 Relationship among HBM constructs

The HBM is displayed in Figure 2.1. On the far-left hand side in red are modifying variables. Modifying variables are basic demographics or baseline information about an individual that may influence a health behavior. Ironically, modifying variables are not usually modifiable through health education.[139] Some common modifying

variables include age, race/ethnicity, gender, and socioeconomic status. The arrows in the figure represent the relationship between constructs. For example, modifying variables are predicted to influence perceived benefits vs. perceived barriers, perceived threat, and self-efficacy. Furthermore, benefits versus perceived barriers, perceived threat, and self-efficacy will influence the individual's likelihood of engaging in health-promoting behaviors. Although perceived benefits and perceived barriers are individual constructs, the HBM combines them. This is because the model emphasizes the relationship between perceived benefits and perceived barriers. For example, in order for a person to engage in a health promoting behavior their perceived benefits must outweigh their perceived barriers; one construct cannot stand-alone. Unlike modifying variables, perceived barriers, perceived benefits, perceived susceptibility, and perceived severity can all be modified through educational interventions.[139] In addition, beliefs are stemmed from modifying variables that can differentiate people from different groups.[139]

Figure 2.1 also shows that perceived seriousness and perceived susceptibility are categorized as perceived threat. This is to enforce simplicity of the model since both perceived severity and perceived susceptibility are essentially serving as a "threat" to explain why some individuals engage in health-related behavior change and others do not. However, for analysis purposes perceived susceptibility and perceived severity will be measured separately. Failure to measure perceived susceptibility and perceived severity separately violates the expectancy-value structure of the HBM.[142] The expectancy-value theory is based on the concept that human behavior is based on expectations, values and beliefs.[142] However, a "personal threat" index should not be used. The construct 'cue to action' is the only construct not related to modifying variables

because cues to action are external strategies that are unrelated to individuals' personal qualities. Figure 2.2 illustrates how cervical cancer and Pap smear screening fits within the HBM.

Figure 2.1 Detailed Theoretical Framework of the HBM for Cervical Cancer and Pap smear

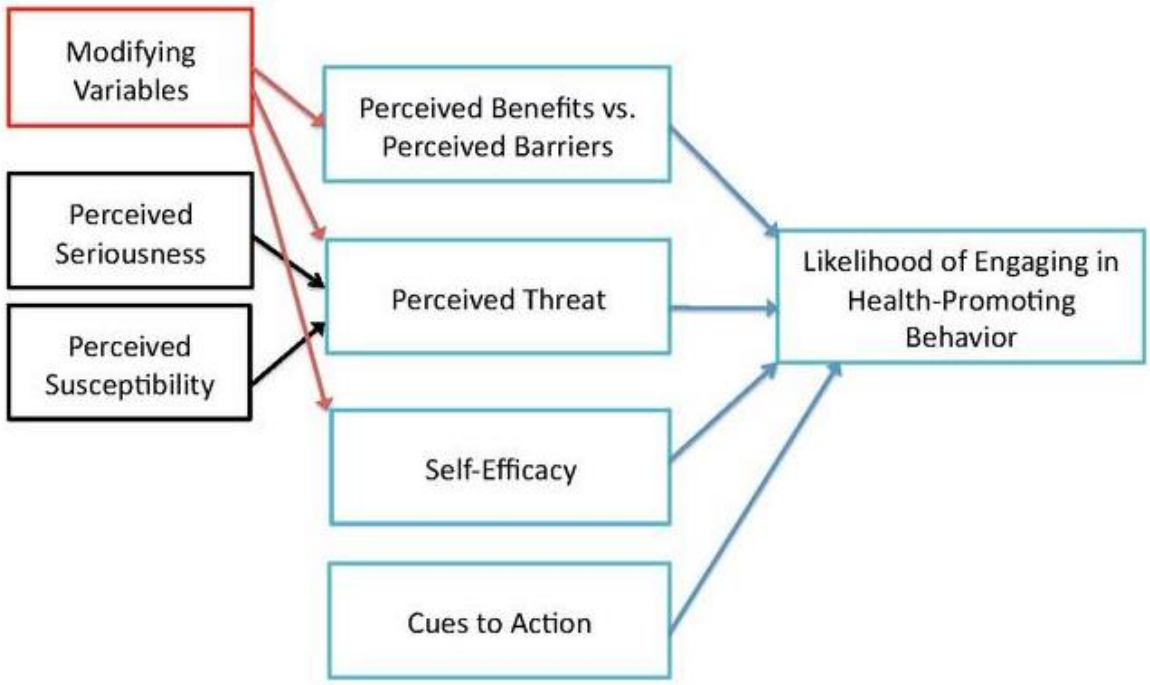
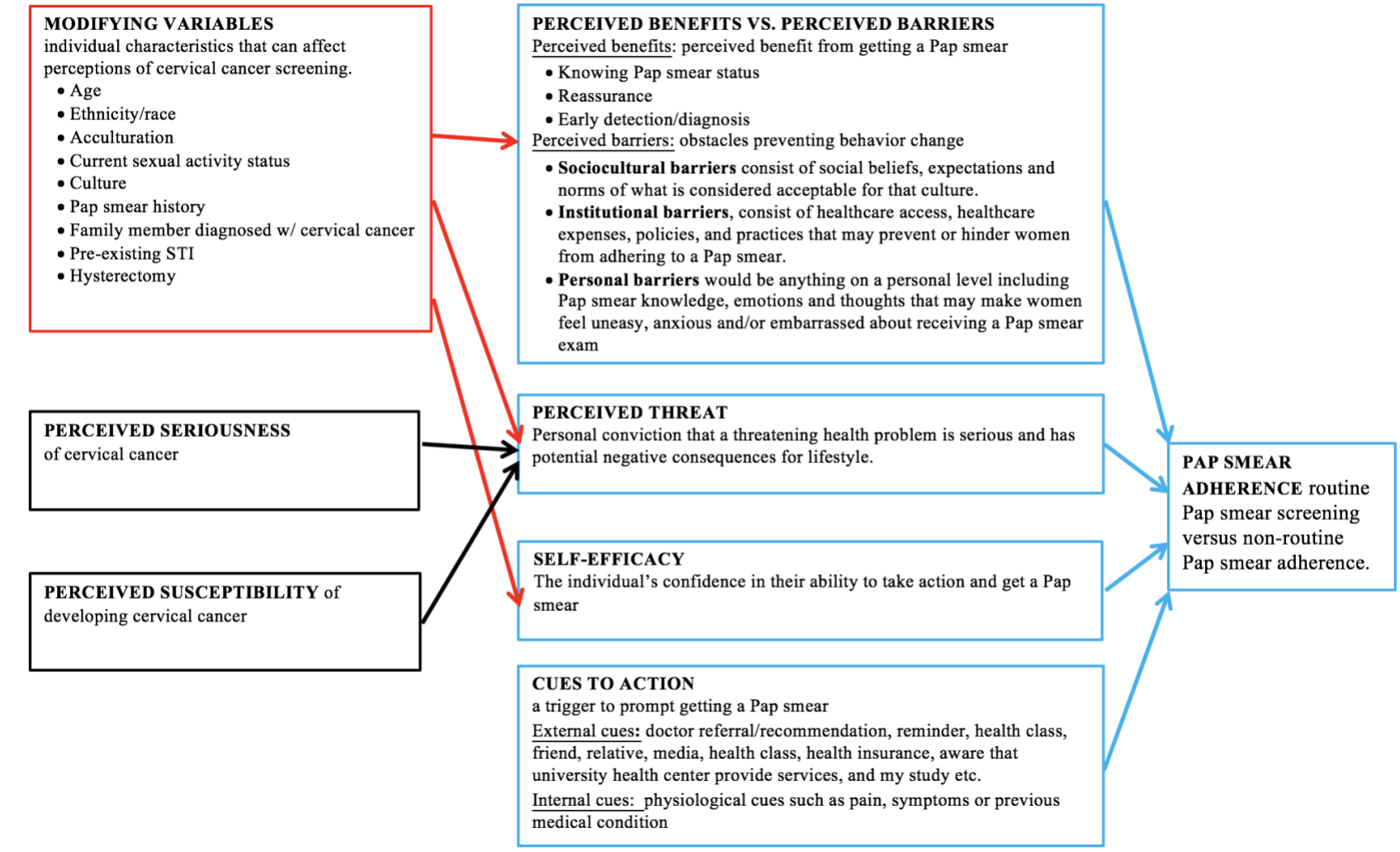


Figure 2.2 Detailed Theoretical Framework of the HBM for Cervical Cancer and Pap smear



2.8 Review of Pap Smear Research using the HBM

The HBM has been previously used to address cervical cancer and Pap smear adherence, however the constructs and findings have not always been consistent.[143-147] For example, some studies have used the original HBM constructs (perceived susceptibility, severity, benefits, barriers, and cues-to-action), while others have incorporated "health motivation" as an additional construct or a variation of the original constructs.[143-147]

An international study conducted in Turkey in 2007 assessed the development and the psychometric testing of the HBM for cervical cancer and Pap smear screening.[147] In an effort to explain why cervical cancer and Pap smear screening are low among women, Guvenc and colleagues adapted The Champion Health Belief Model scale in order to explain the beliefs of women regarding cervical cancer and Pap smear screening. The Champion Health Belief Model scale was found to be a valid and reliable instrument for Turkish women.[147] The HBM scale in this study comprised of the following constructs: benefits and health motivation, barriers, seriousness, susceptibility, and health motivation.[147] Similar to several other studies, this study provided evidence that the health beliefs of women affect Pap smear adherence.[144-147] All constructs with the exception of perceived barriers were positively associated with Pap smear adherence.[146,147] In other words, women who had never received a Pap smear had lower perceived susceptibility, severity, benefits, but had higher perceived barriers compared to women who have never received a Pap smear.[146]

In another study that utilized the same Champion Health Belief Model scale for cervical cancer and Pap smear screening, perceived barriers was the only construct that

significantly affected Pap smear adherence.[144] It was suggested that the target population of interest may influence the factors predicting adherence. This finding, however, was not unusual, as other studies have also noted perceived barriers to be the most powerful construct in predicting Pap smear adherence.[146] Furthermore, in a study conducted by Hajializadeh and colleagues, perceived benefits, barriers, and susceptibility were all found to be good predictors of Pap smear adherence.[146]

In another study, researchers conducted a quasi-experimental to evaluate whether a HBM-based educational program would affect Pap smear adherence.[145] In the study, the following constructs were evaluated: perceived susceptibility, severity, benefits, barriers, and cues to action.[145] The study found that after the one month post intervention follow-up, perceived susceptibility, severity, and benefits increased among women.[145] Surprisingly, the educational intervention increased perceived barriers significantly among the intervention group.[145]

Finally, another study has suggested that the HBM may not be the best framework for predicting Pap smear adherence.[143] In this study there were no significant associations between any of the HBM constructs or women's Pap smear history.[143] The constructs of perceived susceptibility, severity, benefits, and barriers were very similar among women who had received a Pap smear compared to women who had never received a Pap smear.[143] Since Pap smear or cervical cancer knowledge was not explored, it is possible these groups of women had limited knowledge of Pap smears or cervical cancer. Alternatively, there may have been other barriers not tested in the current study that could have contributed to the lack of significant findings.[143] Overall, the research on HBM and

Pap smear screening suggests that more work needs to be done to better determine predictors of adherence among women.

2.9 Chapter summary

Research has identified several predictors and barriers related to Pap smear adherence among women. Some of the most common predictors for Pap smear adherence are higher socioeconomic status, cervical cancer and Pap smear knowledge, and health insurance coverage. While these factors may increase women's likelihood of getting a Pap smear, there are other factors (barriers) that may decrease women's likelihood of getting a Pap smear. Some common barriers include social influence, cultural beliefs, healthcare expenses, lack of physician/provider recommendation, lack of knowledge, and emotional thoughts and feelings about getting a Pap smear. Since Pap smear adherence is an ongoing public health concern, several interventions have been implemented to reduce Pap smear barriers among women. Based on previous literature, the HBM is the most promising theory in exploring factors related to women's Pap smear adherence. In particular, the construct of perceived barriers may be especially important in predicting adherence.

CHAPTER 3: METHODS

3.1 Purpose of the Study and Research Questions

The purpose of this project is to examine the application of the Health Belief Model to Pap smear adherence by examining the predictive utility of perceived benefits, perceived susceptibility, perceived severity, self-efficacy, cues to action, and perceived barriers in order to identify solutions to Pap smear non-adherence among women. This study will inform health care professionals and the public of possible solutions to help minimize and/or eliminate barriers for women who are hesitant to comply with Pap smear recommendations.

A primary goal of this project is to 1) add to the pre-existing Health Belief Model Scale for Cervical Cancer and Pap Smear Test in order to identify a complete list of barriers that prevent women from obtaining a Pap smear and 2) to explore participants' perceived solutions to overcome and/or eliminate these barriers. The long-term goal of the proposed study is to aid Healthy People 2020 in increasing the proportion of women who receive cervical cancer screening based on the most recent guidelines released in 2008. Currently, 84.5% of females aged 21 to 65 years receive cervical cancer screening.[17] While the ultimate goal is to reach 100%, the current target is that 93% of women in this age range will receive recommended screening.[17] In the long-term, this study will provide important insight to help address Healthy People 2020's goal of 93% of women receiving cervical cancer screening. The specific research questions and that guided this study and the accompanying hypotheses are as follows:

Research Aims

Modify existing measures to develop a new HBM scale for Pap smear adherence.

- Research Question 1: Do the HBM subscales (perceived barriers to Pap smear adherence, perceived benefits of Pap smears, perceived susceptibility and perceived severity of cervical cancer, cues to action for Pap smears, and/or Pap smear self-efficacy) have adequate internal reliability?
- Research Question 2: Does the modified barriers scale adequately capture the barriers reported by women?

2) Test the predictive utility of the HBM for predicting Pap smear adherence.

- Hypothesis 1: Perceived barriers will have a negative relationship with Pap smear adherence, such that as a person's level of perceived barriers increases, their likelihood of adherence will decrease.
- Hypothesis 2: Perceived benefits will have a positive relationship with Pap smear adherence, such that as perceived benefits increase, their likelihood of adherence will also increase.
- Hypothesis 3: Perceived susceptibility will have a positive relationship with Pap smear adherence, such that as a person's threat level increases, their likelihood of adherence will also increase.
- Hypothesis 4: Perceived severity will have a positive relationship with Pap smear adherence, such that as a person's threat level increases, their likelihood of adherence will also increase.

- Hypothesis 5: Cues to action will have a positive relationship with Pap smear adherence, such that as a person's cues to action increase, their likelihood of adherence will also increase.
- Hypothesis 6: Pap smear self-efficacy will have a positive relationship with Pap smear adherence, such that as a person's self-efficacy increases, their likelihood of adherence will also increase.

3) Explore participants' proposed solutions for reducing barriers to Pap smear adherence.

- Research Question 3: Using an interactive focus group discussion, what solutions do women propose for increasing Pap smear adherence?

3.2 Study Design

This study used a cross-sectional mixed-methods design utilizing a questionnaire and focus groups. For simplicity, the study has been divided into two parts: Phase 1 and Phase 2. Phase 1 consists of quantitative data and utilizes an adapted HBM Pap smear screening questionnaire to identify barriers among women. Phase 2 is comprised of focus groups to explore participants' suggested solutions to Pap smear non-adherence among women. For the remainder of this chapter we will refer to Phase 1 for the quantitative data, and Phase 2 for the qualitative data. This study was approved by the Institutional Review Board at the University of Georgia (UGA).

PHASE 1: IDENTIFYING PAP SMEAR BARRIERS

3.3 Study sample and recruitment

The selected study population were women between the ages of 21 and 65, since the USPTSF recommends that women be at least 21 years of age or older to receive a Pap smear. Both women who never had a Pap smear and those who have had a Pap smear

were included in the study. Excluded from this study were women who have never heard of a Pap smear since they could not accurately identify barriers to Pap smear screening if the test was foreign to them. Also, women were excluded if they had a hysterectomy since their uterus had been removed and a Pap smear is no longer needed or recommended. In addition, women younger than 21 years of age were also excluded because the USPTSF guideline recommends Pap screenings for women 21 years of age or older.

According to the United States Census Bureau there were 191.99 million (191,998,520) residents between the ages of 21 and 65 residing in the United States in 2017.[148] Of the 191.99 million residents approximately, 50 percent (96,623,183) are females.[148] Recruitment strategies were focused on this group of women, except those who were outside the age limit or had a hysterectomy.

3.4 Recruitment strategies

The research team recruited women through multiple modes, using a combination of convenience and snowball sampling, in order to improve response rate and coverage among women. Methods of recruitment included social media posts, word of mouth, email blasts, and flyers (see Appendix A for recruitment flyer and Appendix B for recruitment letter). The primary mode was through social media (Facebook). It is estimated that approximately 2.2 billion people worldwide are active Facebook users.[149] Therefore, the study was posted on individual Facebook pages and shared with several organizations and groups on Facebook, such as UGA's Graduate and Professional Scholars and Black Ladies in Public Health. However, since not every American is actively engaged in social media, other methods of recruitment were utilized. Word of

mouth was used, as participants were encouraged to share the study information with their peers. In addition, recruitment e-mails were sent to students at UGA via their department listservs. Lastly, flyers were posted on UGA's campus in locations highly visited by students (student center, housing facilities, locker rooms, bus stops, and some department bulletin boards). Overall, 468 females were recruited to complete the study across all recruitment methods. It is also important to note that African American women were purposefully recruited due to higher rates of cervical cancer.[44]

3.5 Data collection, management, and procedures

Following the pilot test, data collection occurred in the Spring of 2018 and continued for approximately four weeks. Once prospective participants had expressed interest in participating in the study, a link to the questionnaire was available either through social media sites, email or flyers. All questionnaires were administered online to ensure privacy using Qualtrics and were completed at the participants' leisure. Inquiring about a participant's Pap smear screening practices and Pap smear and cervical cancer attitudes and beliefs can be a sensitive and personal topic for some women. Administering an electronic survey helped to reduce participant discomfort that could ultimately lead to inaccurate responses.

