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# PAP TEST SCREENING EXPERIENCES OF HIV-POSITIVE WOMEN

by

Siri Alicia Ogg

A Dissertation

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

Major: Social and Behavioral Sciences

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# DEDICATION

This work is dedicated to Elizabeth, whose life and story inspired my research in this area.

#### ACKNOWLEDGEMENTS

Thank you first and foremost to the women who participated in this study. Without your willingness to share your stories, this study could not have happened. You gave insights into your lives and personal experiences by talking openly and honestly with a relative stranger, which is no easy task, and I am grateful for your time and contribution.

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#### ABSTRACT

The Human Papillomavirus (HPV) is the most common sexually transmitted disease, and is known to cause genital warts, cervical intraepithelial neoplasia (CIN), and cervical cancer. HIV-positive women are at greater risk of contracting HPV, experiencing CIN, having more advanced-grade CIN, and developing cervical cancer due to their compromised immune status. Since becoming an essential part of women's preventive healthcare, the Papanicolaou test, commonly known as the Pap smear, has helped to reduce cervical cancer incidence and mortality; however, many HIV-positive women do not meet recommended Pap test screening guidelines. This study addressed the following research question: What psychosocial, cultural, contextual, and organizational factors influence HIV-positive women's engagement in cervical cancer screening? Using a qualitative grounded theory approach, one-on-one interviews were conducted with 19 HIV-positive, African American women of childbearing age in Shelby County, TN. Additionally, participants completed a questionnaire to assess demographic and socioeconomic characteristics, health history, and Pap test screening knowledge. Seven major themes emerged from the data: General Lack of Knowledge, Benefits Outweigh Barriers, Limited Role of Social Support, Disconnect Between Health and Religious Beliefs, HIV as a Facilitator, Reliance on Healthcare Provider, and Intersectionality. The findings presented here provide insight into what motivates HIV-positive women to engage in regular Pap test screening as well as how factors across the social ecological spectrum are related. This information will help public health practitioners to develop interventions for increasing and preserving cervical cancer screening compliance.

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# LIST OF ABBREVIATIONS

<u>Acronym</u>	Definition
AGUS	Atypical Glandular Cells of Undetermined Significance
ASCUS	Atypical Squamous Cells of Undetermined Significance
BRFSS	Behavioral Risk Factor Surveillance Survey
CDC	Centers for Disease Control and Prevention
CIN	Cervical Intraepithelial Neoplasia
HAART	Highly-Active Anti-Retroviral Therapy
HAB	HIV/AIDS Bureau
HBM	Health Belief Model
HHS	Department of Health and Human Services
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immunodeficiency
	Syndrome
HPV	Human Papilloma Virus
HRSA	Health Resources and Services Administration
HSIL	High-Grade Squamous Intraepithelial Lesions
IRB	Institutional Review Board
LEEP	Loop Electrosurgical Excision Procedures
LSIL	Low-Grade Squamous Intraepithelial Lesions
MSM	Men who have Sex with Men
PLWHA	People Living with HIV/AIDS
SEM	Social Ecological Model
STD	Sexually Transmitted Disease
TGA	Transitional Grant Area
TPB	Theory of Planned Behavior
WIHS	Women's Interagency HIV Study

#### **CHAPTER 1. INTRODUCTION AND LITERATURE REVIEW**

#### **HPV and Pap Test Screening**

The Human Papillomavirus (HPV) is the most common sexually transmitted disease (STD), affecting approximately 25 million Americans, and is known to be the cause of genital warts, cervical intraepithelial neoplasia (CIN), and cervical cancer (Chin-Hong & Palefsky, 2005; Friedman & Shepeard, 2007). In the United States, cervical cancer is the second most common gynecologic cancer in women and the tenth leading cause of cancer deaths (Ackerson, 2010; Anderson et al., 2006). Each year since 2010, more than 12,000 new cases of cervical cancer have been diagnosed in the United States, and at least 4,000 women died of the disease annually (Benard et al., 2014; Head & Cohen, 2012; Yoo et al., 2017).

The Papanicolaou test, commonly known as the Pap smear, has been an essential part of women's preventive healthcare for several decades. Developed in the 1950s, the Pap smear involves scraping cells from the cervix using a small spatula or brush for placement on a slide and examination by a pathologist (Callahan & Caughey, 2007). Since its use became widespread, the Pap smear has helped to reduce cervical cancer mortality by nearly 90% through early detection of cervical neoplasia, lesions, and other abnormalities (Ackerson, 2011; Callahan & Caughey, 2007). Incidence of cervical cancer has decreased from 14.8 per 100,000 persons in 1975 to 6.4 per 100,000 persons in 2013 (Nardi, Sandhu, & Selix, 2016). Current guidelines recommend Pap test screening every three years following the onset of sexual activity for women ages 21 to 65 years old (Duffett-Leger, Ledourneau, & Croll, 2008; Montgomery, Bloch, Bhattacharya, & Montgomery, 2010; Moyer, 2012). Women ages 30 to 65 years old should receive both a Pap test and HPV test, which is similar to a Pap smear except it checks for the

presence of HPV rather than cancer, every five years (Benard et al., 2014). Women over the age of 65 may forego Pap test screening if they have been adequately screened in the past and are not thought to be high risk (Nardi et al., 2016). However, more frequent testing may be needed for women in high-risk groups or with abnormal results (Duffett-Leger et al., 2008; Montgomery et al., 2010; Moyer, 2012).

If a woman's Pap smear results come back abnormal, identifying the presence of atypical squamous cells of undetermined significance (ASCUS) with HPV, atypical glandular cells of undetermined significance (AGUS), low-grade squamous intraepithelial lesions (LSIL), or high-grade squamous intraepithelial lesions (HSIL), follow-up colposcopy is recommended within six months to determine the severity of proliferation of the abnormal cells (Curry, Sage, Vragovic, & Stier, 2012; Keller et al., 2012). The colposcopy is a biopsy involving magnification and staining of the cervical sample to identify lesions and make a more definitive diagnosis (Callahan & Caughey, 2007). CIN are graded on a I to III scale based on the portion of the cervix with abnormally developed cells, with CIN I indicating only mild dysplasia, CIN II representing moderate dysplasia, and CIN III meaning severe dysplasia (Anderson et al., 2006; Callahan & Caughey 2007). While CIN I should be treated and monitored, CIN II and III are cause for greater concern since they are thought to be direct precursors to invasive cervical cancer (Badial et al., 2018; Chin-Hong & Palefsky, 2005).

Some women, including those who are immunocompromised, are at greater risk of contracting HPV, experiencing CIN, having more advanced-grade CIN, and developing cervical cancer (Badial et al., 2018; Fletcher, Vidrine, et al., 2014; Liu, Sharm, Tan, & Barnabas, 2018). The U.S. Department of Health and Human Services (HHS) has estimated women who are

positive for the Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome (HIV/AIDS) are at least five times more likely to develop cervical cancer than women in the general population (Fletcher, Buchberg, et al., 2014; Lambert et al., 2015). Additionally, the mortality rate from cervical cancer in HIV-positive women is nearly two times higher than that of HIV-negative women (Liu et al., 2018). Thus, it is especially important for members of such high-risk groups to receive regular Pap smears. The purpose of this study is to better understand cervical cancer screening practices among HIV-positive women living in the Mid-South in order to inform public health interventions that would further promote this type of screening practice.

### Women Living with HIV/AIDS

In 2008, women accounted for nearly a quarter of all new HIV/AIDS diagnoses (Hosek, Brothers, Lemos, & The Adolescent Medicine Trials Network for HIV/AIDS Interventions, 2012). Among women diagnosed with HIV/AIDS, minorities are disproportionately affected by the disease. African American women have been the fastest growing group to acquire HIV in recent years (Raiford, Wingood, & DiClemente, 2007). In fact, as recently as 2016, African American women have accounted for 61% of new HIV diagnoses among all U.S. women, approximately 16 times higher than the diagnosis rate of white women (Rao, Andrasik, & Lipira, 2018). Women living with HIV/AIDS may face unique challenges from those encountered by men who have the disease. For instance, one research team discussed stigma with more than 150 women living with HIV/AIDS in New York City and found that, regardless of race, they believed they were judged more harshly than their male counterparts (Lekas, Siegel, & Scrimshaw, 2006). The women also felt blamed for acquiring the disease and said they were

often deemed immoral or irresponsible for certain sexual and drug use behaviors, and minority women even more so.

## Significance

#### **HPV Incidence and Prevalence**

HIV-positive women are at greater risk of cervical cancer largely because they are more likely to acquire HPV and have persistent HPV infections, including with oncogenic HPV subtypes (Fletcher, Buchberg, et al., 2014; Liu et al., 2018). Although highly active antiretroviral therapy (HAART) has vastly improved survival, transitioning HIV from a terminal disease to a chronic illness, it has not affected HIV-positive women's susceptibility to HPV or cervical cancer (Lambert et al., 2015). To determine how HPV affects HIV-positive women specifically, several studies have compared rates and outcomes between HIV-positive and HIVnegative women. Addieh and colleagues (2001) compared HPV infection in HIV-positive and HIV-negative women to understand how varying levels of immunosuppression relate to the natural history of the disease. Participants in this study were recruited from four sites in the Northeast region of the United States in the mid-1990s, and included almost 900 HIV-positive and 500 HIV-negative women. Despite reporting fewer sexual partners, HIV-positive women had consistently higher rates of HPV infection, including being infected with multiple types of HPV at once, than their HIV-negative counterparts across the study period. By types of infection, HIV-positive women were 1.8, 2.1, and 2.7 times more likely to be infected with high-risk, medium-risk, and low-risk types of HPV, respectively, compared to HIV-negative women. Additionally, there was a positive correlation between immunosuppression and HPV infection, such that HIV-positive women with higher CD4 counts, indicating less immune deficiency, had

lower rates of HPV incidence and prevalence than HIV-positive women who were more immunocompromised.

A similar study described the pathology of HPV and anogenital disease in HIV-positive women compared to their HIV-negative counterparts (Chin-Hong & Palefsky, 2005). Not only were HIV-positive women more likely to be infected with HPV, including high-risk types and multiple strains, than HIV-negative women, but they also had a shorter transformation from CIN to invasive cervical cancer and at a younger age. Although the study found a negative relationship between CD4 count and HPV incidence, the association did not hold for the diagnosis of cervical and other HPV-related cancers. The authors conclude that immunosuppression is likely related to HPV incidence and prevalence, but not necessarily the progression to cancer.

One retrospective study compared diagnostic outcomes after abnormal Pap test results between HIV-positive and HIV-negative women (Curry et al., 2012). Charts were reviewed for more than 650 HIV-positive and 750 HIV-negative women who received gynecologic care at Boston Medical Center from 2002 to 2008. HIV-positive women who underwent colposcopy after an abnormal Pap smear were twice as likely to have results graded at CIN II or III than HIV-negative women. Overall, the outcomes after colposcopy revealed no CIN diagnosis in 22%, CIN I in 46%, and CIN II or III in 32% of the HIV-positive women, compared to 45%, 34%, and 21%, respectively, in HIV-negative women. These results indicate HIV-positive women are more likely to be diagnosed with CIN, and advanced-grade CIN, after an abnormal Pap smear compared to women who are HIV-negative.

Since 1994, the Women's Interagency HIV Study (WIHS), a long-term, multicenter cohort study, has been assessing the health outcomes of HIV-positive women in the United States. Massad and colleagues (2014) used this dataset to compare the long-term cumulative risk for CIN II and CIN III, or worse, following an abnormal Pap smear result between HIV-positive and HIV-negative women. The study sample included 56% of the women enrolled in the WIHS, including 1,824 HIV-positive and 472 HIV-negative women, representing those who had an abnormal Pap test and subsequent colposcopy within twelve months. Initial cytology indicated HIV-positive women were more likely to present with more severe abnormality, with 72% having ASCUS, 26% LSIL, and 2% HSIL compared to 88% ASCUS, 11% LSIL, and 2% HSIL in HIV-negative women. Colposcopy results indicated 21% of HIV-positive women had CIN II or worse and 9% had CIN III or worse. Although the findings were not statistically significant, this study found HIV-positive women had consistently higher risk, 1.66 times as likely, for CIN II or CIN III or worse compared to their HIV-negative counterparts.