To be eligible to complete the questionnaire participants must have been a female between the ages of 21 and 65 who have heard of a Pap smear but have not had a hysterectomy. Participants that met the above inclusion criteria were directed to complete the questionnaire assessing their current Pap smear practice and history, perceived benefits, perceived barriers, perceived threats, self-efficacy, and cues to action towards Pap smear adherence. All participants were required to consent to participating in the

study prior to having access to the questionnaire. Upon completion of the questionnaire, participants were asked about their willingness to participate in the second phase through a question at the end of the survey. Phase 2 was explained as a group discussion with other women, discussing barriers to Pap smear screenings and brainstorming about possible solutions. Further details for recruitment for Phase 2 is explained in section 3.9

The questionnaire was developed and administered using Qualtrics. Participants were not asked to record their name or contact information, unless interested in Phase 2, and all identifiable information that was incidentally collected was removed from the final dataset. E-mail addresses for those interested in the focus group were deleted immediately following focus group completion. The exact recruitment question read, "If interested in Phase 2, a group discussion with other women about your experience, ideas, thoughts, and feelings about Pap smears and cervical cancer, then please provide your name and email for meeting details." Only the research team had access to the participants' data.

At the completion of the questionnaire participants were given the option to be entered into a drawing to win a $50 Amazon gift card. For every 50th participant, a winner was selected and rewarded the $50 Amazon gift card. Participants who expressed interest in the drawing were redirected to a separate site to enter their email address to ensure anonymity.

3.6 Measures

Several pre-existing instruments were compiled and adapted to identify Pap smear-related variables. The instruments consisted of the Health Belief Model Scale for Cervical Cancer and Pap smear Test,[147] Self-efficacy Scale for Mammography,[150] the

Health Belief Model Cues to Action to Cervical Cancer Screening scale,[151,152] and demographic questions. In this section, a brief description of each instrument is provided with information on modifications that were made. Appendix C contains the complete and final survey items. To ensure clarity and to identify problematic areas, a pilot test was conducted on a group of women similar to the study group, as described in section 3.7.

The Health Belief Model Scale for Cervical Cancer and Pap smear Test

The Health Belief Model Scale for Cervical Cancer and Pap smear Test was developed by Guvenc and colleagues[147] but was originally adapted from Champion's breast cancer scale.[153] The Health Belief Model Scale for Cervical Cancer and Pap smear Test consists of thirty-six questions from the subscales: perceived benefits, barriers, seriousness, and susceptibility. The Cronbach's alpha ranged from 0.78 to 0.82 and the test-retest reliability ranged from 0.84-0.87.[147] For each subscale, the response was recorded on a five-point Likert scale (1- strongly disagree, 2- disagree, 3- neutral, 4- agree, and 5- strongly agree).[147]

The subscale *perceived benefits* consists of nine items. It has been shown to have good reliability, with a Cronbach's alpha of 0.86 and a test-retest correlation of 0.87.[147] Participants were asked to rate their level of perceived benefit for each item. An example item is *"Having regular Pap smear Tests will help to find changes to the cervix, before they turn into cancer."*[147]

The subscale *perceived barriers* consists of fourteen items assessing the barriers for women in receiving a Pap smear. This subscale has had good reliability in previous studies, with a Cronbach's alpha of 0.82 and a test-retest correlation of 0.88.[147] An

example barrier question is as follows; *"I am afraid to have a Pap smear Test for fear of a bad result."*[147] In order to further explore additional barriers to Pap smear adherence for this study, seven additional questions were added to the perceived barrier subscale to add depth and thoroughness. All items were based on findings from previous focus group research. The item *"I had a bad experience with my last Pap smear test"* was added to inquire about women's previous Pap smear experience. It is common for women to experience pain, or feel uncomfortable during a Pap smear exam that could deter them from future exams.[99,105] The item *"A friend or family member has made negative comment(s) concerning me getting a Pap smear*" was added due to the possible negative social influence from others about getting Pap smear."[98,100,101,104,105] The item "*The media has discouraged me from getting a Pap smear,"* was added due to the possible media influence.[98] This item was followed by another question inquiring about the relationship to that individual. The item *"I had a previous traumatic experience with a previous medical procedure that deters me from getting a Pap smear"* was added due to some women experiencing previous unpleasant medical procedures.[105] The item *"I was sexually abused and do not feel comfortable getting a Pap smear"* was added to address the role of previous sexual abuse in predicting adherence.[105] The item "*I do not want others (parents, significant others, etc) to find out I had a Pap smear"* was added due to the common misconception that Pap smear adherence is related to sexual activity or STIs and most women do not want their peers or family members to know that they are sexually active.[100] The item *"I am afraid of tearing my hymen or "popping my cherry"* was added to explore Pap smear avoidance in women who fear "losing their virginity."[106] The last item "*Are there any other barriers not mentioned in the survey that deter you*

from getting a Pap smear? If yes, please describe them:" was added to capture barriers not mentioned in the scale.

The subscale *perceived seriousness* consisted of seven items identifying the perceived seriousness of cervical cancer. This subscale also has good reliability, with a Cronbach's alpha of 0.78 and a test-retest correlation of 0.85.[147] An example item is "The thought of cervical cancer scares me."[147]

The subscale *perceived susceptibility* consisted of three items identifying the participant's perceived likelihood of developing cervical cancer. The Cronbach's alpha of this scale has been found to be 0.78, and the test-retest correlation was 0.84.[147] An example item is *"It is likely that I will get cervical cancer in the future."*[147]

Self-efficacy Scale for Mammography

The *Self-efficacy Scale for Mammography* was developed by Champion and colleagues.[150] The construct self-efficacy was examined in this study by modifying the Mammography Self-efficacy Scale questionnaire to read "Pap smear," instead of "mammography."[150] The scale has 10 items measured on a five-point Likert scale (1- strongly disagree, 2- disagree, 3- neutral, 4- agree, and 5- strongly agree). The Cronbach's alpha for this scale in previous research was 0.87, and the test-retest reliability was 0.53.[150] An example item is *"You can arrange transportation to get mammogram."*

HBM cues to action to cervical cancer screening

The *HBM cues to action to cervical cancer screening* scale developed by Burak and colleagues[151] resulted in a low reliability score on the pilot test (see section 3.7), and was replaced with a scale developed by Matterne and Sievverding for prostate cancer.[152]

The internal reliability and test retest reliability was not reported in the original article for Matterne and Sievverding's scale, but it had good reliability for this study (see section 4.2 for details). The scale consists of two parts and was adapted to change wording related to prostate cancer screening to wording related to Pap smears. Part 1 asked *"Have you ever received information about a Pap smear from the following people or institutions?"*[152] Response options included health insurance, print media, television/radio, health promotion fair, and physician.[152] The response option, "sexuality or health education classes" was added based on previous literature suggesting sexual education taught in schools may influence Pap smear sdherence.[151] Part 2 asked *"Have the following people ever recommended for you to get a Pap smear?"*[152] Response options included physicians, friends/acquaintances, colleagues, family, and spouse/partner.[152] The response option "television/radio" was added to include influence from external sources.[98] All response items were measured on a three-point scale: never, once, or more than once.[152]

Demographic questions

There were approximately 15 demographic questions included in the survey. The age of the participants was asked in numeric form. Race was categorized in the following categories; White, Black/African American, American Indian/Alaska Native, Asian, and Native Hawaiian/Pacific Islander, Multiracial, and Other. Ethnicity was categorized as Hispanic/Latino or NOT Hispanic/Latino. Highest level of education was categorized in the following categories; less than high school degree or GED, high school graduate or GED, some college but no degree, graduated from college, and post-graduate. Participants were asked to report if they had health insurance, and whether they were

covered under someone else's insurance. They were also asked about their current marital status categorized as; single, in a relationship, but not living with partner, living with a partner, married, or divorced.

Participants were also asked a few questions regarding their sexual activity and sexual health. Participants were asked whether they were currently sexually active or had been within the last 6 months (Yes/No) and if they had ever been diagnosed with a STI (Chlamydia, gonorrhea, genital herpes, HIV/AIDS, HPV or syphilis, etc.). If they indicated that they had been diagnosed with an STI, they were asked if they had specifically been diagnosed with HPV. Participants were also asked if they had personally had a friend or family member that was diagnosed with cervical cancer. If they had a family member diagnosed, they were asked about their relationship to that individual. Lastly, participants were asked to report their current Pap smear practice, whether they had never had a Pap smear, received a Pap smear within the past one to three years, or received a Pap smear more than three years ago. This question was based on current ACOG and USPSTF guidelines for Pap smear screening. Participants that reported receiving a Pap smear sometime during their lifetime were also asked to report whether they had ever received an abnormal Pap smear result and how frequently do they get a Pap smear. Table 3.1 depicts the original source for each construct used in the study.

Table 3.1 Derived HBM Constructs used in Modified Cervical Cancer and Pap Smear Questionnaire

	Perceived benefits	Perceived barriers	Perceived seriousness	Perceived susceptibility	Self-efficacy	Cues-to-action
Health Belief Model Scale for Cervical Cancer and the Pap Smear Test[147]	Yes	Yes	Yes	Yes	No	No
Self-efficacy Scale for Mammography[150]	No	No	No	No	Yes	No
Cues-to-action Scale for Prostate Cancer Screening[152]	No	No	No	No	No	Yes

3.7 Pilot test

Prior to data collection approximately 10 graduate students in a questionnaire development course reviewed and critiqued the questionnaire and recruitment material. Their role was to identify problems in the structure and flow of the questionnaire, and to ensure that participants would understand and correctly interpret the questions being asked of them. All feedback was positive and confirmed simplicity of survey navigation and participants' understanding. Minor changes were made to the questionnaire structure and item wording, but no substantive edits occurred.

Once the questionnaire and recruitment material were reviewed a pilot test was conducted on 35 participants. These participants were recruited from a research lab at

UGA. The students were asked to complete the proposed online questionnaire and provide feedback. Areas of concern were wording of questions, readability, confusing phrases, and technical problems through Qualtrics. A brief pilot analysis was conducted to ensure that the data collected would be useful (Table 3.2). The maximum time to complete the survey was 8 minutes.

The pilot analysis demonstrated that each item had an acceptable level of variance among responses. In addition, all but one construct, cues-to-action, showed promising reliability amongst items as shown in Table 3.2. As a result of the low alpha score for cues-to-action, the scale was replaced with a different cues-to-action scale to achieve a higher reliability amongst items (see Measures section for more detail). During the reliability test for "barriers" the item inquiring about the participants' bad experience with a Pap smear was removed due to a Qualtrics error resulting in a no response rate. In addition, the item inquiring about a woman's preference for a female doctor was also removed, as pilot participants noted that the item did not actually reflect a true barrier.

Table 3.2 Preliminary reliability analysis

Construct	**Number of items**	**M**	**SD**	**Mean Item Mean**	**Alpha**	**Notes**
Health motivation	3	10.41	2.945	3.471	0.74	
Benefits	9	37.24	3.340	4.137	0.647	
Barriers	19	37.09	10.147	1.952	0.896	• Variable "bad experiences" was removed due to error in Qualtrics. • Female doctor variable was removed from analysis due to

						not being a barrier
Seriousness	7	22.94	4.645	3.277	0.783	
Susceptibility	3	6.50	1.796	2.167	0.814	
Self-efficacy	10	43.76	5.14	4.376	0.912	
Cues-to-action	3	4.91	1.042	1.636	0.411	• Items replaced for final survey due to low alpha score

3.8 Data analysis

Following data collection 468 women were eligible and expressed interest in the proposed study. However, once the dataset was cleaned and screened for missing data, 44 subjects were removed due to extensive missing data. The total working sample size was 424 as shown in Figure 3.1. The Statistical Package of Social Sciences (SPSS) was used for all data analysis. Pap smear adherence was recoded for study purposes and dichotomized into adherence or non-adherence. Adherence was defined as if the female has received a Pap smear within the past one to three years. Non-adherence was defined as if the female has never received a Pap smear or received a Pap smear over three years ago. Descriptive statistics were performed on all demographic variables. The data analysis plan for each aim is listed below.

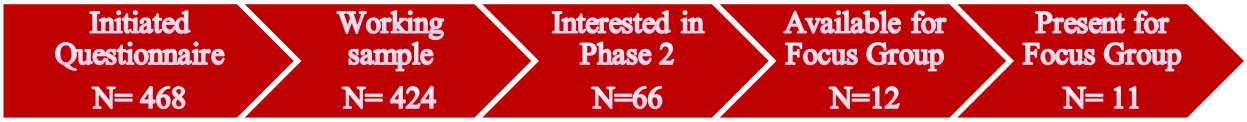


Figure 3.1 Sample flow chart

Aim 1: Modify existing measures to develop a new HBM scale for Pap smear adherence

Research question 1:

Do the HBM subscales (perceived barriers to Pap smear adherence, perceived benefits of Pap smears, perceived threat of cervical cancer, cues to action, and/or Pap smear self-efficacy), have adequate internal reliability?

Data analysis:

An internal consistency reliability analysis was conducted to explore the constructs of perceived benefits, perceived barriers, perceived seriousness, perceived susceptibility, self-efficacy, cues-to-action and health motivation. Each subscale was explored to ensure variance and adequate distribution among responses. Cronbach's alpha was calculated to test the reliability of each subscale for the targeted audience. A Cronbach's alpha score of 0.7 and higher was deemed acceptable. All subscales indices for the Adapted Health Belief Scale were computed using means.

Research question 2:

Does the modified barriers scale adequately capture the barriers reported by women?

Data analysis:

Descriptive statistics were calculated to examine frequencies of barriers identified by participants. An "other" option was added for barriers not mentioned in the scale and participants were allowed to type additional barriers that were applicable to them. The frequency of "other" responses was examined to determine if the barriers scale was extensive enough to cover all possible response options. Qualitative data from the focus groups was also examined for additional barriers mentioned during the group discussion. The top five barriers, according to the percentage of participants who chose "strongly

agree" and "agree" from phase 1, were presented to participants during the focus groups and they had the option to add any additional missing barriers. See section 3.12 for more detail about the qualitative data analysis process.

Aim 2: Test the predictive utility of the HBM for predicting Pap smear adherence

Hypothesis 1: Perceived barriers will have a negative relationship with Pap smear adherence, such that as a person's level of perceived barriers increases, their likelihood of adherence will decrease.

Hypothesis 2: Perceived benefits will have a positive relationship with Pap smear adherence, such that as perceived benefits increase, their likelihood of adherence will also increase.

Hypothesis 3: Perceived susceptibility will have a positive relationship with Pap smear adherence, such that as a person's threat level increases, their likelihood of adherence will also increase.

Hypothesis 4: Perceived severity will have a positive relationship with Pap smear adherence, such that as a person's threat level increases, their likelihood of adherence will also increase

Hypothesis 5: Cues to action will have a positive relationship with Pap smear adherence, such that as a person's cues to action increase, their likelihood of adherence will also increase.

Hypothesis 6: Pap smear self-efficacy will have a positive relationship with Pap smear adherence, such that as a person's self-efficacy increases, their likelihood of adherence will also increase.

Data analysis:

Individual and grouped logistic regression analyses were performed to assess if the HBM constructs predicted Pap smear adherence. The individual logistic regressions were conducted between each construct and Pap smear adherence, with control variables, to examine the impact of the individual variables in absence of the other HBM constructs. The grouped logistic regression contained all the HBM constructs and controls as independent variables in order to examine effects on Pap smear adherence. The independent variables were the subscale indices (perceived barriers to Pap smear adherence, perceived benefits of Pap smears, perceived severity of cervical cancer, perceived susceptibility to cervical cancer, cues to action for Pap smears, and Pap smear self-efficacy). The dependent variable was Pap smear adherence, dichotomized as "adherent" (1) or non-adherent (0). Participants were categorized as being adherent if they had had a Pap smear within the last three years and were categorized as non-adherent if they never had a Pap smear or had not had a Pap smear within the last 3 years. Although some guidelines offer two options: 1) for women to receive a Pap smear every three years OR 2) for women 30 years and older get a Pap smear and HPV test every five years until the age of 65,[4,6] the current study did not measure adherence based on the alternative guideline but rather focused on the primary guideline of receiving a Pap smear every three years. A correlation analysis was conducted between all possible control variables (age, insurance status, relationship status, knowing someone diagnosed with cervical cancer, and history of an abnormal Pap smear) and adherence, and anything with a significant correlation at the $p < .05$ level was included in the model. The final control variables used in the model were race (included as a categorical variable), if they had had

sex (vaginal, oral, or anal) within the last six months (dichotomized as yes/no), and if they had ever had an STI (Chlamydia, gonorrhea, genital herpes, HIV/AIDS, HPV or syphilis etc; dichotomized as yes/no). The control variables were used to account for additional effects that may be related to the dependent variable. Pseudo R Square (Cox & Snell R Square and Nagelkerke R square) was used to explain variation in the dependent variable explained by the model. The Wald test was used to determine the significance for each independent variable in the model. The overall model significance was evaluated using the Chi-square omnibus test of model coefficients. The predicted probabilities of an event occurring were determined by beta or odds ratios. A p-value of 0.05 or lower was considered to be significant.

PHASE 2: SOLUTIONS TO BARRIERS

3.9 Sample and recruitment

The Phase 2 sample population was a subset of the sample in Phase 1. Therefore, all women were between the ages of 21 and 65 and had heard of a Pap smear but had not had a hysterectomy. Participants were asked at the completion of the questionnaire in Phase 1 if they were interested in participating in Phase 2 of the study, which consisted of open discussion with other women concerning Pap smear barriers and possible solutions. Participants expressing interest were asked to record their name and email, and were informed that they would be contacted regarding further details of the focus groups. Once data collection ended participants who expressed interest in Phase 2 of the study were emailed to inquire about their availability. The email included three dates when focus groups would be held and requested for the participants to select the dates when they

would be available, if any. Prospective participants for the focus group were then selected based on their availability according to the time slots listed in the form.

3.10 Data collection and management

The three focus groups were conducted following survey completion in Spring 2018. Each focus group comprised of 3-4 participants. One group was recruited to consist entirely of African American women, including the interviewer and note taker. This was done because African American women have higher rates of cervical cancer[44] and previous research has demonstrated that they may have different barriers to Pap smear screening than other races.[105] Due to the exploratory nature of this study, there was no further intentional categorizations of participants.

Focus groups were held in a classroom on the UGA Health Sciences Campus. Each group lasted approximately 1.5 hours,[154] and light refreshments were served to foster a more comfortable and relaxing environment.

All focus groups were recorded on a digital recorder. The Principal Investigator, who is African American, moderated each focus group and at least one note-taker (female) was present to document non-verbal cues. Once the focus groups were completed, all recordings were transcribed, and all documents were stripped of identifiable information that could be linked to an individual participant. The original recording of the focus groups was destroyed following transcription. Prior to deletion, all digital recordings were stored on a password-protected computer.

3.11 Measures: Focus group protocol

The purpose of the focus group was to explore women's perceived solutions to Pap smear barriers. Participants were presented with the top five barriers from Phase 1

and were asked to brainstorm solutions to help eliminate or reduce those barriers. They were directed to think of themselves as problem solvers. The moderator emphasized to participants that these barriers may not be applicable to them but asked what they would suggest for "other" women who may identify with the barriers. The moderator was also female to help increase participants' comfort level.

Equipment consisted of one digital recorder that was tested prior to every focus group. Chairs were positioned together to help facilitate discussion (see Figure 3.2 below). A note taker sat in the back of the room to take detailed notes that may not be captured on a digital recorder during each session, such as nonverbal communication, gestures, or behavioral responses. The note taker was trained and given a handout on what to report during each focus group and the moderator was trained on techniques to use to assist in facilitating focus groups.

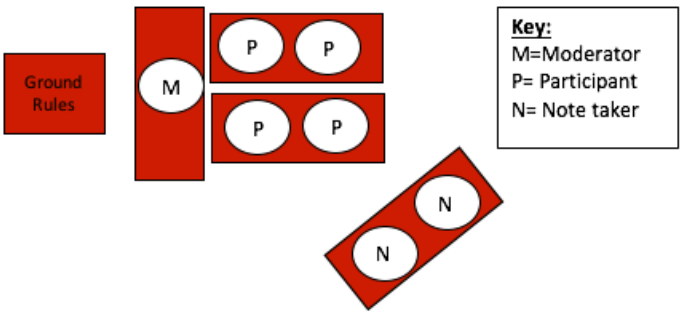


Figure 3.2 Focus group layout

Prior to initiating the focus group, the facilitator reviewed the consent form, informing members of the study's purpose, rights, benefits, and risks. After the moderator reviewed the consent form each participant signed the consent form in agreement. The moderator then went over ground rules with the participants, which was posted in front of the classroom for all participants to view (refer to Appendix D) and explained that the

environment is a safe, free, and non-judgmental zone in which disrespect or ridicule are not tolerated.

Once the rules of the focus group were explained, the moderator answered any questions or concerns from the group. Once questions or concerns were addressed each participant were given five color coded index cards with a barrier listed on each of the cards. The discussion began with the primary barrier and ended with the 5th barrier. At the end of the session participants were given the opportunity to mention any additional barriers not discussed. For each barrier the moderator read the barrier out loud (also written on each participant's index card) and asked each participant to take 2-3 minutes to write their solutions to that barrier on the back of their index cards. Writing on the index cards was to ensure four things: 1) that each participant had the opportunity to collectively gather their thoughts, 2) that participants did not forget their thoughts or ideas, 3) if we ran out of time each participant's ideas were captured, and 4) if a participant did not feel comfortable sharing their ideas in front of the group, their ideas are still being captured. Participants were told their solutions can be provider or individual specific. Once each member was finished writing their solutions to the barrier they were discussed as a group and each participant was given an opportunity to share their ideas. For each barrier the group discussion lasted for approximately 10 minutes. The moderator made sure to remain neutral when communicating to participants and to not give cues for discussion points. The focus group had a nondirective approach, so group interaction was encouraged among participants. At the conclusion of each focus group each participant was given a $10 Amazon gift card for their participation. The focus group moderator script can be viewed in Appendix G.

3.12 Data analysis

Aim 3: Explore participants' proposed solutions for reducing barriers to Pap smear adherence.

Research question 3: Using an interactive focus group discussion, what solutions do women propose for increasing Pap smear adherence?

After completion of the focus groups, all recordings were transcribed. An application called Descript was used to transcribe the data. The principal investigator and research assistant then made edits to ensure transcription accuracy. The Grounded Theory approach was used to analyze the qualitative data.[155] The Principal Investigator read all the transcriptions and highlighted recurring ideas related to each barrier and potential solutions. The unit of analysis for the coding process consisted of individual responses to questions, or utterances in response to other participants. Once all the common responses were highlighted and extracted, a codebook of themes was developed by the Primary Investigator for each barrier and its corresponding solutions. All ideas were then categorized into their appropriate themes. This codebook was also compared with each participant's index cards to ensure coverage of solutions. Notes taken during the focus groups by the note takers were also reviewed and utilized when they provided additional insight about the proposed solutions or group/participant dynamic.

Following completion of the coding process, quotes corresponding to each theme were pulled to provide supporting evidence.

3.13 Chapter summary

This chapter described the research design for this study and highlighted the independent and dependent variables, as well as the type of analysis used to conduct the

study. Phase 1 consisted of identifying Pap smear barriers among women via survey research, and Phase 2 included brainstorming possible solutions to Pap smear non-adherence through a focus group. Statistical procedures used to analyze the data, including logistic regression and content analysis, were discussed in this chapter as well. Overall, the goal of this study was to use a mixed-methods approach to testing the applicability of the HBM to predicting Pap smear adherence among women, exploring the utility of an adapted perceived barriers scale, and examining women's perceived solutions for addressing such barriers.

CHAPTER 4: RESULTS

PHASE 1: IDENTIFYING PAP SMEAR BARRIERS

4.1 Descriptive statistics

Table 4.1 list sample characteristics of the study participants. The average age of participants was 31.73 (±9.1). The majority of the sample were Black/African American (61.8%), non-Hispanic or Latino (95.9%), had a post-graduate degree (60.0%), were single (39.4%), and had health insurance (95.3%). Regarding sexual history, the following statistics were reported: 75.5% of women had sex within the past six months, 30.3% had been diagnosed with a STI, 46.9% had been diagnosed with HPV, 18.4% knew someone who was diagnosed with cervical cancer, and 40.2% of women reported ever having an abnormal Pap smear. When asked to report their Pap smear practice 89.9% of the sample reported receiving a Pap smear within the past three years, 6.6% never received a Pap smear, and 3.5% received a Pap smear more than three years ago.

Table 4.1 Descriptive statistics

Variables (N=424)	***n* (%)**
PAP SMEAR ADHERENCE	
Never had a Pap smear (non-adherent)	28 (6.6)
Last Pap smear 1-3 years ago (adherent)	381 (89.9)
Last Pap smear more than 3 years ago (non-adherent)	15 (3.5)
PAP SMEAR FREQUENCY/HISTORY	
Every year	121 (30.9)
Every 1-3 years	199 (50.8)
Every 3-5 years	31 (7.9)
5 or more years	5 (1.3)

I have only received a Pap smear once	36 (9.2)
Had an abnormal Pap smear	158 (40.2)
RACE	
White	120 (28.4)
Black/African American	261 (61.8)
American Indian or Alaska Native	1 (0.2)
Asian	22 (5.2)
Native Hawaiian or Pacific Islander	0 (0)
Multiracial	12 (2.8)
Other	6 (1.4)
ETHNCITY	
Hispanic or Latino	17 (4.1)
Not Hispanic or Latino	402 (95.9)
AGE	
Mean= 31.7	SD=9.1
EDUCATION	
Less than high school degree or GED	0
High school graduate or GED	3 (0.8)
Some college but no degree	32 (9.0)
Graduated from college	107 (30.1)
Post-graduate	213 (60)
*Currently in graduate school	69 (6.8)
HEALTH INSURANCE	
Yes	404 (95.3)
No	21 (4.7)
RELATIONSHIP STATUS	
Single	167 (39.4)
In a relationship but NOT living w/ partner	95 (22.4)
Living w/ a partner	46 (10.8)
Married	109 (25.7)
Divorced	7 (1.7)
SEX HISTORY	
Had sex within 6 months	320 (75.5)
Diagnosed w/ STI	128 (30.3)
Diagnosed w/ HPV	60 (46.9)
Know someone w/cervical cancer	78 (18.4)

4.2 Phase 1 (quantitative) results

Aim 1: Modify existing measures to develop a new HBM scale for Pap smear adherence

Research question 1:

Do the HBM subscales (perceived barriers to Pap smear adherence, perceived benefits of Pap smears, perceived threat of cervical cancer, cues to action, and/or Pap smear self-efficacy), have adequate internal reliability?

Results:

Table 4.2 shows the results from the internal consistency reliability analysis. Health motivation and perceived benefits did not have adequate reliability among variables, with their respective alpha scores being 0.527 and 0.605. The construct health motivation was eliminated from future analysis, and the construct perceived benefits remained in the study but was deemed questionable. The remaining constructs (perceived barriers, perceived seriousness, perceived susceptibility, self-efficacy, and cues-to-action) all demonstrated acceptable to excellent internal consistency.

Table 4.2 Reliability of constructs

Construct	Number of items	M	SD	Mean Item Mean	Alpha
Health motivation	3	10.31	2.480	3.437	0.527
Benefits	9	36.84	3.525	4.093	0.605
Barriers	20	30.47	8.622	1.523	0.875
Seriousness	7	21.59	4.549	3.084	0.750
Susceptibility	3	5.98	2.274	1.993	0.879
Self-efficacy	10	45.78	4.759	4.578	0.919
Cues-to-action	12	22.42	5.251	1.869	0.786

Research question 2:

Does the modified barriers scale adequately capture the barriers reported by women?

Results:

Table 4.3 shows the ranking and mean scores of the barriers presented in the questionnaire. Response options included 1=strongly agree, 2=disagree, 3=neutral, 5=agree, and 5=strongly agree. Therefore, a higher mean signified a significant deterrent among women. Additionally, percentages of those who chose "strongly agree" or "agree" were calculated for each barrier. The top five barriers based on these percentages were used to guide the focus group discussion in phase 2.

Table 4.4 displays the primary categories of "other" barriers not mentioned in the questionnaire in phase 1. Eighty-three women (19.57%) responded that there were other barriers not mentioned in the survey that were applicable to them. The item read, "Are there any other barriers not mentioned in the survey that deter you from getting a Pap smear? If yes, please describe them." This item was open ended and allowed for participants to type in their response if applicable. Table 4.4 lists the barriers mentioned by participants, with responses removed that reflected available questionnaire options and edited for clarity.

Table 4.3 Perceived barriers item means

Rank	Item	Agree/strongly agree %
1	I have other problems in my life that are more important than having a Pap smear	13.9%
2	If there is cervical cancer development in my destiny, having a Pap smear test cannot prevent it	13.7%
3	Having a Pap smear test is too painful	13.5%
4	I would be ashamed to lie on a gynecologic examination table and show my private parts to have a Pap smear test	10.9%
5	I had a bad experience with my last Pap smear test (only for women who previously had a Pap smear)	7.8%
6	I will never have a Pap smear test if I have to pay for it	7.6%
7	I am afraid to have a Pap smear test for fear of a bad result	7.3%
8	I cannot remember to have a Pap smear test regularly	7.1%
9	A friend or family member has made negative comment(s) concerning me getting a Pap smear	5.9%
10	I am afraid to have a Pap smear test because I don't know what will happen	5.2%
11	Health professionals doing Pap smear tests are rude to women	5%
12	Having a Pap smear test takes too much time	4%
13	There is no health center close to my house to have a Pap smear test	3.3%
14	I had a traumatic experience with a previous medical procedure that deters me from getting a Pap smear	2.8%
15	I do not want others (parents, significant others, etc.) to find out I had a Pap smear	2.8%
16	I don't know where to go for a Pap smear test	2.4%
17	I was sexually abused and do not feel comfortable getting a Pap smear	2.1%
18	I am afraid of tearing my hymen or "popping my cherry"	1.6%
19	The media has discouraged me from getting a Pap smear	1.4%
20	I am too old to have a Pap smear test regularly	0.7%

Table 4.4 Other barriers mentioned

Discomfort from medical equipment
Poor test readings
Long waiting period for test results
Ineffective test
Possible follow-up tests
Tight vagina
Infrequent doctor visits
PTSD due to sexual abuse/assault history
Invincible, not sexually active (virgin)
Timing during menstrual cycle
Rough health professional
Culturally incompetent/stereotypical providers
Inconsistent Pap smear recommendation from providers
Ignorance of the procedure
Lack of provider options due to insurance coverage (lack provider trust)
Ignorance of Pap smear recommendations/unclear guidelines
Offensive OBGYNs to LGBT community
Depressed (other problems)
Inconvenience of scheduling a doctor's appointment
Provider insensitivity to overweight people
Lab fees not covered by insurance
Have not established care with an OBGYN
Provider judging patients based on personal life choices

Aim 2: Test the predictive utility of the HBM for predicting Pap smear adherence

To examine Hypotheses 1-6, a series of individual logistic regressions were calculated to examine the impact of individual predictors on adherence. Additionally, a grouped logistic regression was conducted to determine the overall impact of HBM variables on adherence. See Table 4.5 for a correlation analysis of all the HBM variables.

Table 4.5 Correlation analysis of all the HBM variables

	1.	2.	3.	4.	5.	6.	7.
1. Pap smear adherence	1						
2. Perceived benefits	0.214**	1					
3. Perceived barriers	-0.199**	-0.388**	1				
4. Perceived seriousness	-0.109*	-0.123*	0.257**	1			
5. Perceived susceptibility	-0.079	-0.186**	0.203**	0.233**	1		
6. Self-efficacy	0.326**	0.296**	-0.635**	-0.115*	-0.169**	1	
7. Cues-to-action	0.203**	0.270**	-0.185**	-0.059	-0.109*	0.232**	1

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

LOGISTIC REGRESSION WITH INDIVIDUAL PREDICTORS:

Hypothesis 1: Perceived barriers will have a negative relationship with Pap smear adherence, such that as a person's level of perceived barriers increases, their likelihood of adherence will decrease.

Results: The overall logistic regression model was significant, $\chi^2(8)=24.32$, $p=0.002$, and the individual variable of perceived barriers was significantly related to adherence (B=-0.96, $p=0.003$). The odds ratio indicated that, for each one-unit increase in perceived barriers, participants were 1.1 times less likely to be adherent.

Hypothesis 2: Perceived benefits will have a positive relationship with Pap smear adherence, such that as perceived benefits increase, their likelihood of adherence will also increase

Results: The overall logistic regression model was significant, $\chi^2(8)=46.69$, $p=0.000$, and the individual variable of perceived benefits was significantly related to adherence

(B=0.176, p=0.002). The control variables of STI history and sex history were also significant, B=-1.884, p=0.012 and B=-1.0, p=0.005, respectively. The odds ratio indicated that, for each one-unit increase in perceived benefits, participants were 1.193 times more likely to be adherent. Additionally, when a woman had history of being diagnosed with an STI or had had sex within the past 6 months then their likelihood of adherence increased by 6.58 and 2.72 times respectively.

Hypothesis 3: Perceived susceptibility will have a positive relationship with Pap smear adherence, such that as a person's threat level increases, their likelihood of adherence will also increase

Results: The overall logistic regression model was significant, $\chi^2(8)=38.04$, p=0.000, but the individual variable of perceived susceptibility was not significantly related to adherence (B=-0.124, p=0.135). The control variables of STI history and sex history were significant, B=-2.03, p=0.007, and B=-1.127, p=0.001, respectively. So, when a woman had history of being diagnosed with an STI or had had sex within the past 6 months then their likelihood of adherence increased by 7.63 and 3.11 times respectively.

Hypothesis 4: Perceived severity will have a positive relationship with Pap smear adherence, such that as a person's threat level increases, their likelihood of adherence will also increase

Results: The overall logistic regression model was significant, $\chi^2(8)=39.28$ p=0.000, and the individual variable of perceived severity was significantly related to adherence (B=-0.95, p=0.021). The control variables of STI history and sex history were significant, B=-2.05, p=0.006 and B=-1.09, p=0.002, respectively. The odds ratio indicated that, for each one-unit increase in perceived severity, participants were 1.1 times less likely to be

adherent. Additionally, when a woman had history of being diagnosed with an STI or had had sex within the past 6 months then their likelihood of adherence increased by 7.75 and 2.97 times respectively.

Hypothesis 5: Cues to action will have a positive relationship with Pap smear adherence, such that as a person's cues to action increase, their likelihood of adherence will also increase

Results: The overall logistic regression model was significant, $\chi^2(8)=46.16$ $p=0.000$, and the individual variable of cues-to-action was significantly related to adherence (B=0.12, $p=0.004$). The control variables of STI history and sex history were significant, B=-1.92, $p=0.011$ and B=-1.1, $p=0.002$, respectively. The odds ratio indicated that, for each one-unit increase in cues-to-action, participants were 1.127 times more likely to be adherent. Additionally, when a woman had history of being diagnosed with an STI or had had sex within the past 6 months then their likelihood of adherence increased by 6.80 and 3.00 times respectively.