Some strains of HPV are more aggressive than others, particularly Types 16 and 18, which together cause approximately three-quarters of cervical cancer (Lambert et al., 2015; Schlecht et al., 2005). Silverberg and colleagues (2006) examined HPV-16 in both HIV-positive and high-risk, HIV-negative women by measuring the optical density of the antibodies. Contrary to other research, no significant differences in infection rates were found between HIV-positive and HIV-negative women; however, HIV-positive women, especially those who were immune compromised, were more likely to sustain and have increases in HPV-16 antibodies, which could mean active replication is occurring more among HIV-positive women. While the findings from

this study indicate rates of infection with HPV-16, which is one of the high-risk types linked to cervical cancer, are similar between HIV-positive and HIV-negative women, the continued presence of and increases in antibodies suggests the infections are at least more persistent among HIV-positive women.

Another study used data from the WIHS to examine the presence of oncogenic HPV types among women with normal Pap results at baseline (Keller et al., 2015). Analysis included 1,021 HIV-positive and 518 HIV-negative women. Their results indicate women who were HIV-positive were significantly more likely to test positive for any HPV than those who were HIV-negative, and this finding held true for oncogenic types of HPV as well, with detection in 15% of HIV-positive women versus 5% of HIV-negative women. More specifically, testing positive for HPV-16 was associated with a 13 times greater risk of developing CIN III or worse among HIV-positive women with a normal Pap test result at baseline. This study highlights the importance of continuous, consistent screening among HIV-positive women, regardless of a history of normal results.

The increased risk for an abnormal Pap test result faced by HIV-positive women is even present after a hysterectomy. A retrospective study of a cohort of almost 240 HIV-positive women in Houston who had undergone a benign hysterectomy, meaning the cause was unrelated to cervical dysplasia or cervical cancer, found that nearly one-third had an abnormal Pap smear test, with 5% having ASCUS and being HPV-positive, 23.1% having LSIL, and 2.9% having HSIL (Smeltzer, Yu, Schmeler, & Levison, 2016). These women did not have a history of abnormal Pap tests, and no demographic risk factor could be identified, indicating HIV-positive women may still need to engage in screening efforts even following hysterectomy. Liu, Sharma, Tan, and Barnabas (2018) provide a recent systematic review of the literature regarding HIV-positive women's risk of HPV, precancerous lesions, and cervical cancer. Their meta-analysis included 38 studies, nearly half of which included HIV-negative women as a comparison group, and covered the relationships between HIV status and HPV incidence, HPV persistence, progression to LSIL and HSIL, regression from LSIL and HSIL, and progression to cervical cancer. All studies found HIV infection to be associated with higher incidence and perseverance of HPV. Studies showed an inverse relationship between CD4 count and HPV acquisition, where the risk of contracting HPV increased as CD4 count decreased, while there was a direct relationship between viral load and risk of HPV infection, meaning one increased with the other. The relationship between HAART and HPV was unclear. Being HIV-positive was associated with higher incidence of LSIL and HSIL, suggesting immunodeficiency may especially impact early progression of HPV. Also, women who were HIV-positive were more likely to have persistent HPV infection and even HPV reactivation, which led to greater disease progression and cervical cancer.

### **Treatment Outcomes**

The current evidence indicates HIV-positive women are at greater risk of contracting HPV, being infected with multiple and high-risk types of HPV, as well as experiencing faster progression to more severe CIN grades and cervical cancer than their HIV-negative counterparts. In addition to these studies of the natural history of HPV, other researchers have examined outcomes following surgical excision treatment of CIN, which includes loop electrosurgical excision procedures (LEEP), laser ablation, or cold-knife conization, in HIV-positive women (Lodi et al., 2011; Massad et al., 2007). LEEP is the current standard of care for CIN treatment

and involves removing the affected part of the cervix with a cauterizing wire loop. Laser ablation is similar to LEEP, but uses a laser instead of a cauterized loop to remove the abnormal cervical tissue; one benefit of laser ablation is that it is more precise so removes less of the normal cervix. Before LEEP, cold-knife conization was the standard CIN treatment procedure, in which a wedge of the affected area of the cervix was cut out and removed (Callahan & Caughey, 2007).

Massad and colleagues (2007) looked at the rates of treatment failure and success based on CIN grade in HIV-positive and HIV-negative women enrolled in two multi-site, prospective studies. Initial treatment failure was indicated by the continued presence of CIN six months after treatment; nearly half of the HIV-positive women in the sample experienced initial treatment failure, while only one-third of the HIV-negative women did so. Of the women who initially experienced treatment success, over half eventually experienced reinfection with HPV, and HIVpositive women had a significantly shorter HPV-free time interval than did HIV-negative women, 30 months versus 70 months, respectively. Interestingly, although HIV-positive women were more likely to experience subsequent HPV infections after initial treatment, these may actually represent new, opportunistic infections rather than recurrence of the previous infection.

One study examined correlates of CIN recurrence after conization through LEEP in HIVpositive and HIV-negative women (Lodi et al., 2011). In this case-control study, three-quarters of HIV-positive women experienced CIN recurrence compared to only one-quarter of HIVnegative women, a rate of more than four times higher. Contrary to the authors' hypothesis, there were no differences in CIN recurrence in HIV-positive women based on CD4 count or grade of the cervical lesion, suggesting that severity of disease may not be the primary risk factor for recurrence. Additionally, women who experienced glandular involvement, which occurs when

dysplastic cells deep in the cervix are protected from destruction during treatment, were 11.78 times more likely to experience CIN recurrence. Therefore, glandular involvement was the greatest risk factor for CIN recurrence after LEEP treatment in all women, but being HIV-positive also increased this risk.

## **Pap Test Screening**

### **Current Recommendations**

As stated previously, current guidelines recommend women engage in Pap test screening every one to three years beginning at age 21 (Duffett-Leger et al., 2008; Montgomery et al., 2010; Moyer, 2012). However, because HIV-positive women are at greater risk of both contracting HPV and suffering its negative consequences, their screening guidelines are more stringent (Williams, Moneyham, Kempf, Chamot, & Scarinci, 2015). The Ryan White Part A Program HIV/AIDS Bureau (HAB) oversees the core elements of primary care for people living with HIV/AIDS (PLWHA) and establishes recommendation guidelines (Health Resources and Services Administration (HRSA) HAB, 2010). Regarding Pap test screening for HIV-positive women, the HAB currently recommends two Pap tests during the first year of enrollment with Ryan White, one at the initial visit and another six months later, with annual screening beginning in the second year. If an HIV-positive woman has an abnormal Pap smear, follow-up colposcopy should be completed within six months and another Pap test should be performed in the six months following that (HRSA HAB, 2008).

#### Accuracy

The Pap test is an essential part of women's preventive healthcare used to identify CIN. While it has often been assumed the Pap test is accurate in all populations of women, one study sought to actually test whether the sensitivity and specificity of the test was different for HIVpositive women (Anderson et al., 2006). The participants in this sample included almost 200 HIV-positive and 100 HIV-negative women who were recruited in Baltimore, MD in the mid-1990s and enrolled in the study until 1999. In this case, HIV-positive women with a more compromised immune system, defined as a CD4 count of <500 cells/mm, had greater risks of false negative results, meaning the incidence of low-grade CIN was not detected despite it being truly present. However, the overall accuracy of the Pap test was the same in both HIV-positive and HIV-negative women, being highly sensitive and specific for both populations.

## **Demographic and Socioeconomic Characteristics**

Several studies have sought to identify demographic and socioeconomic covariates associated with Pap test screening in HIV-positive women. One such study examined prospective screening behavior in a cross-sectional study with 209 HIV-positive women at a comprehensive healthcare center in Houston, TX (Ogunwale et al., 2016). More than 85% of the women adhered to recommended Pap test screening guidelines; these women also tended to have more clinic visits, were more likely to have their physician recommend a Pap smear to them, and indicated their partners were supportive of them engaging in Pap test screening. Those who did not achieve Pap test screening guidelines tended to be younger and report multiple sexual partners.

Another study retrospectively examined the medical records of HIV-positive women who were patients at an urban clinic in Boston, MA (Baranoski, Horburgh, Cupples, Aschengrau & Stier, 2011). In this case, women who were older, Hispanic or White, born in the United States, unemployed, current or past drug or tobacco users, or who had a baseline CD4 count of <200

cells/mm were less likely to have received a Pap smear in the previous year. Looking at records over a period of eighteen months, the authors concluded that most HIV-positive women in this setting did at least receive occasional Pap smear tests, but not always on an annual basis as recommended; however, still nearly one-third of the sample did not receive a Pap test at all during the study period.

In a similar study, retrospective chart reviews were conducted to determine both rates of initial and follow-up Pap smears in 69 HIV-positive women who received at least one year of care at a county-based HIV clinic (Rahangdale, Samquist, Yavari, Blumenthal & Israelski, 2010). Over a four-year period, more than three-quarters of the participants received at least one Pap smear. Two-thirds of the women had normal results from this initial Pap test, but of these, only 60% received a second Pap smear within the next 18 months. For the one-third of the sample who had abnormal results from the initial Pap test, 51% were identified as ASCUS<sup>1</sup>, 36% were LSIL<sup>2</sup>, 10% were HSIL<sup>3</sup>, and less than 2% were AGUS<sup>4</sup>. Only 62% of these women had a follow-up Pap smear within one year. Also, HIV-positive women who had ever had a CD4 count <200 cells/mm were less likely to engage in Pap test screening at all, which may reflect their overall engagement in care.

Yet another study involved the random selection of 200 HIV-positive women's medical records to determine how well patients attending a health department clinic between 2000 and 2006 met the Ryan White Part A Program HAB guidelines for Pap test screening (Logan,

<sup>&</sup>lt;sup>1</sup> ASCUS: Atypical Squamous Cells of Undetermined Significance

<sup>&</sup>lt;sup>2</sup> LSIL: Low-Grade Squamous Intraepithelial Lesions

<sup>&</sup>lt;sup>3</sup> HSIL: High-Grade Squamous intraepithelial Lesions

<sup>&</sup>lt;sup>4</sup> AGUS: Atypical Glandular Cells of Undetermined Significance

Khambaty, D'Souza & Menezes, 2010). The sample was largely made up of low-income, racial/ ethnic minority women. In their first year of care at the clinic, over 80% of the participants received at least one Pap smear; however, less than 25% completed the two that are recommended. Approximately 40% of women with abnormal results on the initial test received a second Pap smear, while only 20% of those who had normal results on the first Pap test had a second one. Meeting the Ryan White Part A Program HAB Pap smear guidelines was significantly associated with having more than just Ryan White coverage as health insurance and receiving care at one particular clinic within the health department setting. While the rate of initial Pap test screening was fairly high, the recommended second Pap smear was less complete, even among those who had abnormal results from the first test.

If a Pap smear returns abnormal results, follow-up appointments for further testing through colposcopy are needed, especially for HIV-positive women who are at greater risk of developing CIN. However, rates of attendance for follow-up care are often lower than those for initial screening, resulting in delayed diagnosis and treatment of infections or cervical cancer (Abercrombie, 2003). Baranoski and Stier (2012) conducted a retrospective study to identify independent variables associated with time between receiving an abnormal Pap test result and attending a follow-up appointment in 177 HIV-positive women. Overall, only 59% of participants received a colposcopy within 6 months of receiving their initial Pap test results. Variables associated with decreased time between initial and follow-up appointments included higher grade CIN on the abnormality index of Pap test results, seeing the HIV clinic nurse practitioner versus an outside gynecologist for the initial Pap test, having a CD4 count >500 cells/mm, being married, and having private insurance. At one year from the initial Pap smear,

still only 68% of the women with an abnormal Pap test result had attended a follow-up appointment, with no changes in covariates being identified. While it is promising that more than two-thirds of the sample received a colposcopy within a year of their initial Pap test and that women with higher grade CIN tended to receive follow-up care earlier, 14% of women with high grade CIN and one-third of women with low grade CIN did not attend a follow-up appointment within a year of receiving an abnormal Pap test result.

## **Psychosocial Influences**

Psychosocial factors concentrate on the beliefs and perceptions which affect individual health behaviors and lifestyle choices. Stokols (1996) offers three forms of influence at the intrapersonal level: Cognitive, which involves a person's beliefs and opinions, Affective, or a person's evaluation of something, and Behavioral Modification, or changes in a person's actions. These are often simplified and packaged together as Knowledge, Attitudes, and Beliefs. Public health researchers examine psychosocial influences of health to identify them, determine their source, understand their role in decision-making, and develop interventions to modify them in hopes of promoting better health. For Pap screening, like other preventive health behaviors, researchers are interested in learning what women know about Pap smears, HPV, and cervical cancer as well as why they do or do not comply with recommended guidelines, and how public health practitioners might be able to affect these decisions.