Hypothesis 6: Pap smear self-efficacy will have a positive relationship with Pap smear adherence, such that as a person's self-efficacy increases, their likelihood of adherence will also increase

Results: The overall logistic regression model was significant, $\chi^2(8)=63.382$ $p=0.000$, and the individual variable of self-efficacy was significantly related to adherence (B=0.189, $p=0.000$). The control variable of STI history was significant, (B=-1.89, $p=0.014$). The odds ratio indicated that, for each one-unit increase in self-efficacy, participants were 1.21 times more likely to be adherent. Additionally, when a woman had history of being diagnosed with an STI then their likelihood of adherence increased by 6.62 times.

LOGISTIC REGRESSION WITH ALL HBM VARIABLES:

Results: Table 4.6 shows that perceived barriers were the only significant variable when combined with the other HBM constructs (perceived benefits, perceived susceptibility, perceived seriousness, self-efficacy, and cues-to-action) in a grouped logistic regression. The overall model was significant, $\chi^2(8)=28.01$ $p=0.009$, and the individual variable of perceived barriers was significantly related to adherence (B=-0.13, $p=0.01$). The odds ratio indicated that, for each one-unit increase in perceived barriers, participants were 1.14 times less likely to be adherent when combined with all the HBM constructs.

Table 4.6 Summary of logistic regression analysis with all HBM variables

Variable	B	Wald χ^2	Odds Ratio
Race (control)	-	4.027	-
STI history (control)	-0.709	0.727	0.492
Sex history (control)	-0.422	0.443	0.656
Perceived benefits	0.004	0.001	1.004
Perceived barriers	-0.127	6.691*	0.881
Perceived seriousness	0.132	2.717	1.141
Perceived susceptibility	-0.055	0.136	0.946
Self-efficacy	-0.007	0.009	0.993
Cues-to-action	-0.080	1.750	0.923
Model χ^2 = 28.014			
Cox & Snell R^2 = 0.075			
Nagelkerke R^2 = 0.256			
***p ≤ 0.01**			

4.3 Phase 2 (qualitative) results

Aim 3: Explore participants' proposed solutions for reducing barriers to Pap smear adherence

Research question 3: Using an interactive focus group discussion, what solutions do women propose for increasing Pap smear adherence?

Based on recruitment in phase 1, 66 women expressed interest in the focus groups, however only 11 women participated due to responsiveness and availability. Phase 2 consisted of three focus groups each lasting approximately 1.5 hours. Focus group 1 consisted of all African American women and four participants were present. Focus group 2 consisted of three African American women and one Caucasian female. Focus group 3 unintentionally consisted of all (3) African American women. The goal of the focus groups was to discuss the top Pap smear barriers among women, based on the survey responses, and generate proposed solutions. The top five barriers retrieved from phase 1 were: 1) other problems in their life that are far more important than having a Pap smear, 2) belief that if cervical cancer development is in their destiny then having a Pap smear cannot prevent it, 3) belief that having a Pap smear is too painful, 4) feeling ashamed to lie down on a gynecologic examination table and show their private parts to have a Pap smear, and 5) a bad experience with their last Pap smear. A summary of these themes is provided below, along with representative quotations. Pseudonyms have been used to protect the participants' privacy.

Barrier 1: Other problems in their life that are far more important than having a Pap smear

This barrier was defined as having other issues that were perceived by women as being more important than getting a Pap smear. Other issues included non-health related issues and health related issues. The themes accompanying this barrier were: education, convenience, and social support.

Theme 1: Education

The lack of education about Pap smears and cervical cancer was the primary perceived cause for this barrier, and in turn improved education was proposed to be an important solution. Participants mentioned that some women are unaware of the importance of getting a Pap smear, are unfamiliar with the procedure, or are unclear about the recommended frequency of the test. One participant stated if women do not understand the importance of getting a Pap smear and their provider fails to mention it then they will be less likely to get a Pap smear. The supporting quote is below.

> "*If the doctor doesn't tell me that it's important, I don't have a concern about it. It's no reason for me to get it you know that's just an extra hassle."* -Amber (Focus Group 3)

It was also suggested that pamphlets be readily available in the waiting room of the doctor's office, or that advertisements on television could be beneficial:

> *"Um maybe even like the pamphlets telling you this in the waiting room or they put commercials for everything else they got a commercial for Gardasil on and tell you why you need to get a Pap smear instead of getting the shot. Why are you even doing this in the first place?"* –Brittany (Focus Group 1)

It was also mentioned that women are learning about a Pap smear too late in life. It was proposed that women should be taught about the importance of getting a Pap smear at a

younger age, preferably in Elementary School in a health class. The quote below illuminates this point.

> *"… I think they should start talking about this in Elementary School. And so, the same way we talked about getting like HIV and STI testing. Um also talking to girls about getting those type of tests and the importance of that." -Jennifer* (Focus Group 3)

Once participants are aware of the importance of getting a Pap smear, they need to make it a priority. Some women mentioned if women do not view themselves as being at risk for cervical cancer or if they view a Pap smear as a less-important health screening then they may be less likely to get screened. The quote below suggests that health professionals should review the risk factors for cervical cancer, reiterate that all women are at risk, and explain the importance of overall health and wellness on a broad spectrum.

> *"I remember a friend of mine. She wasn't sexually active, but she, is very anti getting her Pap smear, kind of saying the same things like well, it's not really that important. And jokingly, I said 'Your vagina is going to fall off if you don't get one,' just trying to make light of it, but I was like 'but seriously just because you're not sexually active that doesn't mean that this isn't for you guys,' I said 'You can get cervical cancer' and she had no idea."* -Erica (Focus Group 2)

<u>Theme 2: Convenience</u>

Another theme related to Pap smear adherence was the inconvenience of the exam. The first issue with getting a Pap smear was having to take time off from work and being penalized for doing so. The solution to this dilemma was for employers to offer their employees an incentive for getting their Pap smear and/ or allow them to engage in regular health exams and check-ups without penalty.

> *"When I read other problems, I merely thought I have like work or financial and so I thought if there was maybe an incentive at work. Where people are allowed to go to get like just Healthcare checkups and general and still be paid. I think that a*

> *lot of people worry about if I take off work. I get fired or something like that."* - Jessica (Focus Group 1)

It was also suggested for health professionals to do Pap smear exams at the office or in mobile vans outside of workplaces. This solution will prevent employees having to take time off from work and having to go through the hassle of finding a provider, as described below:

> *"And so, if people* [health providers] *had come out like the same way they do like testing and like blood stuff. …having a couple providers like come to a worksite or somewhere close to where maybe there's not like the Health Center close by and having like a week of where they're doing these types of tests. Just so people can just be able to do it in a lunch break or during times when they are at work, so they can kind of get it done."* -Jennifer (Focus Group 3)

Women also described the challenge of having to schedule multiple medical appointments because their primary care provider did not perform Pap smear exams. Therefore, it was suggested that health professionals make visits more inclusive where a Pap smear can be administered during their annual physical exam or in conjunction with another medical visit.

> *"So I kind of thought it would be good to have like an inclusive screening where like you're already going to get this type of check-up, or you're already going to get like a mammogram or whatever to also like lump that in as like a part of it because I know that my doctor was like no this has to be a separate appointment which was limiting for me."* -Tiffany (Focus Group 1)

Outside of the inconvenience of showing up for a Pap smear it was also mentioned that it was inconvenient to wait for a long period of time for their test results from the lab. Women mentioned feeling anxious while they waited for their results which could serve as an additional barrier for future tests. They recommended more rapid results to reduce the fear and anxiety surrounding waiting for your Pap smear results.

> *"It's like most of the time the fear and anxiety doesn't even come from the test because the test is quick. It is like all the build-up and then the wait afterwards*

> *and you're thinking about all those things, that's like, oh okay, and then you get the test, and you're like oh, it wasn't even painful."* -Jennifer (Focus Group 3)

Theme 3: Social support

Women mentioned that having some level of social support from their peers or family members was very important in terms of addressing barriers. It was important to have someone available that they trust and respect to share their concerns regarding the test, especially for someone who is ignorant about Pap smears or is getting their Pap smear for the first time. The direct quote is listed below.

> *"... being open and honest and like having those conversations with our friends who may not know and accompanying them to those doctor's appointments. Um, because I think that's where it can start. Um, just having those conversations with them to like debunk some of those myths that they have..."* -Jasmine (Focus Group 2)

It was also emphasized that in the community of color it is very common for young women to not be familiar with a Pap smear, and that it is imperative that we have more dialogues and conversations surrounding young women getting a Pap smear.

> *"Just having more dialogue and conversations about it because I mean, especially when you're talkin about in the community of color, Um, those are not really discussions that we have all the time with, you know, our young girls or even with other women in itself."* -Megan (Focus Group 2)

To hone in on the idea of depending on a peer, women also mentioned an accountability partner. An accountability partner, whether a friend or family member, can not only address and debunk myths but also prompt them into getting a Pap smear. It was stated that if someone that they respect prompts them to get a Pap smear then they will be more likely to do so. The following quote suggests that peers and social interactions can influence an individual's decision to get a Pap smear.

> *"So sometimes girlfriends talk to girlfriends and they can kind of say, well um, this is a great way for you to take care of yourself so that you have less issues later in life…"* – Mary (Focus Group 3)

Barrier 2: Believe if cervical cancer development is in their destiny having a Pap smear cannot prevent it

This barrier was defined as having the preconception that cervical cancer is not preventable and, if they are "destined" by fate or higher power to have cervical cancer, then there is nothing they can do to prevent it. The themes accompanying this barrier were: education, spiritual and religious beliefs, and discussion and mentorship.

Theme 1: Education

Again, education was the most common theme for women who believe cervical cancer is in their destiny. It was emphasized that most women do not understand the purpose of a Pap smear and are uninformed about its importance. It was indirectly suggested that providers and/or family members adequately explain the role of a Pap smear in preventing cervical cancer. The common misconception that Pap smears are a diagnostic test for cervical cancer or that it will make them invincible to cervical cancer may deter some women if they are fearful of a positive result or do not believe they are susceptible. The quote below confirms the confusion behind getting a Pap smear.

> *"Acknowledge that I think sometimes people think that a diagnostic test is a preventive measure in the sense that it will prevent the disease and there's some confusion as to what the test does and I think maybe there should be a little more education about what, okay, maybe it doesn't prevent cancer, but what does it do? Maybe when the test comes back, this is what it means."* -Ciara (Focus Group 3)

In addition to understanding the purpose of a Pap smear it was also suggested that women are educated on the risk factors and how they can reduce their risk of cervical cancer development even if it does run in their family.

> *"Educating them on how they develop and um, what might be some of the causes such as like genetics or like lifestyle issues or like how much sex you may have whatever but uh that way they understand, you know where it would come from because you say cancer and you just automatically go into like primal fear of oh my God, something's out to get me but I feel like it would eliminate a lot of the fear and a lot of the fatalism."* -Lauren (Focus Group 2)

It was also stated that some women have the mentality that if their family member has cervical cancer then they are destined to get it too, despite preventative measures, so proper education about how cervical cancer is developed is imperative.

> *"Some people read health information and that is you know how they get their source of information. Well, they said it was 25%* [chance], *so three people in my family, you know already have it, so it must going to hit me one day and I'm just going to wait for it."* -Amber (Focus Group 3)

One participant shared her personal experience with breast cancer running in her family. She mentioned when she heard her grandmother was diagnosed with breast cancer she immediately wanted to go and get a mammogram to prevent cancer development, however, her doctor informed her that because of her young age, the mammogram was not necessary. However, expressing her concern with her provider and having that conversation alleviated her anxiety. She indirectly suggested for women to address their concerns with their provider and to have a conversation with them.

> *"My grandmother had um not brain cancer but breast cancer and so like after I was like, I need to get a mammogram right now, um, because I don't want to have breast cancer. I want to know now. I don't want to like wait till I'm older to find out. But then also being told, no you don't need it right now. And so but having that conversation with my gynecologist was really helpful."* -Jennifer (Focus Group 3)

Another solution was to promote sex education in schools. As mentioned previously, it was suggested many people do not understand the risk factors for cervical cancer and as a result do not know how to protect themselves and they are not linking it to HPV or STIs. For this dilemma it was proposed that a disease course be taught in high schools.

> *"So, I think in general people don't recognize how cervical cancer can be prevented in the first place because they're not linking it to sex at all. I think the best way to deal with that is to have a high school course. That's not what was on sex at all but focus on diseases, and how it is transmitted."* -Jessica (Focus Group 1)

This participant took it a step further by providing an example (below) which suggested if people actually linked HPV to cervical cancer then they will be better able to protect themselves.

> *"But like people are not linking it to HPV or um and so a big thing that I have seen, and I tell my friends all the time is that a lot of times with their partners they'll ask have you been tested. The partner will say yes, and then if you push further to see what they have been tested for they'll say everything and then you say what's everything, and they can't say yeah, because what they're doing is they're getting tested for HIV and nothing else."* -Jessica (Focus Group 1)

It was also mentioned that a lot of times health-related information is not accurately displayed in the media. One participant mentioned that the news, but more commonly entertainment television shows, are ignorant of most health topics and misinform the public, which can adversely affect health-related behavior. As a solution to this barrier, it was suggested for some media to be restricted in the topics they discuss if they are not experts in the field or for a script to be provided. The accompanying quotation is listed below.

> *"I really think that there needs to be somewhat of a mandatory um accurate disease representation in media…. Can you just accurately represent this? But the news is not what I'm typically talkin about, but I have seen it in news as well that the way things get reported or talked about can sometimes be inaccurate um. Yes, so primarily where I'm referring to like is TV shows however on things like let's say The Breakfast Club. I don't know if we can police that is a live show right ignorant things one that they are on the all the time you know, so I'm not really sure how we would check that but I think that we could start with something that has script first."* – Jessica (Focus Group 3)

Lastly, to help overcome some of the anxiety behind cancer development, it was suggested that health professionals teach that there is life after cancer.

> *"It's like there's this idea like there's no life after cancer like once you get diagnosed with cancer your life ends. Like there's no living. There's no happiness. Um, I'm sure it is a challenge and there is a possibility of death… Just go ahead and get it [Pap smear]. And so getting used to these conversations, but also addressing some of the fears, um and the feelings around cancer."* -Jennifer (Focus Group 3)

Theme 2: Spiritual and religious beliefs

For some women when they read this barrier they automatically thought about someone who is religious or spiritual. For this group of women, it was suggested for health professionals to reach out to religious or spiritual leaders for support. Some women suggested workshops at churches while others suggested one-on-one advice from their leader despite this being a controversial topic. It was also suggested that these religious/spiritual leaders emphasize that there are life choices and cervical cancer is not in their destiny. The accompanying solutions are listed below.

> *"Partnerships with like religious groups, like getting into the churches having um workshops, um, having groups similar to this. Um, of course that will be controversial and that would be difficult."* -Jasmine (Focus Group 2)

> *"This* [spiritual or religious leader] *is who you trust, you know, if you don't trust the health provider then maybe if you trust them and they are open to talk about it and say no it is not necessarily your destiny and it's not a guaranteed."* -Amber (Focus Group 3)

Theme 3: Discussion and mentorship

For this theme women suggested that Pap smears are not usually discussed in the home. While some women mentioned that their family members discussed with them the importance of a Pap smear many others did not, even if the parent was well informed.

> *"My childhood best friend, her dad was a gynecologist and he never gave them the talk. She learned about how sex works from Google and me because my parents gave me a very candid talk and she came to me for questions and I'm sitting here like your daddy delivers babies how he is not going to tell you all this."* -Lauren (Focus Group 2)

Solutions for this theme focused on group discussions with family and friends as well as talking to someone who had a Pap smear and listening to their experience with screening.

> *"Maybe people who have had the Pap smear who are older and for them to talk about on the other side. Were the benefits long-term, of actually doing it versus not."* -Ciara (Focus Group 3)

Barrier 3: Having a Pap smear is too painful

For barrier 3 the participants interpreted this statement to include both physiological pain and the psychological pain or fear associated with getting a Pap smear. Solutions for this barrier related to both the woman who is in need of a Pap smear and the provider conducting the screening. The themes accompanying this barrier were: education, provider-patient communication, distractions, social support, provider preference, and policy/training/regulations.

Theme 1: Provider-patient communication

For this theme it was assumed that the reason some women may be fearful of getting a Pap smear was because they are ignorant of the procedure and equipment. The solutions proposed were specific for women who have never had a Pap smear or that did not have someone that they could talk to. Some solutions were to have the provider explain the procedure to the patient and to walk the patient through the process while they are performing the procedure to eliminate the surprise component.

> *"Having the healthcare provider maybe walk you through you know, what's going to happen…"* -Lauren (Focus Group 2)

Along with explaining the procedure to the patient step by step it was also suggested that the provider explain to the patient that the procedure should not be painful but rather uncomfortable, and to make the "pain" relatable by describing it in relation to a similar

sensation. This was suggested to give the patient an idea of how the procedure may feel to help alleviate some of the anxiety associated with the fear of pain, as described below:

> *"And so I had a really great doctor who was like, okay this is exactly what you're going to feel. And like the word she uses is really important. So, I think talking about the type of pain we talk about instead of saying you're going to feel pain because then I'm like, okay. What kind of pain are you saying numbness? Are you saying sharp pain? But she kept saying pressure. You're going to feel a pressure that's very uncomfortable, but it's not like a sharp pain. And so that I can kind of like- pressure versus pain to me sounds totally different."* -Jennifer (Focus Group 3)

It was also suggested that women are informed and given the option to request for a change in speculum size or material and for additional jelly for lubrication if needed. It was stated that most women are unaware that there are different size speculums and that they are allowed to request for something more comfortable.