**Knowledge.** Although many women acknowledge Pap smears as a basic part of women's healthcare, they may lack even a basic understanding of what it is for, the examination itself, and what the results mean (Breitkopf, Pearson, & Breitkopf, 2005). Seeking to understand knowledge of Pap test screening among women with low socioeconomic status, one group of

researchers developed and assessed their own measure (Breitkopf et al, 2005). More than 300 women completed the 20 True-False question knowledge survey between 2002 and 2003, which covered the topics of Pap screening purpose, symptoms of an abnormal Pap smear, what to do if a Pap test result is abnormal, and what follow-up after an abnormal Pap test involves. The sample population was evenly split between White (34.3%), Black (34.0%), and Hispanic (31.7%) women; more than two-thirds were unmarried, approximately 60% had less than a high school education, and nearly half had a household income of less than \$10,000 per year. Several women answered the questions about the purpose of a Pap smear incorrectly; for instance, 61.2% said the purpose was to check ovaries and 73.1% said it was to test for sexual disease. However, more than 85% correctly answered the purpose of a Pap smear is to scrape cells to look for cancer. Only slightly more than half correctly answered unnoticeable or no symptoms (50.9%) and unusual vaginal spotting or bleeding (58.9) were possible symptoms of an abnormal Pap smear, and only 42% accurately identified genital warts as a possible symptom of an abnormal Pap smear. The majority of the women knew they should tell their partner (89.3%) and may need more frequent Pap smears (75.1%) if they had an abnormal Pap test result, and more than twothirds knew an abnormal result did not necessarily mean cancer. However, only slightly more than 10% correctly stated the problem could go away on its own. Answers regarding follow-up after an abnormal Pap smear were wide-ranging; while more than 85% correctly said another Pap smear test would be needed, only 21.6% knew colposcopy as an option. Overall, the women in this study had relatively low knowledge of Pap smears.

Daley and colleagues (2013) assessed knowledge of Pap test screening among three highrisk populations at various points in time: HPV-positive women prior to the development of the HPV vaccine, college women after the development of the HPV vaccine, and minority college women after the development of the HPV vaccine. The primary outcome variable was measured by a single question: What is the Pap smear a test for? Participants selected Agree/Disagree or True/False for 8 sexually-related outcomes: pregnancy, HIV/AIDS, herpes, gonorrhea, HPV, cervical cancer, yeast infections, and vaginal infections. Across all three samples, the majority (75% - 84%) correctly indicated a Pap smear tested for cervical cancer. However, a large number answered incorrectly for HPV (82% - 91%), vaginal infections (76% - 92%), yeast infections (65% - 86%), gonorrhea (55% - 81%), and herpes (53% - 80%). Fewer participants believed the Pap smear tests for HIV/AIDS (22% - 59%) and pregnancy (17% - 38%). While most of the women did know the purpose of a Pap smear is to test for cervical cancer, they incorrectly thought it tested for other issues as well.

One recent meta-analysis found few articles, only 17 overall with 9 in the United States, studied HIV-positive women's knowledge of HPV and cervical cancer screening, but those that did reported relatively low knowledge regardless of region or country (Wong et al., 2018). Some women had never heard of HPV, while others did not know how it was transmitted or about its relationship to cervical cancer. Most women in these studies knew they should have regular Pap smears, but were unaware of the specific guidelines for HIV-positive women. There was also a lack of understanding of the role HIV plays in susceptibility and severity of HPV and cervical cancer. While some of the women assumed they might be at greater risk simply because having HIV lowers their immune system, others thought lack of symptoms, sexual activity, or family history meant they were safe. The role of health literacy varied, with some studies finding it to be significantly related to knowledge and others finding no such association.

Knowledge related to cervical cancer screening can not only affect engagement in regular Pap testing, but also follow-up care if a Pap smear result comes back as abnormal. Sharpe, Brandt, and McCree (2006) interviewed 44 women in South Carolina who had received an abnormal Pap smear in the previous five years to understand their knowledge and beliefs about their results. First, the participants answered True-False questions about HPV; the vast majority, 80%, knew some types of HPV were related to cervical cancer, while only 15% knew HPV was the most common STD. During the one-on-one interviews, seven key themes emerged: 1.) The association between an abnormal Pap smear and developing cancer, 2.) The need for more Pap screening, 3.) The need for other additional tests or procedures 4.) Having a low level of concern initially, 5.) Explanations for the abnormal result; 6.) An association between the abnormal result and sexual activity, and 7.) The association between the abnormal Pap test result and HPV or other STDs. Although more than three-quarters of the women discussed the link between an abnormal Pap smear result and developing cancer, less than half named cervical cancer specifically and some were confused about whether or not they already had cancer. Nearly all of the women understood they would need to have repeat and more frequent Pap smears as well as other tests and procedures. The women seemed relatively unphased by their abnormal Pap test result, and this was largely attributed to the apparent lack of concern by their healthcare provider. The women in this study had experienced an abnormal Pap test result and possessed a basic understanding of the implications as such, but still lacked detailed knowledge of HPV and cervical cancer.

**Beliefs.** A study of more than 300 HIV-positive women in Florida sought to compare the relationships between knowledge, self-efficacy, and the constructs of the Health Belief

Model (HBM), which are Perceived Benefits, Barriers, Severity, Susceptibility, and Cues to Action, and their ability to predict having a Pap smear in the last year (Lambert et al., 2015). The participants were recruited from two local clinics and completed surveys with Likert-scale and multiple-choice questions. Higher knowledge was associated with increased self-efficacy and benefits, while lower knowledge was associated with more perceived barriers. As perceived severity increased, so did perceived susceptibility, benefits, and barriers. There was a strong relationship between self-efficacy and benefits, but only a weak correlation between susceptibility and barriers. Women who had a Pap test in the last year had fewer perceived barriers and more self-efficacy than those whose last Pap smear was more than a year prior. However, no significant differences in time since last Pap smear were found based on knowledge, susceptibility, severity, or benefits.

Using a mixed methods approach, Tello and colleagues (2010) studied covariates and barriers to attending gynecological appointments and receiving annual Pap smears among HIVpositive women obtaining care at a Baltimore, MD clinic. Overall, 69% of the 200 participants missed a gynecological appointment and 22% had not received a Pap smear in the last year. When only those women with a cervix were considered, moderate to severe depressive symptoms were associated with both missing a gynecological appointment and not receiving a Pap smear. Other factors associated with not having a Pap test included completing less than a high school education, being older in age, and having a higher viral load. For African American women, having moderate to severe depression was associated with both missing a gynecological appointment and not having a Pap test in the last year. Also, drug use was associated with missing a gynecological appointment, and having a lower education was associated with not receiving an annual Pap test. Using focus group discussions, barriers to attending gynecological appointments, including for annual Pap testing, were identified by participants; these barriers included fears of discomfort from the procedure, receiving bad news from the examination, simply forgetting about the appointment, and being sick or experiencing bad weather on the day of the appointment.

An important topic in the last decade related to cervical cancer screening is the HPV vaccine. Several studies have assessed knowledge and beliefs about HPV in relation to vaccine acceptability and uptake, both in young adults and in parents. One such study conducted in rural North Carolina compared HPV beliefs and vaccine acceptability among African American and Caucasian mothers (Cates, Brewer, Fazekas, Mitchell, & Smith, 2009). Nearly 100 Black and 50 White mothers participated in the study, and the majority were considered middle class, with at least a high school education, a full-time job, and health insurance benefits. Less than one-quarter of Black women, compared to nearly 60% of White women, had ever heard of HPV, and Black women scored significantly lower on the knowledge test. Fewer Black women believed they or their daughters were at risk for developing cervical cancer compared to the White participants. Despite these differences, beliefs about and acceptability of the HPV vaccine, and all had moderate views of its safety and efficacy. However, Black mothers had less intention of vaccinating themselves or their daughters than did White mothers.

#### **Sociocultural Factors**

Culture is a shared system of values, beliefs, behaviors, social patterns, and other customs, and has a significant impact, whether consciously or subconsciously, on an individual's

health (Steele-Moses et al., 2009). Humans are social creatures; as such, social networks significantly influence social identity (McLeroy, Bibeau, Steckler, & Glanz, 1988). An individual's social network describes their system of interpersonal relationships and social support, both their characteristics and functions (Heaney & Israel, 2008). Social interactions, shaped by society and culture, figure into an illness experience through relationships and interactions with others and become a central part of the experience of suffering (Miles, Isler, Banks, Sengupta, & Corbie-Smith, 2011). Thus, interpersonal relationships, whether formal or informal, with family and friends or professional contacts and acquaintances, shape health beliefs and behaviors.

**Social Network.** Much of the social network research on cervical cancer screening concentrates on marital status and relationships with significant others. One such study, using data from the 2012 Behavioral Risk Factor Surveillance System (BRFSS) survey, found married women were significantly more likely than never married and separated, divorced, or widowed women to engage in cervical, breast, and colorectal cancer screenings, with rates of 83.9% versus 78.7% and 75.1%, respectively (Hanske et al., 2016). These findings appear consistent with other literature indicating married people have better screening rates and cancer morbidity and mortality than unmarried people (Aizer et al., 2013; Saghari, Ghamsary, Marie-Mitchell, Oda & Morgan, 2015).

However, other research shows significant others may actually hinder women's engagement in cervical cancer screening, particularly within certain cultures. For instance, using the Witness Project as a model, which is generally thought of as successful, Erwin and colleagues (2007) conducted thirteen focus groups with more than 100 Latina women in both New York City and Arkansas. One of the major themes expressed by the women in discussing cervical cancer screening was the issue of gender roles. Many of the women said their husbands were not supportive or even disapproved of them getting Pap smears, as demonstrated through this representative quote:

"Our husbands don't understand anything about women's health and sometimes it gets to the point that they even get jealous or upset if the wife has a gynecologist appointment. And the first thing the husband will ask her is not how the physician's appointment went, but did a man or a woman physician see you" (p. 373).

The authors' conclusions suggested including men in educational interventions might be helpful in changing these detrimental views.

A meta-analysis of violence against women and its impact on cervical cancer screening found only 8 articles covering the topic between 2002 and 2013 (Leite, Amorim, Primo, & Gigante, 2016). Seven of the studies were conducted in the United States and the other was done in Australia, and sample sizes ranged from 100 to 30,000. No significant relationship between intimate partner violence and Pap test screening was identified in three of the studies, although one did find an association within the p < 0.10 threshold (p = 0.062). The remaining studies showed significant associations between violence and Pap screening, but the nature of these relationships was inconclusive. In two studies, experiencing intimate partner violence increased a woman's likelihood of having a current Pap smear, while the others showed a negative correlation. Another study found women with a history of emotionally abusive relationships were 87% less likely to have a Pap smear than other women, another study showed women who had been sexually abused as children were less likely to be screened, and the last found women who had experienced physical abuse were 70% more likely to not follow up after an abnormal Pap smear result. The findings in this meta-analysis prove violence against women can impact engagement in cervical cancer screening, but the relationship is complex and not straightforward. Another issue affecting this may be access to healthcare, but it is difficult to distinguish if access is limited because of intimate partner violence or if access is already limited due to socioeconomic status but is made worse by such violence.

**Social Support.** Like social network characteristics, social support comes in a variety of forms, from tangible, emotional, and informational support (Cohen, Mermelstein, Kamarck, & Hoberman, 1985) to received versus perceived (Dukel-Schetter & Skokan, 1990), and from both formal, such as healthcare providers, and informal, including family and friends, sources (Heaney & Israel, 2008). The role of social support and its impact on quality of life for PLWHA is well-studied. Communities may avoid the topic of HIV, possibly in an effort to deny its existence so close to home, express negative views about HIV, or even openly discriminate against PLWHA (Miles et al., 2011). A study in the rural South found these behaviors were a heavy burden for PLWHA, as they felt isolated from their social networks and lonely from carrying such a burden on their own (Miles et al., 2011).

Social support has been shown to help minimize stress, depression, and other negative effects associated with HIV-related stigma (Vyavaharkar et al., 2010). In their study of 340 HIVpositive African American women living in North Carolina, South Carolina, and Alabama, Vyavaharkar and colleagues (2010) found social support had a significant, negative relationship with depression, while stigma was positively correlated with depression. Specifically, women who believed social support was available to them, who reported multiple sources of support, and who were satisfied with the support they received were less likely to be depressed. Conversely, those who felt more isolated and stigmatized were more likely to experience depression. A separate intervention used support groups to help HIV-positive, African American women cope with stigma (Rao et al., 2018). In this case, not only did increasing social support help reduce the stress and depression associated with stigma, but these changes were also linked to decreases in viral load.

The role of social support in cancer screening is less clear; while some studies have shown aspects of social support to be positively related to Pap test screening (Gamarra, Paz, & Griep, 2009; Silva, Griep, & Rotenberg, 2009), others have found no connection between the two (Kang, Bloom, & Romano, 1994; Silva et al., 2009). A study of more than 2,100 non-Hispanic White and Hispanic Black women in Allegheny County, which encompasses Pittsburg, PA, determined social support and higher education were significantly associated with having a current Pap smear (Documet et al., 2015). Additionally, the interaction between social support and education was such that social support moderated the relationship between Pap test screening and education, meaning social support was more important for maintaining Pap test compliance among those with lower education. Based on their findings and other literature, the researchers offer three reasons for social support having a protective health effect. First, social support serves as a buffer and coping mechanism for stress. Second, social relationships encourage screening compliance through knowledge sharing, social norms, and peer pressure. Lastly, social support could compensate for educational, financial, and emotional barriers by increasing social capital.

A qualitative study of 20 HIV-positive, African American women in Alabama, 11 of whom had a Pap smear in the last year and 9 of whom had not, were interviewed about Cultural Empowerment as well as Relationships and Expectations (Williams et al., 2015). The main
enabling factor was the sex of the healthcare provider performing the Pap smear; some participants were not bothered one way or the other, while others felt embarrassment or concerned about partner jealousy. Some of the women reported nurturing relationships with family and friends who encouraged the women to take care of their health, and the women were also motivated to keep up with their health to spend more time with their family. Conversely, other women, especially those who did not have a current Pap smear, said their family and friends did not discuss Pap smears with them, and many expressed concern of stigma and discrimination. These findings affirm the inconclusive, complex relationship between social support and cervical cancer screening.

**Religiosity.** Religion can be described as a formal system of beliefs and practices or an outward expression of worship, and is generally measured by importance, attendance of religious ceremonies, and belief in God and prayer (Szaflarski, 2013). On the other hand, spirituality is more the internal, personal belief and connection with God, and is assessed by peace and comfort derived from faith, coping, and spiritual well-being (Szaflarski, 2013). The concepts of religion and spirituality are distinct, but nonetheless overlapping, and both are complex (Szaflarski, 2013). Spirituality, whether formal or informal, may improve coping and increase resilience by providing a sense of purpose, reason for living, or belief in second chances (Rao et al., 2018). Historically, the church has been more than a worship center for African Americans, providing resources and support for the community (Holt, Roth, Huang, Park, & Clark, 2017; Prado et al., 2004). Spirituality plays a significant role in the mental and emotional well-being of HIV-positive, African American women, serving as a source of guidance, comfort, peace, and protection (Dalmida, Holstad, Dilorio, & Laderman, 2012). A review of the literature on the role

of religion and spirituality among PLWHA revealed several themes, including religion as a source of support, spirituality as a barrier or facilitator to treatment, personal faith as a coping strategy, and spirituality in palliative AIDS care (Szaflarski, 2013).

A study of 20 HIV-positive, African American women in the Atlanta metropolitan area used focus groups to assess the women's meaning and use of spirituality (Dalmida et al., 2012). Nearly all of the women, 95%, considered spirituality as "very" or "extremely" important to them. Three main themes emerged: Spirituality as a process, journey, and connection to a higher power, Expressions of spirituality, and Benefits of spirituality or a relationship with God. In describing their spiritual journey, many of the women discussed how their spiritual beliefs and practices changed as a result of their HIV diagnosis, bringing them closer to God. Church played a central role in the women's lives and was their main expression of their spiritual beliefs. Praying, helping others, and sharing their testimony were other ways the women conveyed their faith. Many of the participants described God as a healer, and attributed improvements in their health with incorporating their spirituality in the care they receive from medical providers. Several of the women said their beliefs provided them with inner peace, support and strength, and a purpose for living. Most of the women had grown up in church and, as such, identified it as a part of their culture, but going through the stress of an HIV diagnosis renewed their relationship with God. Thus, spirituality was a positive influence on the women's mental and physical health and well-being.

One prospective study examined the influence of religiosity on medication adherence among 350 PLWHA in San Diego, CA (Vyas, Limneos, Qin, & Mathews, 2014). Being affiliated with a religious institution was significantly and positively associated with at least 90% adherence with HAART. Exploring further, it was found participants who said their beliefs gave their lives meaning, connected them with a higher being, helped with their recovery, and helped them feel connected to humanity were significantly more likely to achieve greater than or equal to 90% adherence. However, those who believed God created all of the universe and God would not turn away from them as well as those who attended religious services, participated in rituals, and prayed to communicate with God were significantly less likely to reach 90% adherence. While some of the findings from this research were expected, such as religion providing a sense of purpose and offering hope, this study also found religious coping to be a predictor of medication adherence. However, when religious beliefs turned fatalistic, meaning they trusted God had total control regardless of their own actions and behaviors, medication adherence was poor.

The precise coping mechanisms through which religious beliefs affect health outcomes is less established. Prado and colleagues (2004) sought to inspect the nature of the relationship between religious beliefs and coping with stress in a sample of more than 250 HIV-positive, African American mothers in Florida. Three types of coping were examined: Active, which involves facing the stressor directly, Support, when help is sought to address a problem, and Avoidance, where there is an attempt to evade or ignore the issue. In this case, religious involvement was significantly, positively associated with stress and significantly, negatively associated with psychological distress; however, religious involvement did not mediate the relationship between stress and psychological distress. Participants who experienced more stressors were more likely to be religiously involved, but the more psychological distress a mother faced, the less likely she was to participate in religion. As for specific coping mechanisms, religious involvement was positively associated with social support, active coping, and support coping, but negatively related to avoidant coping. Thus, mothers who participated in organized religious activities perceived greater social support and responded to stress with active and support coping strategies rather than avoidance.

Hotz (2015) studied the link between religion and medical fatalism among twenty-one African American women with diabetes who were enrolled in a healthy living class at a local clinic in Memphis, TN, where the present study also took place. Using qualitative interviews, she identified three overlapping facets: Belief that "not claiming" a disease keeps it from entering the body, Faith-based clinics helped restore relationships with marginalized communities, and Provider understanding of social nuances influences the meaning of compliance. Many of the women responded to diagnoses by stating "I don't claim that" (p. 2215). While it might sound like simple denial, the participants explained that claiming a diagnosis is accepting it, taking ownership of it, and essentially giving in to it. However, it was acknowledged that sometimes lack of claim does lead to lack of treatment, but not for them personally, as evidenced by their participation in a healthy living program. Not only are many African Americans distrusting of the medical system, but some congregational leaders equate seeking health care with lack of faith, which further deepens the issue. A compromise the women used was seeking care from a faith-based health clinic, which kept them actively engaged in their own health versus accepting fatalism. Compliance is another concept that is often over-simplified, and Hotz offers vignettes to demonstrate this issue. For example, one participant worked three jobs, but planned to decrease to two once she paid off some debt. In the meantime, she had less flexibility in her schedule to attend appointments and take medication at the appropriate time, even though her

health was important to her. In these situations, non-compliance does not stem from a lack of understanding or unwillingness to follow doctor's orders, but rather from circumstances beyond the patient's control, a truer form of fatalism.

The literature on the impact of religious beliefs on cervical cancer screening practices is limited; however, one study did look at religious affiliation, family structure, defined as traditional or non-traditional, and HPV high-risk and protective practices among college-aged women (Wigfall et al., 2012). More than three-quarters of the 467 participants identified themselves as religious, most affiliating as protestant Christians. Nearly 93% of the women had engaged in sexual intercourse, more than 70% before the age of 18, with an average of three to four partners. There was a significant relationship between religious affiliation, family structure, and condom usage, which was considered a protective behavior. Participants raised in a traditional family structure who identified as religious were more likely to use condoms. Highrisk behaviors were categorized as sexual, mainly number of partners, or substance use, smoking cigarettes or marijuana and drinking alcohol; religious affiliation was only associated with smoking marijuana. This study found relatively no difference in sexual activity and substance use between religious and non-religious college women; however, religious college women who had been raised in a traditional family structure were significantly more likely to use condoms as a protective measure. Although they may use safe-sex measures, such as condoms, religious young women were as sexually active as their non-religious counterparts, which still puts them at risk for contracting HPV and developing CIN or cervical cancer.

## **Contextual Considerations**

Living with HIV/AIDS. The HIV landscape has changed since the advent of HAART in 1996, becoming a chronic illness more than a terminal disease (Baumgartner & David, 2009). Still, being diagnosed with HIV can be a traumatic experience, filled with shock, disbelief, guilt, shame, worry, etc. (Miles et al., 2011). Following up on an initial study conducted with PLWHA diagnosed before 1995, Baumgartner and David (2009) sought to understand the process of integrating being HIV-positive into self-identity by talking with individuals who had been diagnosed after HAART became widespread. In their latest study, three general steps to the process were identified: Diagnosis, Post-Diagnosis Turning Point, and Integration. The first study had two additional steps, Immersion and Post-Immersion Turning Point, as the third and fourth components. Participants reported feeling shock, fear, denial, sadness, and fatalistic after their diagnosis. Many had not expected to be diagnosed with HIV and so were in disbelief, while those who knew they had engaged in risky behavior were more likely to experience fatalism. Although they knew about HAART, fear of dying and an unrealized future were common. Others went through a period of denial, where they forgot or avoided thinking about their diagnosis. Sadness was sometimes experienced immediately after diagnosis, but more often was a secondary emotion after the initial shock and denial wore off. At some point after their diagnosis, all of the participants faced a turning point, either from learning more about HIV, disclosing their status to others, or receiving medical intervention. Integration of HIV into one's identity occurred over time as the participants received support from others, both inside and outside of the HIV community, and educated others on their disease. They also reported their HIV-positive identity started to imprint on their identities, helping with acceptance and

immersion. Disclosure of their status occurred in stages as well, starting with significant others, family, and friends shortly after diagnosis to public disclosure at support groups and more broadly to selective disclosure as needed.

Accepting being HIV-positive as part of one's identity is a progressive step that comes with time, but this balance may be fragile if other stressors come onto the scene. Using case studies to acquire in-depth descriptions of experiences as presented from their own perspectives, Aranda-Naranjo, Barini-Garcia, and Pines (2005) offer two illustrations of the complex psychological, physical, and cultural processes that affect HIV-positive women's follow-up gynecologic care after an abnormal Pap smear result. In one case, the woman lived with HIV in isolation, not telling her family and co-workers or attending support groups, and with constant fear that someone would find out about her disease. Upon learning of her abnormal Pap result, she assumed she had cancer and began praying, crying that this is "too much for one person to take" (p. 89). The other participant described herself as a strong woman, having always been the responsible one in her family and working to raise her children on her own after leaving an abusive husband. She was open with her family about her disease, but took great pride in maintaining her independence. Upon learning of the need for colposcopy, she told the nurse "I can't take no more bad news!" (p. 89). While the women in these cases dealt with their HIV disease very differently, one struggling to cope in isolation while the other seemed strong and had family support, they both were very stressed about their abnormal Pap test results and what another diagnosis would mean for them.

**Fatalism.** Fatalism refers to the belief that health is a matter of destiny or chance, outside of individual control or influence (Potter, Allen, & Roberto, 2018). As a public health

construct, fatalism encompasses beliefs, locus of control, and self-efficacy (Drew & Schoenberg, 2011). While religious fatalism, as discussed previously, assumes what happens is God's will and in God's control, medical fatalism is the belief a diagnosis or health outcome is inevitable (Hotz, 2015). Marginalized individuals may be more fatalistic because their internal locus of control may already be diminished (Drew & Schoenberg, 2011).