> *"…there's not one speculum because sometimes people use the wrong speculum there are smaller ones. But people don't know, women don't think to ask that. You can use jelly. I mean, there's all kinds of things but we don't we don't know what we don't know.* -Ciara (Focus Group 3)

Women also stressed the importance of a good provider-patient relationship. It was mentioned that the female should feel comfortable communicating with their provider and vice versa. It was suggested that once a relationship has been formed then a mutual respect and understanding for one another will help guide and achieve a positive Pap smear experience. Some of the qualities that they look for in a provider was that they are caring and a good listener. It was also mentioned that it was common for health professionals to rush the procedure in order for them to get to their next client, which felt disrespectful and dismissive. Therefore, women proposed for providers to be on time for appointments, take their time, and go through the process of explaining the procedure,

answering any questions or concerns, but ultimately making sure the patient is comfortable. Below are the specific solutions women proposed for providers.

> *"I recognize the doctors see us on like a mass spectrum like they get many patients in a day, but that is our one day to go to a doctor and recognizing that that one moment is incredibly important and deserves that amount of sensitivity is kind of its everything otherwise they can be really biased about female's pain tolerance."* -Tiffany (Focus Group1)

> *"I think sometimes they come late, so it adds to the stress. Yeah, and they want to get it done and it's like no I've been waiting here in this cold room and you're late. I get in trouble if I'm late to the appointment."* -Ciara (Focus Group 3)

One participant later elaborated and compared women getting a Pap smear to an animal being slaughtered.

> *"Slaughterhouses goes through like 60,000 animals per hour, and in that animals moment that is everything that is happening to it, but a person is going through 6,000 of those in that hour, and I was like-- you wouldn't want to be that cow just experiencing one of 6,000 you wouldn't want to be that that lamb or that chicken or that whatever, so like let's not treat people like they're factory farm. Let's treat people like they're humans."* -Tiffany (Focus Group 1)

Women also proposed that doctors directly ask their patients if there is anything they can do to make them feel comfortable before beginning the procedure. In addition, it was suggested for providers to check-in on the patient throughout the procedure to confirm that they are ok, versus waiting until the end or for them to verbalize. Below is the quote supporting this theme.

> *"So, kind of thinking does this hurt? Is it uncomfortable? And so asking those questions while it's happen as opposed to waiting for me to like verbalize ouch this hurts because there is like that power dynamic you are saying between like you're the doctor and I'm just a patient who doesn't know anything, and I don't know any better."* -Jennifer (Focus Group 3)

Expanding on the idea that some women may not verbalize whether they are in pain, it was recommended for women to establish a relationship with their nurse. It was stated that nurses are key to a pleasant experience because they can advocate for the client. For

example, one participant mentioned in her experience the nurse helped to build her confidence so if she was in pain or needed something to be explained she was aware she had the right to communicate that to her provider. A section of her quote is inserted below.

> *"The nurses are key to that…but the nurses in my experience have said now this is it, if you feel pain, tell the doctor. And I think when the nurse says that it gives the person the ability to feel a little more sense of self-efficacy and asking because a lot of times it's like the physician is the dominant in the room and your just, I'm just going to have to do whatever they say, but the nurse is kind of like that your advocate."* -Ciara (Focus Group 3)

Theme 2: Distraction(s)

The third theme consisted of distraction techniques. Distraction techniques were defined as anything that will distract or take the patients' focus off of the procedure. The distraction techniques proposed included decoration on the ceiling of the exam rooms, and simple conversation with the provider. Brief description for each solution is provided below.

> *"My first one had like light dims with like stars on the ceiling, and I thought that was so cute. She was like yeah, this used to be a pediatrician's room and so like we actually find that it's like really soothing, and I was like this is actually incredibly soothing, and so it was just like you know there's something. Like occupy your mind while somebody's going through your business."* -Tiffany (Focus Group 1)

> *"My gynecologist she used to have conversation with me. So, when I was applying to graduate school, she was asking me questions and we're having a conversation. She's like, yeah, what do you want to study? And I was like yeah. She like put it in but you also like told me she was going to and so we're like talking and she's like, yeah, so she kept asking me questions to get me to focus on conversation versus like what's happening. And so I think a good person who's like doing the work and knows how to like keep you distracted enough that like you're not worried about this, but you're aware of what's happening will be good."* -Jennifer (Focus Group 3)

While most women agreed that they appreciate distractions, one participant specifically opposed distraction techniques of any kind. However, it is important to note that this specific participant had an extreme fear of pain in getting a Pap smear.

> *"I don't want you to distract me. Don't talk. None of that noise, right? I'm not trying to be rude. You know, I just, like I know I just feel like I can't relax I can't do it."* – Megan (Focus Group 2)

Theme 3: Social support

Social support was another common solution for women whether it was from a family member, friend, or a health provider. Women reported it was comforting to have someone physically there with them while they are getting the procedure or having someone supporting them emotionally from a distance. They stressed that having someone available to ask questions or address their concerns was essential. Below are some examples of how social support was proposed from participants.

> *"But the main key thing I wrote down because I had to do that for myself is to find somebody you feel comfortable with and find somebody who's going to make you accountable, so it may not be your doctor, it may be a close friend."* -Megan (Focus Group 2)

> *"Maybe they could ask like a friend who's had that procedure done and maybe that friend could tell them okay this is kind of what it looks like."* -Lauren (Focus Group 2)

Another participant shared her experience of a nurse serving as her social support. She goes on to say a nurse came in the room while she was getting her Pap smear and comforted her by holding her hand.

> *"I had a lady once like when I was younger like for my first one that she had a nurse. She came and held my hand. The procedure was just like super awkward… She said hold my hands and just squeeze and let's breathe, I was like you are really nice. This isn't a terrible experience as terrible as I thought I would be in here. Thank you for your hands."* -Brittany (Focus Group 1)

It is important to note that not all women felt comfortable with someone outside of the provider being present in the room with them and prefer emotional support from a distance.

> *"I rather experience it on my own because it's so intimate even with a spouse. And you know, if you know my spouse is in the room and then you know, I'm used to what's going on and you see a male, you know, what's going on, why? It just takes the focus off.*" -Amber (Focus Group 3)

One participant discussed a bad Pap smear experienced by one of her friends, and another participant responded by saying that if that had happened to her, she would never go back. Another participant commented on her reaction stating that having an accountability partner is so important because for some people if they had a bad experience or heard about someone's bad experience they may be less likely to go back. Her comment is listed below.

> *"Wow, I just thought that was interesting at her reaction, when you told us about your first experience and she was like, I would never go back. Can you imagine somebody who doesn't have someone who holds them accountable? They would never go back and that's what happened. So many times. It's like they know that they have to do it. They had a bad experience and like I'm done I did it once so I'm good. Yeah. I don't have to go back again."* –Megan (Focus Group 2)

Theme 4: Provider preference

Some women indicated a preference when it comes to their gynecologist or a provider doing their Pap smear. Provider preference included gender and race. Some women preferred for their provider to be female, while others had no gender preference. Women explained that a female provider will be more considerate and understanding compared to a male provider, as explained below:

> *"I said making sure that the patient and the provider is comfortable because for a lot of women, especially if it is a male gynecologist, its uncomfortable. They don't*

> *have the same body parts. They don't understand, you know, what you're feeling."* -Amber (Focus Group 3)

In addition, some African American women preferred for their provider to be African American as well or someone of color while others did not have a racial preference. Their rationale was that someone who is of the same race will be more cautious or aware of certain health-related conditions or symptoms that someone not of their race may overlook or not be aware of, as described here:

> *"I do prefer to uh work with um, a gynecologist who is African-American. Okay, if I cannot find someone who is African-American then I do prefer to work with a woman of color and the reason why and it's like once again everybody. I'm sure there are plenty of gynecologists out there who are great, but I just feel as women of color we deal with certain things. Um that I just feel like somebody of color may study into something a little bit more and they have a little bit more insight when it comes to that."* -Megan (Focus Group 2)

It was also mentioned that race and gender may not matter to some but for this participant their provider preference was based on their provider's expertise, vibe, and ability to make them feel comfortable. The following is the accompanying quote.

> *"Does race matter or the sex of the doctor matter and for me no… I think for me it's really important about the rapport. Like if I get a sense that you really like provide well or like you have my best interest and you're not just there to like check off boxes that for me um is what's important? So, it doesn't necessarily matter what you look like. Just as long as I feel comfortable with you. "*-Jasmine (Focus Group 2)

Theme 5: Policy/training/regulations

The thought and fear of pain was also associated with women who have a history of sexual abuse or trauma. It was mentioned that women with a sexual abuse history are often forgotten and were identified as needing additional care and attention to avoid being re-traumatized or adverse health outcomes. It was suggested that these group of

women are pre-screened and then referred for counseling prior to them getting a Pap smear if needed. Suggestions for policy, training, and regulations were also mentioned.

> *"I think also some conversation about trauma history. And so every time I go to the gynecologist they never ask that. And so, for people who are touching you and putting something in you, that can be like re-traumatizing for people. And I asked my doctor here about like why we don't have those conversations and she was like, I never thought to ask. She just assumed that those people are like expecting it or they cool with it and I was like no, for people who have like sexual or physical trauma like that kind of pain and that kind of like just going in like that without there being some I don't know some walk through some warming up to it."* – Jennifer (Focus Group 3)

When the pre-screening was described a little further, it was suggested that providers inquire about women's sexual abuse history (if any) and address their concerns. It was proposed that prior to every appointment, preferably while women are in the waiting room waiting to receive their Pap smear, they are given a form for them to write their fears, concerns, or if they have ever been sexually abused. It was emphasized that this form should be reviewed by their provider and discussed with the patient at every visit. Below are the accompanying quotes for this solution.

> *"When you first go to the doctor's office, uh for your yearly exam, they give you that form. So, on that form if they leave a section for your fears or an open response so before we start, you know, I'm going to go over the questions but at the same time. I see you wrote something. So there needs to be an open dialogue. There needs to be a conversation before we go further. So that way we know versus at the end of the appointment. You totally uncomfortable, you were fearful, and you know if I was a physician um, I want to care for my patients and if I care I want to know, because then that means you probably will never come back."* - Amber (Focus Group 3)

> *"And then if the person goes to the same provider like overtime kind of also just always checking in, because sexual assault doesn't always just happen earlier or at one time it could happen with your spouse or coworkers so just kind of always leaving that door open, um to kind of have those conversations."* -Jennifer (Focus Group 3)

Jennifer later added the following

> *"…but even just having something on there that ask about have you ever experienced, you know, assault or rape, like clearly defining it and having them write on it and they can say like do you want to talk about this in our session, check yes or no. Do you want to discuss this? Yes, or no? How you feel? Like it can kind of be open but it can also leave some room for them to kind of decide whether this is something important or imperative enough to like talk about in my session or don't worry about it, I just wanted to let you know that this is something that can happen so you have some kind of knowledge around it."* - Jennifer (Focus Group 3)

It was also suggested if the trauma is too severe then the provider should refer the patient to a specialist or counselor that is trained to treat or manage someone with sexual trauma or abuse.

> *"I* [provider hypothetically speaking] *didn't get the training but I think they maybe feel a little more comfortable if okay, let me at least refer my patient."* - *Ciara (Focus Group 3)*

Barrier 4: Ashamed to lie down on a gynecological examination table and show their private parts to have a Pap smear

This barrier was defined as the accompanying feeling of shame and embarrassment due to being exposed while a stranger is examining their vagina. Solutions were specific to women, health professionals, and the society as a whole. The themes accompanying this barrier were: education, body image, social support, patient-provider relationship, societal change, spiritual and religious beliefs, and distractions.

<u>Theme 1: Education</u>

Education was reinforced to help eliminate or reduce the shame associated with getting a Pap smear. Women suggested that reminding themselves of the importance of getting a Pap smear will help alleviate the temporary discomfort of the exam itself. It was

also mentioned that focusing on the benefits of the exam far outweighs the temporary emotional distress or discomfort. One participant stated:

> *"Remember why you're doing it because I rather be embarrassed for a short period of time and think and think like I really don't want to do that this in the moment rather than later on to say, oh, you know I have cancer or I don't know, you know huge fibroids or something and you know, I could have gotten to taking care of a now I'm having a hysterectomy or something. You know, I'd rather do that than to worry about it."* -Megan (Focus Group 2)

Other solutions were very specific to the exam itself. Women proposed re-iterating that the health professionals performing the exam are trained to examine vaginas all day and that their vagina is no different than anyone else's as a technique to desensitize the women.

> *"…and explain that these gynecologists or practitioner, they're doing their job. So, they're fully expecting to examine you and they look at vaginas all day. It's like an assembly line, so yours isn't unique. You're probably one of ten vaginas that they're going to look at during the day."* -Erica (Focus Group 2)

For women who are concerned about being exposed to a male provider and having unwanted events occur, one participant emphasized that there is always another female or health professional present to ensure protocol:

> *"I know for me, I see a male doctor, so there's always um a female like nurse in the room with me. If that's something that makes one feel uncomfortable, just having that peace of mind that, there's another woman in the room with you."* -Jasmine (Focus Group 2)

Theme 2: Body image

The topic of body image was another important theme. Women mentioned that it is crucial for women to feel comfortable with her own body in order to have a positive Pap smear experience. This included being comfortable looking at yourself naked, as well as knowing what your vagina looks like, and owning your body.

> *"Look at yourself in the mirror, you know just take clothes off and look at yourself in the mirror trying to get comfortable with that. Once again, this is me. Uh, I don't feel comfortable being in front of anyone. I don't even undress in front of my own mother. So, I'm gonna lay down on the bed and allow people to see my private parts? So, um before I go I just try to make myself comfortable just look at myself in the mirror naked."* -Megan (Focus Group 2)

Women suggested to combat this issue to maybe have a mirror present during the exam room so that the women can see their vagina and the procedure being done as a way to help alleviate some of the anxiety and discomfort, especially if the women have been sexually abused.

> *"…like when they're doing the procedure like allowing the woman to be able to see like I don't know having some sort of mirror allowing her to be able to see what's going on down there and like maybe letting her see what the doctors doing especially if she has like a history where you know, maybe an assault or trauma where that way she feels like she has more control because she sees everything that goes on to her."* -Lauren (Focus Group 2)

Lastly, for this theme women mentioned that they like to have their vagina groomed and cleaned prior to getting a Pap smear. Grooming included getting waxed, shaved, and trimmed, while being clean consisted of hygiene, and smelling pleasant. Below are the direct quotes from women pertaining to this solution.

> *"I make sure I am groomed because if you have to see it, it needs to be groomed and to look really nice and clean."* – Erica (Focus Group 2)

<u>Theme 3: Social support</u>

Social support was also mentioned to overcome the feeling of shame and embarrassment. Women mentioned that having someone (a friend or family member) to talk to or physically present during the examination can be extremely beneficial, as was previously suggested for the barrier of Pap smears being too painful. However, making sure that person had had a positive Pap smear experience is essential. Women mentioned the peer-to-peer relationship is so strong that if a peer, someone they respect and trust,

had a negative Pap smear experience then that could deter the other friend from getting her Pap smear done. This is discussed in the following quote:

> *"And so one of the biggest things that starts with family, but also having girlfriends who are willing to have those conversations. Like word of mouth is like my biggest promotion. I don't care how many commercials I see about different examinations. If my friends are like you get that great, I'll go get it. Like because you said it. I trust you. You've been through it. But you tell me that it's bad, I'll be like hmm. I might I do a lot more homework and I probably still get it, but it's something about having to assurance that people who like know you, care about you, but also kind of share your same experience and makes a lot more comfortable to get the exam."* -Jennifer (Focus Group 3)

Another woman mentioned her spouse was her biggest supporter. She continues by saying her husband held her hand while she was getting her Pap smear but after the fact she educated her husband on the importance of a Pap smear and its procedure. She also acknowledges that everyone is different and may not want another person let alone their significant other in the room with them.

> *"I would feel more comfortable knowing that I got his* [spouse] *hand I could squeeze the crap out of all that's like the two minutes that that's going on, but everyone's different some people might prefer, you know not have that person in there… Well, I walked him through after I read that thing on Planned Parenthood. I told him what to expect so he kind of knew it too. So, men can be taught they can't be educated with this job."* -Lauren (Focus Group 2)

<u>Theme 4: Patient-provider relationship</u>

It was also encouraged for women to establish a positive rapport with their provider. It was mentioned that women may be extremely nervous or anxious about the exam and that a pre-consultation with their provider, in which they could review the procedure and the exposure involved, may be beneficial:

> *"Maybe like a pre-consultation with your doctor, so you can go in meet your doctor talk to them about the procedure. Maybe not even do it that day, just go ahead and meet them know who this person is and get comfortable with the fact that this procedure, understand what's going on and then just know more about it*

> *and be able to take it and just sleep on it get just get comfortable with it and then try it."* -Brittany (Focus Group 1)

It was suggested that it may also be helpful if providers are direct with their patients and inquire about their comfort level with the procedure. Inquiring to see if they are anxious or uncomfortable with being exposed can help address the issue directly.

> *"Just having a conversation about it, like you know normalize it. 'Most people come in here and they feel really exposed uncomfortable showing their parts to us. How do you feel about that? Like, what is your, you know, feelings about being on this table and you don't really know me. What is it that I could do to make me feel a little bit more comfortable in his space?' Um, so that could be a good way to just even open up conversation even if people don't know at least even at your doctor or nurse actually cares enough to ask."* -Jennifer (Focus Group 3)

It was also mentioned that creating a rapport and indulging in conversation with your provider can help alleviate the shame and/or embarrassment some may feel. Below is a quote that was shared by a participant that appreciates causal conversation with her provider and it gives her the sense that there is an equal exchange between her and her provider and that their provider cares about her on an individual level.

> *"I think that also helped to get to know the patient. Because you are right. It's like 15 minutes and then it's like the stranger put something in you and then they leave, and you never talk there's no dinner involved… so I learned so many things about this person and so it felt like yes, this is an examination. But also, we're both kind of like sharing things about ourselves. And so, it feels more like we're creating like some kind of rapport or relationship."* -Jennifer (Focus Group 3)

Theme 5: Societal change

Discussion concerning normalizing vaginas was also addressed. Women felt strongly that society and the media contributes towards the negative image of vaginas and causes any discussion about the female anatomy to be taboo. The following quotes highlight the discussion pertaining to this issue.