The Women of Color (WOC) study is a prospective, multi-site project designed to assess quality of care among minority HIV-positive women in both urban and rural areas of the United States. Using these data, Eastwood and colleagues (2015) compared barriers to HIV care among more than 920 participants. The two samples differed demographically on all variables except age, with significantly more Hispanic, single, and less educated women being represented in urban areas. In regards to HIV care, urban women were more likely to be transferred to different providers and to be lost to care, but reported a lower frequency of sporadic care than did their rural counterparts. Urban women also reported more barriers, including the need for more information, feeling judged, getting back on track on your own, accepting it, feeling embarrassed, transportation, financial uncertainty, being too upset to deal with problems, and worry that nothing will help, than did rural women, and these barriers more greatly affected them. Interestingly, despite living among larger populations, urban women reported more social isolation than did rural women, which could be related to instability with finances, housing, and HIV care. In addition, the barriers urban women experienced related more to stigma and fatalism compared to the barriers of rural women, leading to more psychological and emotional stress.

Experiencing an abnormal Pap smear and needing additional follow-up care not only have physical ramifications, but psychological and emotional as well. One study used focus groups to better understand how HIV-positive women in San Francisco deal with this news and the factors that influence their decision if and when to attend a follow-up appointment (Abercrombie, 2003). Overall, five major themes were described by the participants, including fear, lack of symptoms, life circumstances, health beliefs, and the healthcare provider. For these women, fear was multi-faceted, including fear of cancer diagnosis, fear due to confusion or a lack of understanding of the Pap test and results, fear of the follow-up procedures, and fear of having another serious diagnosis on top of being HIV-positive. Absence of symptoms made it easy for some women to ignore the initial abnormal results or decide the follow-up appointment was not truly necessary since they could not see or feel anything wrong with them. Many of the women in this sample had other stressors to contend with in their lives, including drug use, homelessness, or abusive relationships, making it difficult to keep follow-up appointments, especially with no symptoms causing them noticeable problems. Other women did not see preventive healthcare services as necessary to staying healthy, and some had an inherent distrust of Western medicine so were suspicious of the Pap smear results and related procedures. A woman's relationship with her healthcare provider was also important; those who felt close with their doctor, who received follow-up services with their usual doctor, or were introduced to the referred physician were more likely to attend their follow-up appointments than those who felt stigmatized, unfamiliar, or disconnected from their healthcare provider. Other factors that facilitated attendance of the follow-up appointment were feelings of empowerment among the women and prompts or reminders from the healthcare providers.

# **Organizational Dynamics**

Healthcare clinics and providers themselves can serve as facilitators or barriers to care, through their facilities, practices and procedures, and overall culture and atmosphere. When organizations are able to facilitate access, the health outcomes of patients improves. For instance, with consistent care and medication adherence, HIV may be suppressed and PLWHA may achieve an undetectable viral load (Hawk et al., 2017). However, the organization can also serve as a barrier to care, which harms patients and public health overall. This issue is particularly salient in rural areas, especially in the South, where many communities have access to fewer medical, mental health, and social support resources (Miles et al., 2011).

Hawk and colleagues (2017) interviewed patients and providers at a Ryan White Part C HIV healthcare clinic in Pittsburgh, PA to understand facilitators and barriers to HIV suppression. Three types of factors related to successful care emerged: Clinic, System, and Provider. The clinic's organizational model and processes were designed to minimize barriers and foster positive relationships. For instance, all patients meet with a medical social worker at intake to conduct a needs assessment. Additionally, there is a team-based approach to care, so all patients are assigned to a multidisciplinary panel of providers; this allows for improved communication and coordinated health management. While providers work in a team to care for patients, they also strive to develop individualized treatment plans, including strategies for medication adherence based on patient strengths and needs. The clinic also offers ancillary services, including mental health counseling and a pharmacy, on site, and they receive funds to help patients cover the costs of their care. Lastly, providers work from a philosophy of reducing harm and valuing the patient, which involves patient education, including patients in decisionmaking, and not judging harmful behaviors. Using this model, 86% of patients are this particular clinic have achieved viral load suppression.

One qualitative study looked at barriers to cervical cancer screening for low-income, HIV-positive women who had not had a Pap smear in more than five years (Andrasik, Rose, Pereira, & Antoni, 2008). Based on Anderson's Behavioral Model of Health Services Use, four types of barriers were identified: Psychological/ Emotional, Enabling Resources, External Environmental and Outcome. The Psychological/ Emotional barriers related to the participants' self-esteem, denial and fear. The women felt they lacked power in their lives and were concerned with HIV-related stigma. They also worried about how another diagnosis would affect them both physically and psychologically, which allowed for denial over needing to engage in screening and preventive care when they were not experiencing any symptoms. External Environmental barriers were generally related to finances, including being under-insured or having no insurance, not being able to pay co-pays, and lacking transportation to and from the appointment. Enabling Resources barriers referred to the participants not having the facilitators and support for getting a Pap smear. Many of the women felt they had too many other issues to deal with in their lives to worry about cervical cancer screening, and they also did not have enough information or social support to overcome this. Outcome barriers related to past experiences with the healthcare system included dissatisfaction with care, negative interactions with providers, and embarrassment or discomfort with the Pap smear itself. The participants in this study had not received a Pap smear in several years, and the reasons they identified were largely based on their conflicting needs and life stressors as well as challenges they faced within the healthcare system.

#### Intersectionality

The concept of intersectionality describes the complex connections between issues that are often considered separately. Although this research does not provide a comprehensive review of intersectionality, it is nevertheless important to consider. Rao, Andrasik, and Lipira (2018) note that HIV research often considers the issues of race, gender, and socioeconomic status separately rather than as interrelated issues, which may be especially detrimental to understanding the impact of the disease on African American women. HIV-positive African American women may face stigma based on multiple of their social identities, including their HIV status, being of minority race, being a woman, risk factors associated with HIV, such as drug use or sexual behavior, and socioeconomic status, which encompasses education, income, history of incarceration, etc. (Rao et al., 2018). Minority women, regardless of their HIV status, have likely been devalued by society related to other challenges, such as poverty, homelessness, low education, intimate partner violence, physical or mental health problems, substance abuse, etc.; thus, stigma related to being HIV-positive is just one more addition (Lekas et al., 2006). These issues could be even more pronounced in the South, where minorities have faced extreme discrimination for generations (Miles et al., 2011). In their meta-analysis of HPV and cervical cancer screening knowledge and disparities among HIV-positive women, Wong and others (2018) note that having synergistic epidemics, defined as simultaneous diagnoses of commonly linked diseases, is "not merely concurrent physical diseases; rather, they are health problems that are exacerbated by historical, sociocultural, economic, and political conditions" (p. e80).

#### **Theoretical Framework**

There are a multitude of factors influencing women's uptake of Pap test screening; however, not all are under their control. Acknowledging this, McLeroy, Bibeau, Steckler, and Glanz (1988) developed the Social Ecological Model (SEM) for health promotion that moves beyond individually-focused, lifestyle change theories of behavior, which at best are limited in perspective and at worst may blame the victim. For them, rather, health-related behaviors are not only affected by, but also affect, society and the environment. Using other ecological models as a guide, the SEM identifies five levels of influence: intrapersonal, interpersonal, institutional, community, and public policy. The intrapersonal encompasses individual's knowledge, attitudes, and beliefs. The interpersonal deals with formal and informal social processes and networks of support. Institutions have their own characteristics and organizational culture, such as formal and informal sets of rules and norms. Community factors describe the relationships between social networks and organizations within defined boundaries. Public policies are the local, state, and federal laws that govern society.

Several public health theories address the intrapersonal level, seeking to modify individual behavior (Stokols, 1996). In regards to screening, including cervical cancer screening, several studies have used existing public health theories, including the HBM and Theory of Planned Behavior (TPB) (Lambert et al., 2015). However, the usefulness of this type of research is limited for several reasons. First, many researchers do not employ the full theory as it was originally intended. A meta-analysis on the use of the HBM in Pap test screening research from 1984 to 2004 found that no single study had employed the full theory, instead utilizing only one or two constructs (Tanner-Smith & Brown, 2010). In fact, none of the twelve studies identified in this review had examined the *Cues to Action* construct whatsoever, despite evidence that such cues may prompt a woman to engage in preventive screenings (Head & Cohen, 2012; Tanner-Smith & Brown, 2010; Tello et al., 2010).

Second, many of the studies are cross-sectional in design, and, thus, the main outcome of interest is often intentions rather than actual behavior. For example, Duffett-Leger, Ledourneau, and Croll (2008) used the TPB to study Pap test screening intentions in a university-based population of women. Their instrument was a 77-item survey known as the Student Pap Test Survey, which included measures of the TPB constructs as well as demographic characteristics, risk factors and knowledge. The results showed *Subjective Norms* and *Perceived Behavioral Control* as well as age at first learning about a Pap test were significantly associated with Pap screening *Intentions*. The authors note these findings are similar to other studies, although *Attitudes* generally have a stronger relationship than *Subjective Norms* with *Intentions*, which they attribute to their relatively young sample. As informative as this study may be, it nonetheless faces a limitation fairly common in TPB research: only *Intentions* are examined. Thus, it is hard to know how these variables are related to actual cervical cancer screening behavior in this population.

Lastly, because only items based on preconceived constructs are included, other factors influencing cervical cancer screening practices may be missed. Qualitative methods are helpful for addressing this last limitation; however, much of the research employing these types of methodologies focus their attention on simply identifying facilitators and barriers rather than explaining how these factors work together to influence cervical cancer screening practices. One study used focus groups to better understand older women's Pap test screening behavior (Guilfoyle, Franco & Gorin, 2007). Although the HBM was used as a guide, themes were generated based on the discussions with participants. For instance, although the women recognized Pap smear testing as a means of early detection, they still viewed cancer as fatal, unpredictable, and dangerous. Many of the women expressed fatalistic spiritual beliefs in relation to cancer. In addition, while they recognized every woman as being at risk for cervical cancer, they felt younger women were more susceptible due to their perceived higher levels of sexual activity, and thus in greater need of testing. Barriers to screening included aversion to the test itself, stigma associated with Medicaid insurance, lack of symptoms and previous abnormal test results or other negative experiences with cancer. While these findings are interesting and helpful, they merely categorize facilitators and barriers to Pap test screening in this population rather than considering the meaningful relationships between these factors and how they influence an older woman's decisions related to cervical cancer screening.

Grounded theory is a qualitative method that involves the development of a substantive theory based on participants' experiences with a particular phenomenon (Draucker, Martsolf, Ross, & Rusk, 2007). One of the benefits of grounded theory is that the framework and its constructs are drawn from those with first-hand knowledge of the experience. As Walker and Myrick (2006) state, "Rather than develop a theory and then systematically seek out evidence to verify it, researchers using grounded theory set out to gather data and then systematically develop the theory derived directly from the data" (p.548). To accomplish this, data collection and analysis are done simultaneously so that initial findings are used to inform future interviews with participants in order to refine the theory as it emerges.

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## **Memphis Transitional Grant Area**

The Ryan White Memphis Transitional Grant Area (TGA) consists of eight counties in southwestern Tennessee (Shelby, Tipton and Fayette counties), northern Mississippi (DeSoto, Marshall, Tate and Tunica counties) and eastern Arkansas (Crittenden county) (Pichon, Morrell, Digney, Montgomery, & Asemota, 2012). Of the 1.3 million residents in the TGA, 70% live in Shelby County, TN, which includes the city of Memphis (Pichon et al., 2012). As of 2011, a total of 7,856 individuals, including those who may not be aware of their status, were believed to be living with HIV/AIDS in the Memphis TGA, which means the HIV infection rate in this area (33.7 per 100,000) is three times greater than the national average (10.4 per 100,000) (Pichon et al., 2012). While the majority of PLWHA in the Memphis TGA are male, approximately one-third are female, with nearly 90% identifying as African American and 60% being in childbearing age (Pichon et al., 2012).

In a recent study using Ryan White data, it was found that only 56% of the nearly 600 women actively engaged in the Part A program in the Memphis TGA received a Pap smear in 2011 (Digney, Morrell, Montgomery, & Pichon, 2013). African American women, women who resided within Shelby County, TN, and women with four or more medical visits in a twelve month period were the most likely to have a documented Pap smear. However, it is important to note that women included in this analysis had all attended at least one medical visit with a Ryan White provider during 2011, and, as such, the true rate of cervical cancer screening among HIV-positive women in the Memphis TGA may be even lower than what was found in this study.