> *"On a large society level like addressing like the fact that we shame vaginas all the time. Like we don't even call them vaginas... And so of course like normalize it, of course you would feel ashamed to be exposed because there's nowhere in society where you're like encouraged to like be proud of your vagina or like love it or know that it needs help and that it needs to be monitored and that it's valuable and it's also just another piece of anatomy, but it still has meaning for people."* -Jennifer (Focus Group 3)

> *"Societal overhaul because there's no reason why you should feel so incredibly uncomfortable like with the idea of a doctor helping you to screen for possible diseases… It's never like oh, I'm so ashamed and that made me a better person shame was always bringing us down in some way. That's never making you do better and so, it's even harder to really get it because it's like chaotic."* -Tiffany (Focus Group 1)

Theme 6: Spiritual and religious beliefs

Religion was also discussed as a barrier for women getting their Pap smear. It was mentioned that some women may perceive being undressed in front of someone outside of their spouse to be a sin regardless of the reason.

> *"My other thought was is this chain coming from like a religious basis? Are you worried that another man or person seeing their private part that is not your spouse is some kind of like a sin of some sort? Maybe having more religious institutions about Women's Health in general."* -Brittany (Focus Group 1)

Another issue concerning religion was that some religious groups are extremely patriarchal and against women seeking help from a health professional. It was suggested that health professionals outreach to religious groups as well as possibly offer a kit where the female can complete her Pap smear exam herself in the privacy of her home.

> *"I know especially for some religious boundaries like there are religions that are so deeply rooted and patriarchy that they are you never going to say yes, you should go to a doctor and then benefit yourself. No, they're going to say figure it out amongst yourselves, so if we got figure it out amongst yourselves, it would be great if we could bring a test home to figure it out ourselves."* -Tiffany (Focus Group 1)

Theme 7: Distraction(s)

Lastly, distraction was another solution to tackle the issue of embarrassment and shame, as was also suggested for the barrier of Pap smears being too painful. Women proposed that music and/or a television screen could help distract the female from the procedure, such as described here:

> *"Even a music or maybe a TV um, anything that can kind of help, um client sorry patient to stop thinking about like being exposed or like- like thinking about the experience."* -Jennifer (Focus Group 3)

Barrier 5: Had a bad experience with their last Pap smear

Having a bad experience with their last Pap smear was almost always associated with a rude health professional(s) or clinic. Solutions to this dilemma were related to the patient as well as to the clinic and/or staff. The themes accompanying this barrier were: patient autonomy, reporting system, and a provider training course.

Theme 1: Patient autonomy

When the group of women were asked to identify solutions to rude health professionals, one of the first suggestions was to have a conversation with their provider. They stressed that sometimes the provider may not be aware that they are coming across as "rude" due to the stressful nature of being a provider and having to see several patients in a day. But it was apparent to most women that a conversation should immediately follow a "rude" event in hopes that it will become a learning opportunity for the provider. Women also mentioned if the conversation addressing the "rude" event does not go well, then it may be time for a provider or clinic change depending on the circumstance. The women stressed that it is their job and right to take ownership over the quality and care

they receive and if they are not happy then they should take their records and go elsewhere. Below are the accompanying quotes supporting this solution.

> *"If someone is rude to you or you don't like what happened, um, and it's like out of the norm type of thing then go somewhere else. I would hope that they could muster up enough like courage to go somewhere else after having this terrible experience."* -Jasmine (Focus Group 2)

> *"Don't feel uncomfortable voicing your opinion in the moment. Um, because that's a teachable moment for them. Like you mentioned. Um, you know, they do this every day day in day out is just like it just becomes an assembly line."* -Megan (Focus Group 2)

It was also noted that when women change their health provider or clinic, they should refrain from taking their negative experience with them because it could interfere with their current care.

> *"…try not take your bad Pap smear experience from provider to provider because just because I had a bad experience here. If I take that already negative thought and it may be something minor, something they had no idea they were doing but because I already had an experience before this I know you intentionally did that, I know, you know that you know, this is wrong."* -Amber (Focus Group 3)

In the all African American group it was believed that this group of women often encounter rude health professionals or health professionals that dismiss certain symptoms or illnesses. It was also discussed that some women may not have the option to choose their provider, let alone the race of their provider, as a result of their health insurance. There was concern regarding what this group of women could do, and it was suggested that a mobile truck offering Pap smears may be an option for these women. The supportive quotes are below.

> *"I'm constantly thinking about black women as we do this, especially when I think about bad health care. I emphasize to people that they have the right to choose because I see so many people stick with someone who is not doing good for them. But then I kind of had a question like what do we do with the people who cannot choose? So, you have to go to this doctor based on your health care or whatever?*

> *What do I do if I cannot get away from a bad doctor? So I think again, we need to do free trucks."* -Jessica (Focus Group 1)

Jessica later shared her personal experience of being dismissed by a provider not of color.

> *"I feel like I won't be dismissed um. I had several things happen even outside a OBGYN. Like if my lips turn dark suddenly and I went to the doctor. He said well, your lips are the color of African American lips, and it's like you don't think that when I woke up I knew that my lips are not the color they were yesterday."* -Jessica (Focus Group 1)

Theme 2: Reporting system

Many women believed if providers or clinics were held accountable for their behavior then the quality of the practice would improve. Women discussed various different reporting modes ranging from a call center, a medical board where patients can report adverse events, or a daily "Rate Your Provider" survey for each doctor's visit. However, the ratings must be anonymous to avoid retaliation. Details to this solution are listed below.

> *"I don't know if there's any incentives for doctors to do better unless if it's like your own practice, but I'm not sure if we actually even have the right to complain to a medical board. Yeah, like I don't know like I don't know if that's been a thing you know because maybe they'll be an incentive to like not to be a bad doctor. We could actually report you and if you're getting all these complaints about from all these different patients, maybe you don't need to be practicing."* -Jessica (Focus Group 1)

> *"Other people are afraid to you know, that this may be their only way is that fear of retaliation, you know? I can't tell on them, you know, because if I tell on them my name is going to be out there. I'm going to look like the bad, you know patient. The patient that makes trouble for everybody. So, let me just be quiet about it. But you should get out could bring other people who say yes, this is true."* -Amber (Focus Group 3)

Theme 3: Provider training course

A provider training course was suggested to ensure all providers are practicing proper bedside manners and are culturally competent to care for diverse populations. Below are the accompanying quotes supporting this suggestion.

> *"…bedside manner needs to be something that they really emphasize for some of these more intrusive kinds of tests."* -Tiffany (Focus Group 1)

> *"I think about the training that our health professionals should have about cultural sensitivity and multiculturalism and issues related to um, diverse populations. Just so you know they have the knowledge then they have the tools and they have the skills to like to engage in conversations with diverse groups of people."* -Jasmine (Focus Group 2)

4.4 Summary of qualitative findings

The findings from the focus group were applicable to a variety of women, regardless of Pap smear history and demographics. However, they did provide interesting insight regarding the unique experiences of African-American women. In addition, some suggestions proposed by women in the focus groups were specific to health care providers, employers, family and friends of women, and society as a whole. The participants' responses often centered on education, provider-patient communication, provider training, and social support as tools for reducing the barriers that might prevent women from getting Pap smears.

4.5 Chapter summary

This chapter included the study's descriptive statistics and quantitative results for Phase 1 and the qualitative results of Phase 2. In Phase 1 a reliability test and logistic regression analysis was performed to test the reliability of the scales and the association between HBM constructs and Pap smear adherence. In Phase 2 a qualitative analysis was performed in order to extract and analyze the proposed solutions to Pap smear barriers

made by women. The following chapter will provide an in-depth discussion of these findings and implications for future research and practice.

CHAPTER 5: DISCUSSION

5.1 Introduction

The purpose of this chapter to is to summarize and apply the quantitative and qualitative data from Phase 1 and 2 of the study. To the Principal Investigator's knowledge, this is the first study that has done an in-depth analysis of solutions to women's Pap smear barriers. This study has also developed and tested a new scale for assessing barriers to Pap smears. This chapter will also discuss the limitations of the study, as well as implications for future research and practice as it applies to the health care field.

5.2 Benefits of the revised HBM scale

To date, the most widely used scale for cervical cancer and Pap smear screening was developed by Victoria Champion, who also developed the health belief model scale for breast cancer in 1984, which has undergone several revisions.[153,156,157] More recently, Guvenc and colleagues adapted Champion's breast cancer scale for cervical cancer and found it to be a valid and reliable tool.[147] Guvenc and colleagues named their cervical cancer and Pap smear scale "The Health Belief Model Scale for Cervical Cancer and the Pap Smear Test." The Health Belief Model Scale for Cervical Cancer and Pap Smear Test consists of five subscales: Benefits of Pap Smear Tests and Health Motivation, Barriers to Pap Smear Test, Perceived Seriousness of Cervical Cancer, Susceptibility to Cervical Cancer, and Health Motivation.[147]

To identify the barriers for women adhering to a Pap smear, the Health Belief Model Scale for Cervical Cancer and Pap Smear Test was utilized in this study. However, based on a review of the literature, the Primary Investigator determined that the scale did not include all relevant barriers. Thus, multiple items were added to cover a wider range of Pap smear barriers identified among women. Items inquiring about women's past traumatic medical or sexual experience, concerns regarding tearing their hymen, and negative social influence from the media or friends/family were also added. Although these added barriers were not among the most common among the current sample, they were represented among this population. In addition, women were allowed to write additional barriers not covered in the questionnaire that were applicable to them (see Table 4.4). Hence, this study identified a wide range of barriers to Pap smears, as well as the relative importance of these barriers. Considering the impact of barriers in determining adherence, as discussed in the following section, the development of a more inclusive barriers scale is a valuable contribution to the literature.

5.3 Importance of "barriers" in the HBM

Perceived barriers are considered the negative consequences of engaging in a health-related behavior change.[138] The key to this construct is that the individual must perceive that the benefits of a behavior outweigh the barriers in order to be successful towards behavior change.[138] Previous research has suggested that perceived barriers may have a stronger impact on health behaviors compared to the other HBM variables.[141] This was confirmed in the current study, as a logistic regression analysis containing all of the HBM constructs found that perceived barriers was the only significant variable (see Table 4.5). This suggests that perceived barriers, when compared with the other HBM

constructs (perceived benefits, perceived susceptibility, perceived severity, cues-to-action, and self-efficacy), is the only variable that predicts Pap smear adherence among women. This finding was also consistent with a study conducted in Thailand, which showed a relationship between perceived barriers and Pap smear adherence but no relationship was found between perceived threat, perceived benefit, and cues-to-action.[158] However, contrary to the current study's finding, another study found that the HBM constructs of perceived benefits, perceived susceptibility, and self-efficacy had the highest relationship towards Pap smear adherence, while perceived barriers and perceived severity were not significant predictors.[159] Inconsistency among the association between HBM constructs and Pap smear adherence in the literature could be due to differences in HBM scales used, as well as the unique "barriers" of concern in specific populations.

In summary, the current study found that women with more perceived barriers are less likely to adhere to Pap smear recommendations. This conclusion is fundamentally logical, because if a woman views getting a Pap smear or any other health-related event as challenging or a hassle, then behavior change will be difficult or not occurring. Therefore, it is important that public health professionals identify and address both physical and psychological barriers in order to increase Pap smear adherence among women.

5.4 Top rated barriers among participants

Based on the combined "strongly agree" and "agree" percentages, the top five barriers for this sample were: 1) other problems in their life that are far more important than having a Pap smear, 2) believe if cervical cancer development is in their destiny then having a Pap smear cannot prevent it, 3) having a Pap smear is too painful, 4) ashamed to

lie down on a gynecologic examination table and show their private parts to have a Pap smear, and 5) had a bad experience with their last Pap smear. Next, each barrier and its relevance to the field will be discussed.

Barrier 1: Other problems in their life that are far more important than having a Pap smear

In the current study, 13.9% of the sample population stated that they had other problems in their life that they perceived as far more important than getting a Pap smear. The term "other barriers" was not defined in the current study but such "other problems" could include health related and non-health related problems such as finances and relationships. Approximately 12,578 women in the US were diagnosed with cervical cancer and 4,115 women died of cervical cancer in 2014,[16] and Pap smears are an effective method to detect and prevent the spread of cancer development of the cervix.[7] However, many women do not perceive getting a Pap smear as an important health exam. One participant in the study stated, "*If the doctor doesn't tell me that it's important, I don't have a concern about it. It's no reason for me to get it you know that's just an extra hassle."* This quote highlights the argument that if the woman does not perceive getting a Pap smear as important and their provider fails to mention it, then the patient may not get a Pap smear. This finding is also consistent with another study that indicated that Pap smears are not being viewed as a priority.[147] In addition, in the Hispanic community, it was revealed that they only visit their doctor when they are symptomatic and do not do so for preventative care.[101] Thus, increasing the perceived priority of Pap smears among women is an important issue.

Barrier 2: Believe if cervical cancer development is in their destiny then having a Pap smear cannot prevent it

In the current study 13.7% of women agreed with this barrier, which is the exact percentage in another study where women also agreed that a test won't prevent them from developing cervical cancer development.[160] In the focus groups, this barrier was discussed in relationship to religious and spiritual beliefs. Some participants believed that a cervical cancer diagnosis was determined by a higher power and the woman has no control. It was also believed that screening tests such as a Pap smear exam are not effective in detecting and preventing cervical cancer development, as stated in Table 4.4. Although the specificity and sensitivity for Pap smear exams are extremely high, it is still possible for false negatives and false positives.[7] It is also unclear based on the available data if the women who selected this barrier had previously received a false positive or negative test, which resulted in distrust of Pap smears in general or if they truly believe cervical cancer is inevitable. This barrier also had high importance among Guvenc's et al study of Pap smear adherence.[147] Thus, false beliefs about the development of cervical cancer and the role of Pap smears in prevention are important to address among women.

Barrier 3: Having a Pap smear is too painful

Although Pap smears should not be "painful" but should instead feel merely uncomfortable, 13.5% of the sample reported pain as a barrier. The belief that Pap smears are painful came from both women who have never had a Pap smear and from women who have had a Pap smear, which makes the fear of pain premature for those who have not had the procedure. Interestingly, the term "painful" seemed to encompass both physical and emotional pain, which was discussed in the focus groups. Emotional pain

was associated with feelings and ideas around getting a Pap smear, whether it stemmed from a previous traumatic experience or other personal factors. In Phase 1 of the study, some women reported a history of sexual abuse or harm from a previous medical procedure that had deterred them from getting a Pap smear.

Physical pain or discomfort was associated with having the speculum inserted in the vagina and having the provider feel around for abnormalities within the cervix.[161] Some focus group participants mentioned that a pain-related comment made by a friend or family member concerning a Pap smear could have deterred some women who have never received a Pap smear, which is consistent with findings in previous literature.[162] Additionally, previous research has found that many women who have had Pap smears reported experiencing pain, with one respondent stating that a Pap smear is very painful and that she always cried after completing the screening.[163] In international research pain as a barrier has been reported more than two times more frequently than in the current study. Pain was reported in 27.7% of Vietnamese women[160] and 31.4% in Malaysian women.[164] In addition, the current study's finding was consistent with previous literature especially among minorities, stating that pain perception may significantly reduce the likelihood of Black, Latino, or Arab women scheduling and receiving a Pap smear.[165] Together, these findings suggest that working toward solutions that combat perceptions and feelings of pain are essential.

Barrier 4: Ashamed to lie down on a gynecologic examination table and show their private parts to have a Pap smear

In the current study 10.9% of women reported that they feel or felt ashamed to lie down on a gynecological examination table for a Pap smear. This specific barrier was

associated with modesty and discomfort. Modesty was linked by focus group participants to cultural barriers surrounding religious and spiritual beliefs, which has also been evident in previous literature.[101,163,166] In a study conducted in Malaysia approximately 70% of women reported that "it is too embarrassing to do a cervical cancer screening.[164] In another study it was reported that 12.6% of women reported not getting a Pap smear due to embarrassment.[161] In the focus group, it was mentioned that being naked and exposed might be seen as a sin to some religious or spiritual associations. In addition, it was mentioned if the provider is male, this may add additional discomfort among women. In an international study, 42% of women did not get a Pap smear due to the lack of female health providers.[164] In another study researchers found that women may still feel uncomfortable even with a female provider performing the Pap smear.[163] However, overall a provider of the female gender tends to be preferred.[147,164] Hence, it may be valuable to address religious and cultural beliefs that may inhibit women from getting screened.

Barrier 5: Had a bad experience with their last Pap smear

In the current study, 7.3% of women reported a previous bad Pap smear experience. Since this specific item has not been studied directly in previous research and was added to the revised scale as an additional barrier, the ability to compare with other research studies is limited. When asked to define a "bad experience," participants in the focus group reported rude or insensitive health professionals. Some examples given by participants in Phase 1 and Phase 2 of the study were that health professionals dismissed their concerns of symptoms/illnesses, rushed the procedure, did not inquire about their comfort level, were late to the appointment, judgmental regarding patients' physical

appearances and lifestyle choices, and were "rough" during the procedure. Populations that emphasized this barrier were African American women, members of the LGBT community, and overweight women. Rude health professionals was also noted as a common barrier in Guvenc's and colleagues study.[147]

5.5 Common solutions proposed by women

Solutions proposed by the women in the focus group were very informative. Some of the solutions were specific to health care professionals and to women in general. This section will be organized based on the population to which the solution applies and then the applicable theme.

Health care professionals

Health care professionals are individuals and groups of people that have influence in the health care field as it pertains to women's health and cervical cancer screening. This includes but is not limited to health practitioners (primary care providers and gynecologists), nurses, and public health professionals.