## **Research Question**

Although it is known that HIV-positive women are at greater risk of contracting HPV and developing CIN, many studies only focus on identifying correlates associated with or facilitators and barriers to Pap test screening. Those that employ a well-known public health theory to guide their research often consider the intrapersonal level only, and thus find the framework does not entirely explain women's actual screening behavior. The purpose of this study is to better understand the influences, facilitators, and barriers, as well as the relationships among them, to Pap test screening decisions and behaviors among HIV-positive women in the Mid-South. Based on this aim, the following research question has been posed:

What psychosocial, cultural, contextual, and organizational factors influence HIVpositive women's engagement in cervical cancer screening?

#### **CHAPTER 2: METHODS**

#### **Study Design**

To answer the aforementioned research question, primary data needed to be obtained directly from members of the population interest. Additionally, to obtain a fuller understanding of their experiences, participants needed to be able to share their stories in their own words. Thus, qualitative research methods were an obvious choice. One-on-one interviews were chosen over focus groups because of the private nature of the conversations.

This study employed a qualitative methodology, using one-on-one, in-depth interviews to understand HIV-positive women's experiences with Pap test screening. A grounded theory approach was used to gain insight into the facilitators, barriers, and processes of obtaining a Pap smear for members of this population. As such, data collection and preliminary analysis were done simultaneously so that early findings could continuously inform data collection in an effort to uncover the full range of experiences (Corbin & Strauss, 1990; Creswell, 2007). One-on-one, in-depth interviews are ideal for grounded theory because each participant's experiences can help inform the discussion with the next participant to support or challenge the findings and refine the framework. The interview guide included broad questions to allow participants to describe their experiences in their own words as well as more specific questions about facilitators and barriers related to cervical cancer screening. The goal of this exploratory study is to begin to explain the cervical cancer screening decisions and behaviors of HIV-positive women in the Mid-South, as well as provide a practical framework for informing future public health interventions to promote annual Pap test screening in this population.

#### **Participant Recruitment**

Participants in this study were HIV-positive women between the ages of 18 and 45 years old who identify themselves as African American and speak English. While the target sample size was set at 30 participants when this study was initiated, the goal of qualitative research is to reach the point of saturation, when no new data is emerging (Creswell, 2007). Women living with HIV can be difficult to access. For one, people living with HIV/AIDS may not want to disclose their status; this may keep them from utilizing available services, even medical care. Second, members of this population may be transient or face unstable living conditions, making it difficult to keep in touch with them. Lastly, women are a smaller subset of the HIV community. With that in mind, identifying and recruiting women for this study relied on partnerships established in previous work.

Purposive sampling is the deliberate recruitment of participants who can provide the necessary data to answer the research question (Draucker et al., 2007; Starks & Brown Trinidad, 2007), and was used in cooperation with local HIV organizations and other community agencies to identify potential participants. The researcher coordinated with one of the largest healthcare clinics and one of the largest social service agencies who assist the HIV research community to identify potential participants. The organizations posted flyers, handed out postcards, and even allowed the research team to spend time in their offices to meet potential participants face-to-face and conduct interviews. Additionally, recruitment flyers were distributed to other providers in the Memphis HIV network via e-mail distribution list. This recruitment flyer included a brief description of the study and contact information of the researcher; a copy of this flyer can be found in Appendix A.

# **Data Collection**

# Instruments

**Interview Guide.** In grounded theory, interview questions revolve around the processes of a particular experience, including questions of *how* and *why* (Creswell, 2007). Using public health theories to guide research is advisable, but qualitative researchers must also remain flexible so as not to limit participants' experiences. The Health Belief Model was chosen as a basis for the interview guide because it has been commonly used to study screening behaviors, including Pap smears, and its constructs relate to the research question of this work. The specific HBM-related questions were based on other interview guides and surveys used in similar studies. Other questions were also developed from the relevant published literature to address specific topics, such as spirituality, social support, and sources of information.

For the purposes of this study, the interview guide contained open-ended questions about psychosocial, cultural, contextual, and organizational influences on the Pap test screening behaviors of HIV-positive, African American women in Memphis, TN. Psychosocial questions were largely based on HBM constructs, including Perceived Benefits, Perceived Barriers, Perceived Susceptibility, Perceived Severity, and Cues to Action. Other questions asked about social support and sources of information on health matters. Participants were also asked about how their religious beliefs and spirituality influence their health, and what role, if any, their church plays. Participants' experiences with Pap test screening, including the process of making and attending appointments, interactions with healthcare providers, and understanding the results of their Pap tests, comprised organizational factors. Additional questions related to having an abnormal Pap test were asked of participants who indicated they had this experience. Because one-on-one interviews are designed to be reflexive and dynamic in nature, the interview guide contained primary questions as well as potential probes to elicit informative responses from the participants (Creswell, 2007). The questions asked the women to reflect on their own beliefs and experiences, but probing questions were sometimes asked in a broader sense if the participants had little to discuss. Appendix B contains a copy of the interview guide.

**Participant Questionnaire.** The participant questionnaire contained questions related to demographic characteristics, socioeconomic status, and health history. In addition, participants' knowledge was assessed using the Knowledge of Pap Testing Survey (Breitkopf, Pearson, & Breitkopf, 2005). This particular tool was selected because it was straightforward and short. Because knowledge was not the primary concern nor was the sample size expected to be large enough for generalizability, this simple measure met the needs of this study. Breitkopf et al's (2005) Knowledge of Pap Testing Survey was developed based on a review of the literature and findings from qualitative formative research. During pre-testing, Cronbach's alpha measured consistency at a fairly good level ( $\alpha$ = 0.82), and this was reliable over a three-week period of time. Internal consistency increased with the study population reported on in the published manuscript, to a rate of  $\alpha = 0.88$ . The survey consists of four subscales: Purpose of a Pap Smear, Symptoms of HPV, Abnormal Pap Smears, and Follow-Up after Abnormal Pap Smears. Questions are in True-False format, and higher scores indicate greater knowledge. Given there may be members of the sample population with limited literacy, the questionnaire was interviewer-administered for all participants. A copy of the participant questionnaire can be found in Appendix C.

## Process

Potential participants were recruited directly by a member of the research team or indirectly by a potential participant contacting the lead investigator via telephone or email with information found on a recruitment flyer, located in Appendix A. The recruitment flyer was shared through local community agencies as well as other public forums and email listservs. Before an interview appointment was scheduled, potential participants were screened using the tool found in Appendix D to ensure inclusion criteria were met. In addition, the last question on the eligibility screening tool asked if participants had ever had an abnormal Pap test so the interviewer could ask additional questions about this experience during the interview session. Once a participant was deemed eligible for the study, they were given a brief overview of the project, invited to participate, and an interview was scheduled. Interviews took place in a private location at a community site convenient for participants, such as an HIV agency or public library.

Over the course of data collection, four public health students served as interviewers: the lead researcher, who was a public health doctoral student, and three masters-level public health students. All interviewers associated with this study completed CITI training and attended an interview training session held by the lead investigator before collecting data. Interviewers discussed the study procedures and data collection materials to become familiar with the process and help standardize participant experiences. In addition, interviewers listened to and read through transcribed interviews from the study to further understand the process.

At the start of each data collection session, the interviewer provided participants with a copy of the informed consent form, located in Appendix E, and read it aloud before confirming

the participant had no further questions and was willing to be involved in the study. Upon agreeing to be in the study, the participant used their unique identifier, a computer-generated random number, to sign the form in order to protect their identity while still being able to link study documents. After informed consent was given, the one-on-one interview discussion began, generally lasting around forty-five minutes. The interviews were audio-recorded for transcription and analysis purposes. The interview began with a brief introduction of what a Pap smear is, the types of questions that would be asked, and a reminder of the voluntary, confidential nature of the study. The interview guide for the in-depth conversations began with a broad question about the participant's overall Pap screening experiences. Next, the questions focused on more specific aspects of Pap test screening, including facilitators, barriers, the exam process, and the meaning of results. If the participant indicated they had an abnormal Pap test in the past, a few additional questions were asked about this experience. A copy of the interview guide can be found in Appendix B. Although the interview guide provided the basic direction for the discussion, the conversations were also reflexive to accommodate additional points and probes (Creswell, 2007).

After the one-on-one interviews were finished, participants completed a brief demographic, health history, and knowledge questionnaire administered by the interviewer. This questionnaire included items about the participant's background, such as age, gender, race, education, income, type of residence, HIV disease status, and Pap test screening history. Participants also completed Brietkopf et al's (2005) Knowledge of Pap Testing survey to assess their knowledge and beliefs. The information gathered from the participant questionnaire helped inform the context in which the participants live as well as how their knowledge and beliefs fit with their cervical cancer screening experiences. Appendix C contains a copy of the participant questionnaire.

At the conclusion of the interview session, participants were thanked for their contribution and given a \$10 Kroger gift card as compensation for their time and effort. They also received 2 brochures created by the CDC: one on cervical cancer and the importance of annual Pap test screening and one on HPV and safe sexual practices, located in Appendices F and G, respectively. Study-related materials were transported in a locked bag and stored in a locked file cabinet and on a password-protected computer in a secure office. No names were included in transcripts or on other documents. Data sources were linked by the participant's unique identifier. All materials and procedures were approved by the University of Memphis Institutional Review Board (IRB protocol #3117).

#### **Data Analysis**

#### **In-Depth Interviews**

**Open Coding.** The first step in grounded theory data analysis is open coding, which entails grouping similar concepts into initial categories (Corbin & Strauss, 1990). Before formal analysis began, completed transcripts were read through to become more familiar with the overall content. Experiences and expressed beliefs seeming to be of particular importance were noted as they emerged across participant discussions, and, where applicable, specific probing questions were incorporated into future interviews. Memos and notes were used to ensure consistency throughout this process (Walker & Myrick, 2006). Once all interviews were finished and transcribed, responses were grouped and inventoried based on the underlying constructs within the interview guide.

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**Axial Coding.** The next phase of the analysis process, axial coding, involves the development of sub-categories and understanding their relationships with each other and higher-level constructs (Walker & Myrick, 2006). With initial cataloging under corresponding questions complete, alike responses were put together as themes began to materialize. Context surrounding participants' statements was also important in consideration of how themes intersect and interact with each other.

Selective Coding. Selective coding is the final step in the data analysis process for grounded theory, and involves unifying the framework under a core concept (Corbin & Strauss, 1990). This central piece begins to materialize as the data and descriptions become thicker through data collection and analysis. In this final phase, the fundamental story of the phenomenon is solidified. With the sub-categories and their contexts known, the keynote themes associated with Pap test screening among HIV-positive women in the Mid-South emerged. Considering these multi-dimensional factors and their dynamic intersections provides a richer, more robust account of cervical cancer screening behaviors among this population, informing public health practitioners as they develop interventions related to these issues.

# **Participant Questionnaire**

The participant questionnaire was used as a supplement to the in-depth interviews to provide additional contextual information about the participants, such as their demographic background, socioeconomic status, and health history. The Knowledge of Pap Testing Survey offered insight into participants' knowledge of HPV, cervical cancer, and Pap test screening (Breitkopf et al., 2005). Questions were in a True-False format, and were grouped into four domains: Purpose of a Pap Smear, Symptoms of an Abnormal Pap Smear, Abnormal Pap Smear Results, and Follow-Up Care. Each correct response was coded as a 1, while incorrect and "Don't Know" responses were coded as 0; higher scores indicated greater knowledge.

#### **Ethical Considerations**

All study-related materials and procedures were approved by the University of Memphis Institutional Review Board (IRB# 3117). Only minimal risks were associated with this study, including the discussion of sensitive topics related to HIV, Pap test screening, stigma, etc. To address this, participants were informed of the voluntary nature of this study and asked only to share what they felt comfortable discussing. However, a potential benefit of participating in this study may have been increased motivation to engage in annual Pap test screening by identifying and discussing specific facilitators and barriers. Additionally, the results of the study will help inform public health practitioners in planning interventions to increase Pap test screening among this population.

Given their HIV-positive status, confidentiality was especially important for participants in this study. As such, interviews were conducted in a private room at a location convenient to the participant, such as the local library or another community organization. No names were recorded on any study-related documents, including the informed consent form, participant questionnaires, and interview transcripts. Instead, participants were assigned a computergenerated random number to use as their unique identifier, protecting their identity while still allowing for linkage between study documents. Transcripts from the audio recordings also did not include names of participants or others that may have been mentioned during interviews. All study-related materials were transported in a locked bag and stored in a locked file cabinet or on a password-protected computer kept in a secure location. Compensation for time and effort in the form of a \$10 Kroger gift card and informative brochures was given to all participants.

## Credibility

Although different from the quantitative measures of validity and reliability, methods of rigor in qualitative studies is used to assess trustworthiness (Krefting, 1991). In phenomenology, the lived experience of the participant is what is being studied, and the researcher must work to ensure their truth is recorded (Krefting, 1991). Given the participants themselves are experts on their experiences, analysis for this study was done using their words verbatim. Additionally, the interviewer summarized and reviewed responses with the participants throughout the interviews and at the conclusion of the discussions to ensure appropriate interpretation.

Qualitative data should be rich and thick with description, and one way researchers can hope to ensure this in what they obtain is through prolonged engagement with participants (Lincoln & Guba, 1985). For this study, allowing the participants to share their truths required building rapport during the interviews and giving them the freedom to talk; thus, there was no set length of time for the interview discussions. Additionally, and with neutrality in mind, interviews were conducted in private, and participants were assured their anonymity and their responses would be kept confidential.

The interview itself also was designed to increase credibility (Krefting, 1991). The interview guide followed a logical flow, beginning with a general description of the participant's last Pap smear and broadening to other aspects of their life that may influence their engagement with annual Pap screening. Also, questions were reframed to ask participants about their individual experiences as well as their thoughts on the experiences of other women. Knowledge

was assessed not only throughout the interviews, but also through an objective test. During analysis, the researcher discussed her methods, initial findings, and emerging themes with a mentor in ensure steps and conclusions were appropriate.

# Reflections

#### Conceptualization

As a graduate assistant, I worked closely with members of the Memphis HIV community on several research projects, including the 2012 HRSA Ryan White Comprehensive Needs Assessment. In this capacity, I helped administer surveys to people living with HIV/AIDS, medical providers, and support service agency employees, and took notes during focus group discussions. One issue the women brought up was feeling left out and neglected, saying that research nearly always focused on men who have sex with men or with transgender individuals. They very much appreciated being included in the Needs Assessment, but felt their specific needs were often overlooked.

My passion has always been for women's health, so I knew my doctoral research would be centered on that area. Specifically, I was interested in breastfeeding, sexual and reproductive health, and prevention and treatment of women's cancers. After talking with women living with HIV/AIDS, I determined to continue working with this population for my dissertation. To identify a need and develop an appropriate research question, secondary data analysis of Memphis TGA Ryan White service surveillance was conducted. In narrowing data analysis to only women, one particular gap in service utilization stood out: Pap screening.

The findings from the formative research study were presented in the previous review of the literature, but what stood out most was how many women were not being screened, despite having access to the care through the Ryan White program. The initial study identified demographic and socioeconomic correlates to Pap test screening, but hardly shed light on *why* some of the women utilizing Ryan White services get Pap smears and others do not. In doing a preliminary literature review, many studies sought to identify facilitators and barriers to Pap test screening. Much of the focus was on logistics, what helped get women to their appointments versus what kept them from making it, but few incorporated multiple levels of the Social Ecological Model. Additionally, few considered the unique circumstances of HIV-positive women. Thus, the research questions for this study emerged organically based on formative research from the existing literature on Pap test screening and with the specific population of interest: What psychosocial, cultural, contextual, and organizational factors influence HIVpositive women's engagement in cervical cancer screening?

# **Study Procedures**

Several women were interviewed shortly after recruitment began in the summer of 2014; these women were highly engaged in care and well-known in the HIV community. However, as time went on, potential participants lessened and became more challenging to recruit. To help accommodate schedules, an MPH student working on her practicum was trained to conduct interviews as well. Participants continued to trickle in, but, as data collection stretched into the spring of 2015, two additional students were trained to conduct the interviews. All went through the same training, which involved completing CITI training, reading the study protocol, listening to and discussing the audio recordings of completed interviews, and reading the verbatim transcripts, but certainly each interviewer had their own styles and may have asked different probing questions. The 19 participants in this study were all recruited over approximately fourteen months; however, recruitment efforts continued for another year, but to no avail.

As mentioned previously, grounded theory involves simultaneous data collection and analysis so initial findings from data analysis may be used to inform future interviews. This technique was utilized for the present study as well; although the main structure and questions did not change, wording and probes were adjusted as needed. Throughout data collection, I transcribed and read through the interviews, developing and refining a thematic codebook, and discussing the process and findings with my mentor. At a certain point, I realized no new themes were emerging, meaning saturation had been reached, so recruitment ended. After the interviews were completed, the discussions were transcribed verbatim from the audio recording by the researcher. However, no specific names of individuals were captured in order to maintain anonymity and protect confidentiality. Coding in qualitative analysis involves grouping similar ideas to develop themes and categories (Creswell, 2007). Although there are some variations, the data analysis process for grounded theory generally involves three types of coding: open, axial and selective (Corbin & Strauss, 1990). Constant comparison is the key in each of these phases (Starks & Brown Trinidad, 2007; Walker & Myrick, 2006). To refine the final theoretical framework, the steps in the data analysis process were reviewed again with all interview transcripts.

#### **Reflexive Analysis**

By the summer of 2015, all of the interviews were completed, and finishing transcriptions and beginning data analysis was the next step. The lead researcher, myself, had moved out of state and begun working full-time at a local health department, planning to complete this dissertation in the evenings and on weekends. However, those plans became suddenly halted at the start of the fall semester when I was diagnosed with Stage II breast cancer. Krefting (1991) describes reflexivity as an "assessment of the influence of the investigator's own background, perceptions, and interests on the qualitative research process" (p. 218). A researcher should draw their conclusions from the data itself, but they must also continuously examine their own perspectives in collecting and analyzing data (Krefting, 1991). What follows is my own experience with a serious condition and undesirable treatment; it is meant to exhibit the context from which analysis was conducted as well as demonstrate the deeper connection I gained from the results.

**Diagnosis**. After participating in a mud run, I felt a lump in the shower. My brain instantly went to breast cancer, but I had a lot of protective factors going for me: I was 30 years old, healthy and in shape, and did not have a strong family history of breast cancer. I searched reputable sites on the internet and found comfort that most cases like mine are simply cysts. Still, I made an appointment at my primary care clinic and the doctor, although confident the lump was only a cyst, referred me for a mammogram and ultrasound to be on the safe side. My worry level at that follow-up appointment was minimal; in fact, in an effort to support a fellow graduate student, I participated in a survey about my mammography appointment and said I was "Not worried at all" about my results that day. However, my worry increased when the radiologist wanted to perform a biopsy right then and there.

Since I had never heard of doing a biopsy on a cyst, I asked the radiologist about it, and was informed the lump was not a cyst but rather a solid mass. This appointment took place on a Thursday, and the radiologist insisted I come in for the results first thing on the following

Monday. I hoped I was overreacting, but nonetheless felt the doctor was indicating the situation was not good. I finally worked up the courage to ask what, if not a cyst, she thought this was, and she stated that was what the biopsy was for.

Although I was definitely concerned, I still could not fathom the biopsy would actually come back as cancer. Not surprisingly then, come Monday morning, when I went in for the results, I was completely dismayed when it actually did. I knew the old adage of not hearing anything else after receiving such news, so I was determined to keep it together, ask meaningful questions, and remember what was being told to me about my treatment plan, which was to involve chemotherapy, surgery, and radiation; I lasted only a few minutes.

**Faith Renewed.** Facing a cancer diagnosis and the treatment that comes along with it was overwhelming. Even with health literacy, social support, adequate insurance and finances, it was difficult to imagine being able to get through everything, especially with any quality of life. The situation felt bigger than myself, and thus compelled reliance on a higher power for strength, comfort, and peace. I had been visiting a church, but began attending regularly and officially became a member while I was in treatment. I gained additional support from my church family, emotional in terms of encouragement and concern but also tangible, mostly in the form of food. I also prayed regularly, giving thanks for good days, venting about bad ones, and asking for help all along the way. I took comfort in certain Bible verses, particularly Romans 5:3, and would often repeat them to myself. When I was finally done with treatment and officially declared in remission, I felt triumphant and strong, but also humble that I had actually been able to get through it all and still have joy.

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**Fatalism.** I had been in remission not quite six months when I was diagnosed with a recurrence. I had been having some sharp pains, but was told it was normal as nerve feeling came back after surgery and radiation; however, one day at work the shooting pain was enough to cause a cramp, and that's when I noticed what felt like a coin slid under my skin. I called my oncologist and they referred me for an ultrasound to get it checked. The ultrasound was inconclusive; the mass seemed to have definitive borders, which was a bad sign, but they could not tell about blood flow. A biopsy was needed to tell if it was malignant or simply scar tissue, and the results would come in a couple of days. I was nervous, of course; the possibility of cancer seemed more real this time since it had happened before, but I still could not believe it actually would be. I tried to rationalize that I had done "the kitchen sink" approach to treatment the first time around, which my doctors had said gave me a good chance of staying cancer free, so how could it have come back so quickly?

I got the call two days later with the news that the biopsy had indeed come back as cancer. Although logically I had known cancer was a potential outcome, I was just as surprised this time as I had been at the initial diagnosis. Treatment, which once again involved surgery, radiation, and chemotherapy, was not as scary this time around since I knew more what to expect, but it was psychologically and emotionally worse. I became depressed and hopeless, it felt like I would never truly be rid of cancer; I was also anxious, a bit paranoid a new lump or symptom of metastases would appear any day. I never considered myself a pessimist, but I definitely felt fatalistic with the recurrence.

**Survivorship.** It has now been a year and a half since I finished treatment and was declared to be in remission for a second time. Initially, I was leery of getting back to "normal"

life, fearing the cancer would come back again just when I was back on track. However, as my hair grew longer and my energy levels increased, it was clear I could not let fear of cancer continue to have a hold on me. I am still in care with a psychiatrist to help me accept my "new normal" and I still get a little bit of "scanxiety" when I am due for follow-up imaging, but ultimately I feel good about being a cancer survivor.

Analytical Insights. The majority of the analysis for this dissertation was done during and after my own experiences with cancer, which provided for a unique lens through which to interpret the results. First, experiencing my own major diagnosis gave me greater insight into the feelings and concerns women who are diagnosed with HIV might feel. At the same time, I now know how difficult it is to speculate on how one would feel or how life would change after another major diagnosis. The stages identified by Baumgartner and David (2009) are all too familiar, and I realize too that incorporating a major diagnosis into one's self-identity is not a linear process. Also, I could certainly empathize with the case studies presented by Aranda-Naranjo and colleagues (2005). When facing a recurrence, I worried I would not be able to get through another diagnosis and more cancer treatment, and I was torn between knowing I had gotten through it before and feeling greater emotional distress.

Second, I can attest firsthand to the benefits of religion in coping with a crisis. My beliefs did not lead to religious fatalism, I engaged in standard treatment recommended by my doctor, but I benefitted from knowing people were praying for me and from having a higher power to lean to and trust. I also received tangible and emotional support from my church family, in the form of meals, hospital visits, cards, etc. Third, fatalistic beliefs may occur over time, as setbacks and challenges are encountered. I certainly found this to be true after my recurrence and with trying to get back into a normal life routine. In a way, it feels like a loss of innocence; I know it is possible to have a life-altering diagnosis come out of nowhere because I have already experienced it. The difficulty for me has been not letting the worry and anxiety take over and keep me from enjoying life. The professional mental health care I have received has provided the most benefit. While I have a lot of social support through family and friends, I often felt like I was not meeting their timeline for "moving on", whether they felt that way or not. My feelings of inadequacy, thinking I was not living up to others' expectations, made me feel increasingly isolated and hyper-aware of where I *should* be.

The journey to completing this dissertation has been longer and more arduous than I would have ever imagined. When it started, it seemed simple and straightforward, examining facilitators and barriers of Pap test screening among HIV-positive women in the Mid-South. However, the findings from this study as well as the relative published literature demonstrate how complex these facilitators, barriers, and their relationships with each other really are. Experiencing a cancer diagnosis firsthand helped me to realize this as well, and gave me a unique insight for interpreting the results.

## **CHAPTER 3: RESULTS**

# **Sample Population**

# **Demographics**

A total of 19 women participated in interviews for this study from May 2014 through May 2015. The women ranged in age from 25 to 45 years old, with the mean age being 35. All of the women were African American, HIV-positive, and resided in Shelby County, TN. More than two-thirds of the women were renting the home they lived in, 15% indicated they were staying in a shelter, 10% were staying with family or friends, and 5% owned their home. When asked their current relationship status, nearly two-thirds of the women said they were single, just over a quarter were married or living with their partners, and 10% were separated or divorced. Table 1 details the demographic characteristics of the participants.