Education

As was expected based on previous research, many women believed that they were not adequately informed of the importance of getting a Pap smear, were unfamiliar with the procedure, and/or were unclear about the recommended frequency of the test.[97,101] As a result the women proposed two suggestions: 1) that providers spend (more) time explaining the importance and logistics of the procedure and 2) that Pap smear literature (pamphlets, or brochures) be readily available in the women's health clinic. Furthermore, as mentioned in the focus group, some women held the following misconceptions; the belief that if they are not sexually active they do not need a Pap

smear, an abnormal Pap smear is a cervical cancer diagnosis, and there is nothing that can be done to prevent cervical cancer development. It is imperative that health care professionals take the time during the health care visit to educate women. Women should know why Pap smears are important, who is at risk, what a Pap smear test is for and what a positive test means, how to reduce their risk for cervical cancer, what happens during a Pap smear, and how frequently one should be screened for cervical cancer. In the literature educational interventions mostly consisted of formal educational sessions with women,[132,145] however this study is proposing that health care professionals take a few extra minutes discussing the procedure and logistics of the exam with their female patients. A patient satisfaction report mentions that the average time a gynecologist spends with their patient is 9.48 minutes.[167] Providers spending approximately ten minutes to inform the patient of the importance of a pap smear, address their concerns, and perform the exam is not nearly enough time. Some women in the focus group mentioned that they were so uninformed about what a Pap smear exam consisted of that they were extremely uncomfortable and anxious during the examination. In regard to the logistics of the procedure, women suggested that providers walk the women step by step through the procedure in order to alleviate the surprise factor from the exam.

The notion that healthcare facilities provide inadequate information about cervical cancer screening is also supported in the literature.[168,169] In the current study, the women suggested that appropriate literature be readily available in the waiting room of the health facility for women to read prior to their procedure. It is unclear if women's health clinics in particular have explored the effectiveness of health material in their waiting rooms, but other health clinics have explored its effectiveness. Print media such as posters and brief

videos have proven to be effective methods in relaying health-related information.[170-172] In addition, one study emphasized the importance of tailoring and addressing some sensitive health topics or procedures with caution in an effort to keep the waiting room a pleasant and relaxing environment.[170] Some health professionals fear that failure to do so can cause any additional stress or anxiety.[170] To address this concern, providers suggest providing the patient with print material during the consultation to reinforce the educational material they receive in the waiting room.[170] This could include information pertaining to post-Pap smear. For example, it could contain information such as what a positive test means, how often patients should be screened, how they can reduce their risk of cervical cancer, and what it means if they are diagnosed with cervical cancer.

Convenience

Convenience was another issue mentioned by women in the study and in the literature. Solutions surrounding convenience included mobile vans, more inclusive visits offering multiple medical procedures, and more rapid test results. Mobile vans conducting Pap smears in the community were proposed to prevent women from having to take time off from work and being penalized for having a Pap smear. Pap smear mobile vans have been successfully utilized in Brazil to reach difficult populations[136] however, the same concept of convenience can be used with busy and hard to reach populations in the U.S. Another solution proposed was to make health visits more inclusive. For example, instead of scheduling an appointment to just receive a Pap smear, women proposed to have a Pap smear in conjunction with another health-related purpose, such as an annual physical or lab test. Combining multiple visits into one could make getting a Pap smear less inconvenient for women that have busy schedules or have

difficulty taking time off from work. Other solutions may include having more primary care professionals or centers that specialize in overall health to include women health exams as well. Lastly, women mentioned that one of the reasons they are discouraged from getting a Pap smear is because the waiting period to receive their lab results is too long and it induces fear and anxiety. It was also mentioned that for some, the waiting period is more uncomfortable than the exam itself. For these women it was proposed to have more rapid test results. According to the U.S. Department of Health and Human Services the average time frame for a women to receive their test result is one to three weeks.[2] Reducing this timeframe could help reduce unnecessary anxiety.

Provider outreach

To address the barrier associated with the misconception that cervical cancer is in their destiny and having feelings of shame and embarrassment, women proposed that health professionals would reach out to their spiritual and religious leaders in the community. For example, some health-related beliefs held by women are deeply rooted in religion and they believe if they are destined to have cervical cancer then there is nothing they can do to prevent it, despite screening and early intervention. The proposed solution suggests that if health professionals reach out to religious leaders for support, then the women will listen and adhere to their leader's recommendations and in turn adhere to Pap smear recommendations. It was also proposed that Pap smear workshops be conducted in the place of worship. This idea to reach out to religious and spiritual leaders within communities has been widely explored in the literature and has been proven effective in gaining trust and reducing barriers.[95,137] In particular, outreaching to African American

churches and religious groups can be even more beneficial in disbursement of health-related information and building trust within the African American community.[173]

Provider-patient communication/rapport

Improving the provider-patient relationship was another common solution among women with several barriers including experiences of painful Pap smears and feeling too ashamed or embarrassed to lie down on a gynecologic examination table. Other barriers to a good provider-patient relationship include patients' fear and anxiety, provider burden, fear of litigation, fear of physical or verbal abuse, and unrealistic patient expectations.[174,175] Regardless of the barrier, the women agreed that having a positive rapport with their provider would help to build trust and increase ease of communication. A national study showed that a friendly and caring obstetrics and gynecology doctor (OBGYN) was associated with higher patient satisfaction.[167] It was also noted that OBGYNs have significantly higher patient satisfaction compared to other health specialists,[167] which is crucial due to the sensitive nature of their health topics and procedures.

In regards to a painful Pap smear experiences, women suggested that providers explain to patients that the procedure may be uncomfortable but not painful. It was also suggested that explaining the type of pain or discomfort that they may experience would be helpful. For example, a sharp pain is a different sensation than the feeling of pressure, which closely resembles the sensation of a Pap smear. Previous literature has not fully explored how explanations of type of pain are related to Pap smear satisfaction. It was also suggested that providers should inform the patient that if the procedure is painful, there are modifications that can be taken to minimize the pain, such as changing the

speculum size or material, or using additional lubricating jelly. It was mentioned in the focus group that some women are not aware that there are other options to ensure patient comfort.

To re-emphasize the importance of communication between the patient and the provider, the patient and provider should feel comfortable communicating with one another at all times. More specifically, it was mentioned that some women may not feel comfortable verbalizing their discomfort (whether from pain or embarrassment) but the provider should check with the patient throughout the procedure to ensure that they are comfortable instead of waiting until the procedure is complete. In the literature, it has been documented that physicians have been known to discourage patients from voicing their concerns and expectations.[176] Dismissing a patients concern should not be tolerated.

In addition, women requested that their provider be on time for appointments, not rush the procedure and be gentle, and answer all their questions or concerns. A web-based report indicates that the average waiting time for women to see their OBGYN was 26.85 minutes.[167] This extended waiting period can cause women to become frustrated, anxious, and annoyed.[104]

Distraction(s)

Distraction techniques were mentioned among women that perceived the procedure as painful and/or were ashamed or embarrassed to lie on a gynecologic exam with their private parts exposed. Solutions included simple conversation with their provider during the procedure, decoration on the walls or ceilings, music, and a TV. Distraction techniques have been used in various health forms to overcome fear of a variety of health-related procedures.[177,178] A study examined burn patients to see if a

virtual reality monitor played while their dressings were being changed would reduce their pain level, and the results showed significant pain reduction.[178] In another study music was played to reduce needle-related pain in children and was also proven effective.[177] However, a similar study showed that a TV screen playing cartoons while a child received an injection did not distract them nor reduce pain.[179] In summary, distraction techniques may not be effective in every population but may be beneficial to some. It is suggested that providers use some form of distraction to help divert the patient from the procedure and their nakedness.

Policy/training/regulations

A previous traumatic event, such as sexual abuse or a previous bad medical procedure, was another common barrier among women. For this barrier, the women suggested the need for pre-consultation or screening prior to exams. It was suggested that all women complete a form prior to their appointment (preferably while they are waiting to be seen) that inquires about their sexual abuse or traumatic medical event history. Studies have shown post-traumatic stress due to sexual abuse or other medical procedures may serve as additional barrier for a women to get a Pap smear.[98,105] The proposed form could include a section where patients can address any concerns that they have and if they would like to speak with a specialist prior to the Pap smear procedure. In extreme cases, it would be ideal for the provider to refer the patient to a counselor or specialist instead of forcing a procedure on a patient that is vulnerable. In non-extreme cases, the provider could openly address the patient's concern prior to performing the procedure.

To combat the issue of impolite or insensitive health professionals, women suggested a reporting system and/or a provider bedside mannerism course be offered.

Furthermore, it was mentioned that in most clinics there are no incentives for providers to be kind and considerate to their patients. To resolve this issue the women in the study suggested a reporting system to be implemented. The reporting system was described as a patient satisfaction survey that will be distributed to each patient after every appointment, asking her to rate her provider and her experience. This anonymous patient satisfaction survey will serve as a learning and self-awareness tool for both providers and clinics for what they can do to improve patients' satisfaction, and as an accountability tool for providers to offer high quality care.

In addition to a reporting system, women also suggested that providers enroll in a communication course on bedside manner for diverse populations. Research has shown that providers are trained in communication skills in medical school, however over time their training tends to decline from a holistic patient care.[176] As a result, it would be beneficial for more continuous communication skills training to be implemented.[180]

Women and their social support system

This section discusses the solutions applicable to women and their social support system, including friends, parents, aunts, significant others, and anyone that the women trust to provide practical and emotional support.

Education

Education about the Pap smear was also perceived as the responsibility of the women. Women knowledgeable about Pap smears suggested re-iterating the importance of a Pap smear to their network and focusing on the idea that the health benefits far outweigh the temporary discomfort of the exam. They also suggested that discussing the Pap smear as a routine procedure that providers do several times a day can help

desensitize the issue. For example, some women feared a person examining their vagina due to privacy concerns, however understanding that providers examine several vaginas a day and that their vagina is no different than other women's can help normalize the issue of embarrassment or discomfort. To the best of the researcher's knowledge, this issue has not been explored in the literature but was suggested by the women in the study.

Social support

Social support was another important solution for women to gain the confidence, encouragement, and strength to get a Pap smear. Social support was conceptualized as sharing their concerns about getting a Pap smear with someone they trust and respect, including family and friends. The women stressed the importance of having someone they trust hold them accountable in regards to positive health-related behaviors. This idea of having a support system to encourage positive health-related behaviors is also supported in the literature, which has indicated that such encouragement can improve adherence to healthy behaviors.[105] The need to have an accountability partner was also emphasized among women. It was mentioned that having an accountability partner can give women that extra push to go get a Pap smear despite their negative thoughts or emotions.

Some women preferred their friends or family members to support them from a distance versus being physically present during the procedure. It was noted some women may prefer to have their significant other or support person in the room with them to hold their hand while the procedure is being performed. Hand holding has been proven to be effective in reducing pain perception,[181] and was proposed by some women in the study. In fact, one participant mentioned that during her first Pap smear, a nurse held her hand

and served as her social and emotional support. Thus, the person serving as the social support does not have to be a friend or family member, they just have to be available to encourage and coach the patient during the procedure.

It was also discussed that peers have a huge influence on individual behavior, so much that if a peer had a negative experience it may serve as a deterrent for their friend to get a Pap smear. In these cases, women suggested being cautious of whom they seek advice from and to be aware that everyone has different experiences. The negative influence of peers and family members have also been demonstrated in the literature, with some women being deterred from receiving health exams due to social influence.[98,100]

Body image

Improving body image was discussed in relation to the barrier that some women feel ashamed or embarrassed to lie on a gynecological table and have their private parts exposed. The solution proposed by women in the study were to get comfortable with their body. The women in the focus group proposed that women who face this issue should get comfortable looking at themselves naked in the mirror and to explore their body parts including their vagina prior to getting a pap smear. It was also suggested for women to have their vagina groomed and cleaned to build additional confidence and boost self-esteem. Getting groomed includes getting waxed, shaved, or trimmed prior to their appointment. To the best of the researcher's knowledge the idea of body image and Pap smears has not been explored in the literature. However, mirror exposure treatment has been found to be effective for individuals suffering from eating disorder and body dissatisfaction.[182]

Patient autonomy

Patient autonomy was proposed for many of the barriers mentioned by women. It was revealed that some women may be deterred from getting a Pap smear if they have a male provider. It was stated even if the male provider had a female nurse or assistant present to ensure protocol many women still do not feel comfortable with a male provider performing their Pap smear. For this group of women, it was suggested that they request a female provider. A male provider performing the procedure was another deterrent supported by previous literature.[98,101,105]

The issue regarding rude or dismissive health professionals is also common based on the literature.[147] Women in the focus group mentioned that they have experienced insensitive and/or dismissive behavior by providers, which has been reported in previous research.[176] It was suggested that women respectfully confront the provider and directly inform them that they are not pleased with their quality of service. The females in the focus group emphasized that it is imperative for women to take ownership of their health and the care they receive. They also mentioned that providers sometimes are unaware that they are coming across as rude or dismissive and this could be a learning opportunity for them. It was also accentuated that if the conversation does not go well or if the woman no longer feels comfortable then women should either request a different doctor at the clinic or switch to a different clinic altogether.

5.6 Issues especially relevant for women of color

Based on previous research African American women are more likely to develop cervical cancer compared to their white counterparts.[183] Findings from the current study emphasized some of the barriers emphasized by African American women, one of which

included rude and incompetent health professionals. For example, the African American women in the focus group mentioned that they had encountered rude health professionals and they attributed the rudeness to racial differences. Many of the women in the focus group preferred a provider of the same race to avoid rudeness as well as incompetence. Furthermore, many of the women mentioned that their medical concerns or symptoms were dismissed by a provider not of color due to their ignorance of illnesses or conditions specific to women of color. For this barrier, the women suggested that providers are adequately trained in how to treat persons of diverse populations. Participants in the focus group also suggested that women request or seek out a provider that is of color to ensure proficiency in care. The literature supports evidence that African Americans often times prefer a provider of the same race if they had a personal experience of discrimination in the health care system.[184]

5.7 Populations most at risk

Based on the individual logistic regression analysis the control variables STI and sex history strongly influenced Pap smear adherence when examined alongside many of the independent variables (perceived benefits, perceived susceptibility, perceived severity, cues-to-action, and self-efficacy). Based on the study's findings women who have never been diagnosed with an STI or who have not had sex within the past 6 months may be less likely to adhere to Pap smear recommendations, likely due to a lack of perceived susceptibility. Although women who have a STI history or are sexually active are at an increased risk for HPV and/or cervical cancer development, women with no STI history or women who are not currently sexually active are still at risk. Furthermore, women can contract HPV or develop cervical cancer as a result of a previous risky sexual

behavior (lack of condom use, drinking alcohol, or having multiple partners) or via genetics.[20,24,32] This misconception of perceived susceptibility is also consistent with the literature that supports evidence that if a women does not believe they are susceptible or at risk then they will be less likely to adhere to Pap smear recommendations.[98,105] It is therefore highly recommended for healthcare professionals to adequately review the risk and protective factors for cervical cancer to their patients. It should be noted, however, that these relationships were no longer significant when considered alongside perceived barriers—demonstrating, again, the scientific importance of barriers in predicting Pap smear adherence.

5.8 Study limitations

This study used convenience sampling to recruit participants for Phase 1 and 2 of the study. Due to the nature of convenience sampling, selection bias was introduced to the study. Furthermore, the majority of the sample population was highly educated and was recruited from public health-related sources or organizations. In addition, according to the sample statistics listed in chapter 4 of this study, the adherence levels among the study population were slightly higher than the national levels. Healthy People 2020 states that approximately 85% of women have received a Pap smear based on the recent guidelines, while this study found that 89.9% of women had done so.[17] This slightly higher statistic could be due to the sample in this study being highly educated and the fact that the more education a woman has the higher her likelihood of being up-to-date with cervical cancer screening.[8] As a result, the study population may not be representative of the general population. However, the sample population was more diverse than the general population, consisting of approximately 62% Blacks/African Americans and

approximately 28% Whites. This racial diversity is beneficial since Blacks/African Americans have higher rates of cervical cancer compared to Whites.[44] In addition, since 21 year olds were included in the sample and are recommended to get a Pap smear, it is possible that some 21 year olds may not have had a chance to get a Pap smear before participating in the study. However, this is unlikely to be a significant issue as there were only two 21 year olds in the sample.

5.9 Implications for future research

The findings from this study provide several implications for future research. The combined logistic regression for the HBM adds to the body of literature using this theory but more exploratory studies are needed to examine the HBM constructs that affect Pap smear adherence. Furthermore, the current study suggests that perceived barriers is the only construct that affects Pap smear adherence, however other research has found conflicting results.[159] Because of the inconsistent results more research is warranted to confirm this finding, especially in light of the fact that a new barriers subscale was developed. In addition, the vast majority of the sample in the current study were highly educated women. Since educated women are more likely to adhere to Pap smear recommendations, [82,83] more research on populations with less education is warranted. It is not certain whether the solutions proposed by educated women will be the same solutions proposed by less educated women. Also, future studies should focus on quantitative research for participants' perceived solutions. This study performed a valuable first step in identifying a variety of solutions proposed by women—future research could examine how effective such solutions would be and their perceived value among this population.

5.10 Conclusions

Pap smears remain an efficacious test for detecting abnormal cells and it is highly recommended for women between the ages of 21 and 65 to be screened. However, due to a variety of barriers, many women are deterred from the screening process. This study found that perceived barriers were associated with Pap smear adherence among women. Multiple solutions related to health professionals and women were proposed by the women in this study that may help reduce or eliminate some of these barriers. To the principal investigator's knowledge, this is the first study to examine barriers to Pap smears in-depth and qualitatively explore proposed solutions to these barriers. This study therefore provides information that can be used to help achieve the Healthy People 2020 goal to increase Pap smear adherence and reduce cancer incidence rate and mortality.[17]

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APPENDIX A: RECRUITMENT FLYER

Let's talk about Pap smears!

About the Research Study:

Cervical cancer is the 4th most common cancer in women worldwide, yet, many women believe they will not get it. Fortunately, Pap smears are an effective procedure for detecting cervical cancer. However, many women are hesitant, or have barriers preventing them from getting screened. So let's talk about it! What are some things you do not like about Pap smears? How can we make Pap smears more comfortable?

Who We're Looking For:

- UGA female graduate students
- Must be at least 21 years of age
- Both women who have or have not received a Pap smear
- Must have heard about a Pap smear

What the Study Involves:

- A 10 minute online questionnaire
  -A chance to win a $50 gift card
- In-person group discussion (optional)
  -$10 gift card per participant

If you would like more information about this research study, please contact **Kayin Robinson** at **kr26144@uga.edu**. If you would like to take the survey please visit the URL provided **http://bit.ly/Papsmears**

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URL: http://bit.ly/Papsmears

APPENDIX B: RECRUITMENT LETTER

Greetings,

My name is Kayin Robinson, and I am in the process of completing my dissertation research for my PhD in Health Promotion and Behavior under the supervision of Dr. Carolyn Lauckner at the University of Georgia. The purpose of my study is to identify what factors influence women's decision to get a Pap smear. Some questions may cause discomfort such as Pap smear practice, and health history. To be eligible for this study you must be a female between the ages of 21 and 65 who has heard of a Pap smear but has not had a hysterectomy.

At the end of the questionnaire you will be asked if you would like to participate in a drawing for a chance to win a $50 Amazon gift card by providing your e-mail address. This e-mail address will be collected in a separate survey, so your contact information will in no way be associated with your survey responses. However, if you are interested in Phase 2 of the study (optional) consisting of a 1.5-hour long group discussion with other females, then your contact information is needed. However, to participate in the focus group you will have to drive to Athens, Georgia. For participating in the focus group, each participant will be given a $10 Amazon gift card. You will be given the option to opt in to phase 2 of the study at the end of the questionnaire.

If you do not wish to participate in the survey but would like to be included in the drawing, e-mail Kayin Robinson at kr26144@uga.edu.

All responses are confidential, and participation is completely voluntary. The survey is completed online and will last approximately 10 minutes.

If you would like to participate, please click the link below to read the consent form and continue onto the survey: Take the Survey http://bit.ly/Papsmears

If you have any questions or concerns please email Kayin Robinson at kr26144@uga.edu.

Thank you very much for your time and participation!

Sincerely,

Kayin Robinson, MPH
PhD Candidate
University of Georgia
College of Public Health
Department of Health Promotion and Behavior
227D Wright Hall
706-542-3313

APPENDIX C: REVISED PAP SMEAR HBM SCALE

ADAPTED HEALTH BELIEF MODEL SCALE FOR CERVICAL CANCER AND THE PAP SMEAR TEST

Screening Questions

Q3.1 Please complete this section to determine your eligibility for the study.

Q3.3 Are you female, as identified at birth?

- ○ Yes
- ○ No

Q3.4 Are you between the ages of 21 and 65?

- ○ Yes
- ○ No

Q3.5 Have you had a (partial or whole) hysterectomy?

- ○ Yes
- ○ No

Q3.6 Have you ever heard of a Pap smear?

- ○ Yes
- ○ No

Q3.7 When was your last Pap smear?

- ○ I have never had a Pap smear
- ○ I received a Pap smear within the past one to three years
- ○ I received a Pap smear more than three years ago

Health Motivation

Q4.1 The next set of questions ask you about your general health-related behaviors. Please read each question and check the box corresponding to your level of agreement for each statement.

Q4.2 I eat well balanced meals for my health

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q4.3 I exercise at least 3 times a week for my health

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q4.4 I have regular health check-ups even when I am not sick

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Perceived benefits

Q5.1 The following questions concern your beliefs about Pap smears. Please read each question and check the box corresponding to your level of agreement for each statement.

Q5.2 If I have a Pap smear test regularly and the result is good, I don't need to worry too much about cervical cancer

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q5.3 Having regular Pap smear tests will help to find changes to the cervix, before they turn into cancer

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q5.4 If cervical cancer was found at a regular Pap smear test, its treatment would not be so bad

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q5.5 I think that having a regular Pap smear test is the best way for cervical cancer to be diagnosed early

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q5.6 Having regular Pap smear tests will decrease my chances of dying from cervical cancer

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q5.7 I want to discover health problems early

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree

- ○ Strongly agree

Q5.8 Maintaining good health is extremely important to me

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q5.9 I look for new information to improve my health

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q5.10 I feel it is important to carry out activities which will improve my health

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Perceived barriers

Q6.1 This section will ask you questions about what may prevent you from getting a Pap smear. Please read each question and check the box corresponding to your level of agreement for each statement.

Q6.2 I am afraid to have a Pap smear test for fear of a bad result

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.3 I am afraid to have a Pap smear test because I don't know what will happen

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.4 I don't know where to go for a Pap smear test

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.5 I would be ashamed to lie on a gynecologic examination table and show my private parts to have a Pap smear test

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.6 Having a Pap smear test takes too much time

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.7 Having a Pap smear test is too painful

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.8 Health professionals doing Pap smear tests are rude to women

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.9 I cannot remember to have a Pap smear test regularly

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.10 I have other problems in my life that are more important than having a Pap smear

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.11 I am too old to have a Pap smear test regularly

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.12 There is no health center close to my house to have a Pap smear test

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.13 If there is cervical cancer development in my destiny, having a Pap smear test cannot prevent it

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.14 I prefer a female doctor to conduct a Pap smear test

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.15 I will never have a Pap smear test if I have to pay for it

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.16 I had a bad experience with my last Pap smear test

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.17 A friend or family member has made negative comment(s) concerning me getting a Pap smear

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.18 The media has discouraged me from getting a Pap smear

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.19 I had a traumatic experience with a previous medical procedure that deters me from getting a Pap smear

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.20 I was sexually abused and do not feel comfortable getting a Pap smear

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.21 I do not want others (parents, significant others, etc) to find out I had a Pap smear

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.22 I am afraid of tearing my hymen or “popping my cherry”

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q6.23 Are there any other barriers not mentioned in the survey that deter you from getting a Pap smear? If yes, please describe them.

_____

Perceived seriousness & perceived susceptibility

Q7.1 The next group of questions will ask you about your feelings regarding cervical cancer. Please read each question and check the box corresponding to your level of agreement for each statement.

Q7.2 The thought of cervical cancer scares me

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q7.3 When I think about cervical cancer, my heart beats faster

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q7.4 I am afraid to think about cervical cancer

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q7.5 Problems I would experience with cervical cancer would last a long time

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q7.6 Cervical cancer would threaten a relationship with my significant other

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q7.7 If I had cervical cancer my whole life would change

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q7.8 If I developed cervical cancer, I would not live longer than 5 years

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q7.9 It is likely that I will get cervical cancer in the future

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q7.10 My chances of getting cervical cancer in the next few years are high

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q7.11 I feel I will get cervical cancer some time during my life

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Self-efficacy

Q8.1 Some women do not believe they have the ability to get a Pap smear. Please read each question and check the box corresponding to your level of agreement for each statement.

Q8.2 I can arrange transportation to get a Pap smear

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q8.3 I can arrange other things in my life to have a Pap smear

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q8.4 I can talk to people at the Pap smear center about my concerns

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q8.5 I can get a Pap smear even if I am worried

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q8.6 I can get a Pap smear even if I don't know what to expect

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q8.7 I can find a way to pay for a Pap smear

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q8.8 I can make an appointment for a Pap smear

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q8.9 I know for sure I can get a Pap smear if I really want to

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q8.10 I know how to go about getting a Pap smear

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Q8.11 I can find a place to have a Pap smear

- ○ Strongly disagree
- ○ Disagree
- ○ Neutral
- ○ Agree
- ○ Strongly agree

Cues-to-action

Q9.1 The following questions concern factors that might impact your ability or willingness to get a Pap smear, as well as your intentions to get a Pap smear. Please read each question and check the appropriate corresponding response.

Q9.2 Have you ever received information about a Pap smear from the following people or institutions?

	Never	Once	More than once
Health insurance provider	○	○	○
Print media	○	○	○
Television/radio	○	○	○
Health promotion fair	○	○	○
Physician	○	○	○
Sexuality or health education class	○	○	○

Q9.3 Have the following people ever recommended for you to get a Pap smear?

	Never	Once	More than once
Physician	○	○	○
Friends/acquaintances	○	○	○
Television/radio	○	○	○
Colleagues	○	○	○
Family member (mom, aunt etc.)	○	○	○
Spouse/partner	○	○	○

Q9.4 Did you know that the health center at UGA provides Pap smears and gynecological exams?

- ○ No
- ○ Yes
- ○ N/A (I am not a student at UGA)

Q9.5 How likely are you to get a Pap smear in the next 12 months?

- ○ Extremely unlikely
- ○ Unlikely
- ○ Neutral
- ○ Likely
- ○ Extremely likely

Q9.6 How likely are you to get a Pap smear the next time you are due for one?

- ○ Extremely unlikely
- ○ Unlikely
- ○ Neutral
- ○ Likely
- ○ Extremely likely

Pap smear knowledge

Q10.1 The following section will ask you questions about Pap smears. Please read each question and choose what you believe to be the correct response.

Q10.2 Generally, all women who are ___ should get a Pap smear

- ○ 15 years of age or older
- ○ 18 years of age or older
- ○ 21 years of age or older
- ○ 25 years of age or older
- ○ Not sure

Q10.3 Once women reach the appropriate age, it is recommended that they get a Pap smear

- ○ Every year
- ○ Every 3 years
- ○ Every 10 years
- ○ Not sure

Q10.4 A Pap smear can be used to help prevent cervical cancer

- ○ True
- ○ False
- ○ Not sure

Q10.5 People who are not sexually active do not need a Pap smear.

- ○ True
- ○ False
- ○ Not sure

Q10.6 A Pap smear is an effective way to screen for abnormal cells that could lead to cervical cancer.

- ○ True
- ○ False
- ○ Not sure

Demographics

Q11.1 Next, we would like to ask you some questions about your background. Please read and complete each item.

Q11.2 What is your year of birth? _____

Q11.3 What is your race?

- ○ White
- ○ Black or African American
- ○ American Indian or Alaska Native
- ○ Asian
- ○ Native Hawaiian or Pacific Islander
- ○ Multiracial
- ○ Other

Q11.4 What is your ethnic background?

- ○ Hispanic or Latino
- ○ Not Hispanic or Latino

Q11.5 What is the highest level of school you have completed?

- ○ Less than high school degree or GED
- ○ High school graduate or GED
- ○ Some college but no degree
- ○ Graduated from college
- ○ Post-graduate

Q11.6 Do you have health insurance?

- ○ Yes
- ○ No

Q11.7 Are you covered by someone else's health insurance?

- ○ Yes
- ○ No

Q11.8 Whose insurance plan covers you?

- ○ Parent(s) or guardian(s)
- ○ Spouse or significant other
- ○ Other (Please specify)

_____

Q11.9 What is your current relationship status?

- ○ Single
- ○ In a relationship, but not living with partner
- ○ Living with a partner
- ○ Married
- ○ Divorced

Q11.10 Have you had sex (vaginal, oral, or anal) within the last 6 months?

- ○ Yes
- ○ No

Q11.11 Have you ever been diagnosed with a sexually transmitted infection (Chlamydia, gonorrhea, genital herpes, HIV/AIDS, HPV or syphilis etc.)?

- ○ Yes
- ○ No

Q11.12 Have you ever been diagnosed with HPV?

- ○ Yes
- ○ No

Q11.13 Have you ever had a friend or family member that was diagnosed with cervical cancer?

- ○ Yes
- ○ No

Q11.14 What was your relationship to them?

_____

Q11.15 Have you ever received an abnormal Pap smear result?

- ○ Yes
- ○ No
- ○ Not sure

Q11.16 How frequently do you get a Pap smear?

- ○ Every year
- ○ Every 1-3 years
- ○ Every 3-5 years
- ○ 5 or more years
- ○ I have only received a Pap smear once
- ○ Not sure

Q12.1 Thank you for participating in Phase 1 of the study. If interested in Phase 2, a group discussion with other women about your experience, ideas, thoughts, and feelings about Pap smears and cervical cancer, then please provide your name and email for meeting details. Your name and email address is needed to be able to link your survey with your focus group participation. However, all identifiable information (name and email address) will be removed from the actual survey data and kept in a separate file. Only the research team will have access to this file containing your personal information. Once data collection is complete, your name and email address will be deleted. Note to participate in the focus group you will have to drive to Athens, Georgia.

- ○ Yes, I am interested in Phase 2
- ○ No, I am not interested in Phase 2

Q12.2 Name:

_____

Q12.3 E-mail:

_____

APPENDIX D: FOCUS GROUP MODERATOR SCRIPT

Materials:

- Colorful index cards (at least 5 colors)
- Pens
- Audio recorder
- Refreshments
- Helper
- Name tags
- List of Guidelines
- $10 Amazon gift cards

Agenda:

I. **Unwind**

As participants enter they will be encouraged to grab refreshments, mingle, and to make themselves comfortable. On each seat there will be a set of index cards, and a copy of the consent form for them to review, sign, and return to me.

II. **Introduction** (10-15 mins)

I am Kayin Robinson, and I will be your moderator for this evening. I would like to personally thank all of you for your participation and willingness to meet today. Without your participation this process would not be possible... As most of you know I am working on my dissertation, which is about Pap smear barriers. Pap smears is an efficient and effective way to detect abnormal cells of the cervix that may become cancerous.

If this is your first focus group or you are not sure what a focus group is, it is simply when a group of individuals come together to talk about a topic of interest to researchers. Today our topic of interest is Pap smear barriers and possible solutions to overcome these barriers. Previously you completed a survey for part 1 of the study, which asked you about your Pap smear experiences, ideas,

thoughts, and feelings. However, today we are going to focus on overcoming obstacles in women getting a Pap smear. I need your help to brainstorm some solutions to Pap smear barriers among women. Your solutions can help alleviate anxiety and hesitation surrounding getting a Pap smear. You should think of yourselves as problem solvers. I am not here to deliver information like a teacher but to rather listen to all of you and to facilitate the discussion. It is expected for the focus group to last for about 1.5 hours or until all the questions are answered and everyone was able to speak.

Since we will be talking about Pap smear barriers and possible solutions (a sensitive topic) tonight, it is best that we set up some guidelines for our discussion. I want everyone to feel comfortable talking. There are no right, wrong, silly or stupid answers. I expect people to have different ideas and that many of you will have different experiences. However, everything that each of you shares is very important and helpful- so please do not be afraid to speak. I will look around the room to make sure that everyone who would like to talk gets a chance to speak. The next guideline is please do not interrupt each other. We want to make sure everyone is heard. Finally, be respectful of one another's comments even if you do not agree. We want to make sure everyone is able to express themselves freely. Does everyone agree to these terms? Women will be asked to nod their heads or to give a thump up if the agree. *Guidelines will be posted in the front of the room for everyone to view throughout the focus group.*

We have a lot to discuss within the next hour or so, so I may speed up or slow down our discussion, depending on how much we are getting through. If we

move on to talk about something else and you would like to share what is on your mind please do not be afraid to stop me at any time. Also, I want to make sure everyone has an opportunity to speak so I may interrupt to allow those people who has not spoken an opportunity to speak. My goal is to hear everyone speak.

It is important that we keep our group discussion confidential. So, please **do not share any of the information discusse**d. Even though our discussion will be audio recorded, your voice or words will not be linked to your name and only me and my dissertation committee will know what you said. For the purpose of tracking the conversation I do ask that you state your real or fake name for the recording. Also, if you have not already done so you may write your real or fake name on the name tags provided.

Finally, if you need to go to the bathroom, or would like some more refreshments, please get up quietly to do so. Then return so we can continue to hear from you.

Any questions? Okay, let's get started!

III. **Review Pap smear barriers & explore Pap smear solutions** (50 mins)

As mentioned earlier there are many women who do not adhere to Pap smear recommendations, which is why we asked about barriers in the survey you took previously. Using the data collected in the survey I have compiled the top 5 barriers among women. I need your help in coming up with ways to help these women to get a Pap smear. As a group let's discuss the top 5 barriers mentioned from the questionnaire, starting with the number 1 barrier. For each barrier we will have approximately 10 minutes to discuss before moving on to the next

barrier. If we run out of time and you did not get a chance to share your ideas then please write them down on the assigned index cards and if we have time at the end you will be given an opportunity to share. If time does not permit, I promise to read each index cards and to include it in the analysis.

The 1st barrier is "Some women are reluctant to get a Pap smear because of *PAIN*." Based on the data collected from the survey x% of women stated they do not like getting a Pap smear because it is too painful. Who would like to elaborate on this barrier? What does this mean? Now let's brainstorm some solutions to this barrier. At this time, jot down some solutions to this barrier on the __ colored index card and then we will discuss as a group. Solutions may be patient or provider specific *(do not provide examples).* Remember no idea is a silly or stupid idea. The *facilitator will follow this process for all 5 of the barriers listed. Once all 5 barriers have been discussed, the facilitator will ask the group if there are any other barriers they would like to discuss. All index cards will be collected at the end of the meeting. Their names does not need to be on index cards. Throughout the discussion the facilitator will call on participants by name in order to track conversation by audio.*

IV. **Closing** (5 mins)

Thank you for talking with me today. This information is very helpful and beneficial in reducing or eliminating the Pap smear barriers among women. Does anyone have anything else they would like to ask? Any final observations or comments? Okay. Before you leave please sign the worksheet so you can receive

your Amazon gift card. Thanks again for your participation. We really appreciate it!