Age	Ν	%	
25 - 29	4	21.1	
30 - 34	4	21.1	
35 - 39	6	31.5	
40-45	5	26.3	
Race			
African American	19	100	
County of Residence			
Shelby Co, TN	19	100	
Living Arrangements			
I own the home I live in	1	5.3	
I rent the home I live in	13	68.4	
I am staying with family/ friends	2	10.5	
I live in a shelter	3	15.8	
Relationship Status			
Single	12	63.2	
Married/ Living with Partner	5	26.3	
Separated/ Divorced	2	10.5	

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1 1101	e 1.	Demograph	$m u \cup n$	urucierisiics
The majority of the participants had less than a high school education, less than one-third had attended some college or vocational school, 20% had completed high school or a GED, and only two participants had completed college or graduate school. Over half of the women indicated they were unemployed and looking for work, just over 20% were working full-time, 15% were unemployed and not looking for work, one participant was working part-time, and another indicated she was working as a volunteer. Two of the participants who said they were unemployed added they were on disability. Two-thirds of the sample population said their annual household income was less than \$10,000, and the average annual income fell somewhere between \$10,000 and \$20,000. Nearly three-quarters of the women indicated they receive TennCare/ Medicaid insurance, four of the women were covered by private health insurance, three received Medicare, and one said she had no health insurance coverage. Ninety percent of the participants were enrolled in the Ryan White program. Table 2 provides a summary of participants' socioeconomic characteristics.

Education	Ν	%
Less than High School	7	36.8
High School or GED	4	21.1
Some College or Vocational School	6	31.6
College Graduate (Bachelor's)	1	5.3
Graduate Degree	1	5.3
Employment		
Working Full Time	4	21.1
Working Part Time	1	5.3
Unemployed (Looking for Work)	10	52.6
Unemployed (Not Looking for Work)	3	15.8
Other - Volunteering	1	5.3

Table 2. Socioeconomic Characteristics

Household Income	Ν	%
\$0 - \$5,000	6	31.6
\$5,001 - \$10,000	6	31.6
\$10,001 - \$15,000	1	5.3
\$15,001 - \$20,000	1	5.3
\$20,001 - \$30,000	3	15.8
\$40,001 - \$50,000	1	5.3
Insurance		
Private Health Insurance	4	21.1
Medicaid/ TennCare	14	73.7
Medicare	3	15.8
No Insurance	1	5.3
Ryan White Program		
Yes	17	89.5
No	2	10.5

Table 2. Socioeconomic Characteristics Cont'd

# Religion

All of the participants identified themselves as affiliated with a religion. More than twothirds of the women identified as Baptists. Slightly more than 15% said they were nondenominational, 10% said other, and 5% said they were Church of God in Christ (COGIC). The two women who chose Other elaborated as African Methodist Episcopal (AME) and Pentecostal. All of the women felt religion was at least a little important in their lives, with the average between somewhat and very important, and closer to very important. Nearly 85% of the participants said religion was very important in their life, 10% indicated it was somewhat important, and 5% said it was a little important. Religious beliefs are detailed in Table 3.

Table 3. Religious Beliefs

What religion do you most identify with?	Ν	%
Baptist	13	68.4
COGIC	1	5.3
Non-Denominational	3	15.8
Other	2	10.5

Tuble 5. Religious Dellejs Cont u		
How important is religion in your life?	Ν	%
Not important	0	0
A little important	1	5.3
Somewhat important	2	10.5
Very important	16	84.2

Table 3. Religious Beliefs Cont'd

### **Health and Healthcare**

As previously mentioned, being HIV-positive was part of the eligibility criteria for this study, and all of the participants met this condition. None of the participants were newly diagnosed with HIV, actually all had lived with their diagnosis for more than 7 years, with the years since diagnosis ranging from 7 to 38 years (mean = 16.4 years). Only two of the women had ever been diagnosed with AIDS. Three-quarters of the participants indicated they went to the doctor immediately after being diagnosed with HIV, and another 10% went within 6 months of being diagnosed. Only three of the women said they waited more than a year to go to the doctor after being diagnosed with HIV. Regarding their HIV care now, all of the women indicated they were actively in care, seeing their doctor between one and four or more times in a twelve-month period. Over half saw their HIV provider at least 3 times in the past year.

All of the women in this study had gotten a Pap smear done in the last three years, and all of the women indicated their most recent Pap smear had occurred between 2013 and 2015. Nearly 85% of the women had ever had an abnormal Pap smear. Fortunately, all of these women followed up with their doctors within a year of their abnormal Pap smear, with 63% indicating they followed up immediately and 16% saying they followed up within 6 months. Just under half of the women had ever been diagnosed with HPV, but only about 20% had been diagnosed with pre-cancerous cells in their cervix. Slightly more than one-third of the sample had received the

HPV vaccine. Table 4 describes the participants' health characteristics as they relate to HIV and

Pap test screening.

HIV Status	Ν	%
HIV-Positive	19	100
Years Since HIV Diagnosis		
7 – 10 Years	4	21.1
11 – 15 Years	6	31.5
16 – 20 Years	4	21.1
21 – 25 Years	4	21.1
36 – 40 Years	1	5.2
Ever Diagnosed with AIDS		
Yes	2	10.5
No	17	89.5
Time to Follow-Up after HIV Diagnosis		
Immediately	14	73.7
Within 6 Months	2	10.5
Longer than 1 Year	3	15.8
HIV Care in the Past 12 Months		
1 Time	4	21.1
2 Times	2	10.5
3 Times	10	52.6
4+ Times	3	15.8
Most Recent Pap Smear		
2013	5	26.3
2014	12	63.2
2015	2	10.5
Ever Have an Abnormal Pap Smear		
Yes	16	84.2
No	3	15.8
Time to Follow-Up after Abnormal Pap Smear		
Immediately	12	63.2
Within 6 Months	3	15.8
Within 1 Year	1	5.3
Ever Diagnosed with HPV		
Yes	8	42.1
No	10	52.6
Don't Know	1	5.3

Ever Diagnosed with Pre-Cancerous Cervical	Ν	%
Cells		
Yes	4	21.1
No	14	73.7
Don't Know	1	5.3
Ever Received an HPV Vaccine		
Yes	7	36.8
No	11	57.9
Don't Know	1	5.3

Table 4. Health Characteristics Cont'd

# **Knowledge of Pap Testing**

As discussed previously, all participants completed Breitkopf et al.'s (2005) Knowledge of Pap Testing Survey during their interview sessions. The knowledge test covered four topics: Purpose of the Pap Smear, Symptoms of an Abnormal Pap Smear, Abnormal Pap Smear Results, and Abnormal Pap Smear Follow-Up Care. Each correct response earned a 1, while incorrect or unknown responses were given a 0. Higher scores indicated higher knowledge, with a perfect score being 20; the overall average knowledge score in this sample of women was 12.3.

### **Purpose of the Pap Smear**

Overall, the women were fairly knowledgeable about the purpose of the Pap smear. More than 40% of the participants got four or five of Purpose-based questions correct. Slightly more than one-third of the women correctly answered two or three of the statements. Twenty percent correctly answered only one question or got them all wrong. The average score was 2.84 out of a possible 5.

More than three-quarters of the women correctly said the purpose of the Pap smear is to scrape cells to look for cancer and just under three-quarters knew that the purpose is not to test for sexual disease. Approximately half of the participants correctly said the purpose of the Pap smear was not to treat cancer. Forty two percent knew the purpose of the Pap smear was not to check ovaries. Slightly more than one-third correctly answered that the purpose of the Pap smear was not to test urine. A detailed breakdown of the Purpose of the Pap Smear sub-scale scores is provided in Table 5.

 Table 5. Purpose of the Pap Smear Sub-Scale

Question (Correct Response)	Correct N (%)	Incorrect N (%)
The purpose of the Pap smear is to		
Check your ovaries (False)	8 (42.1)	11 (57.9)
Scrape cells to look for cancer (True)	14 (73.7)	5 (26.3)
Treat cancer (False)	10 (52.6)	9 (47.4)
Test for sexual disease (False)	15 (78.9)	4 (21.1)
Check your urine (False)	7 (36.8)	12 (63.2)

# Symptoms of an Abnormal Pap Smear

As with the purpose of the Pap smear, the women were fairly knowledgeable about the symptoms of an abnormal Pap smear. Nearly two-thirds of the participants answered at least four of these questions correctly, and more than 20% answered all six right. More than one-third of the women got half or fewer of the questions correct, and 10% answered all of the questions incorrectly. The mean score was 3.68 out of 6.

More than three-quarters of the women correctly stated that unusual vaginal spotting or bleeding was a symptom of an abnormal Pap smear, and nearly three-quarters indicated that genital warts were a possible symptom of an abnormal Pap smear. Almost two-thirds of the participants correctly indicated that both vaginal itch or irritation and pain with sexual intercourse were not symptoms of an abnormal Pap smear. Less than half of the women were correct in saying that a frequent need to urinate was not a symptom of an abnormal Pap smear, and even fewer, slightly more than 40%, correctly indicated that symptoms of an abnormal Pap smear may be unnoticeable or there may be no symptoms. Table 6 shows the knowledge scores

for the Symptoms of an Abnormal Pap Smear sub-scale.

Question (Correct Response)	Correct N (%)	Incorrect N (%)
Symptoms of an abnormal Pap smear are		
Vaginal itch/ irritation (False)	12 (63.2)	7 (36.8)
Pain with sexual intercourse (False)	12 (63.2)	7 (36.8)
A frequent need to urinate (False)	9 (47.4)	10 (52.6)
Unnoticeable/ no symptoms (True)	8 (42.1)	11 (57.9)
Unusual vaginal spotting/ bleeding (True)	15 (78.9)	4 (21.1)
Genital warts (True)	14 (73.7)	5 (26.3)

Table 6. Symptoms of an Abnormal Pap Smear Sub-Scale

### **Abnormal Pap Smear Results**

The women did the worst on answering questions about what to do if a Pap smear result came back abnormal; none of the women got all of the questions correct. In fact, more than two-thirds only got half of the questions right. Slightly more than 20% got three of the four questions correct, and 10% got one questions correct. The average score was 2.11 out of 4 possible points.

All of the women knew they should tell their partner if they had an abnormal result on a Pap smear, and nearly 90% correctly indicated more frequent Pap smears may be needed after an abnormal Pap smear result. However, only 10% correctly answered that an abnormal Pap smear result does not mean cancer or that the problem could go away on its own. Table 7 describes participants' knowledge of abnormal Pap smear results.

Table 7. Abnormal Pap Smear Results Sub-Scale

Question (and Correct Response)	Correct N (%)	Incorrect N (%)
If you have an abnormal result on the Pap		
test		
You should tell your partner (True)	19 (100)	0 (0)
It means you have cancer (False)	2 (10.5)	17 (89.5)
The problem could go away on its own (True)	2 (10.5)	17 (89.5)
You may need more frequent Pap smears (True)	17 (89.5)	2 (10.5)

## **Abnormal Pap Smear Follow-Up**

Knowledge about follow-up after an abnormal Pap smear was fairly high, which may be related to the fact that many of the women had had abnormal Pap smear results themselves. More than 40% answered all of the questions correctly, and another quarter only got one question incorrect. Ten percent of the women got three out of the five questions correct. Slightly more than 20% of the participants answered only one of the questions correctly or answered none of the questions correctly. The total points possible was 5, and the mean score was 3.63.

However, each individual question was answered correctly by a fairly high portion of the participants; in fact, the lowest score still had almost two-thirds of the women answering correctly. Just less than two-thirds knew that follow-up after an abnormal Pap smear did not involve blood tests. Slightly more than two-thirds indicated follow-up after an abnormal involved colposcopy. Nearly three-quarters of the women correctly said follow-up for an abnormal Pap smear can involve both biopsy and HPV testing. Approximately 85% of the participants indicated that follow-up after an abnormal Pap smear often involves another Pap smear. The women's knowledge of follow-up care after an abnormal Pap smear result is provided in Table 8.

Question (and Correct Response)	Correct N (%)	Incorrect N (%)
Follow-up for an abnormal Pap smear can		
involve		
A blood test (False)	12 (63.2)	7 (36.8)
Biopsy (True)	14 (73.7)	5 (26.3)
Another Pap smear (True)	16 (84.2)	3 (15.8)
Colposcopy (True)	13 (68.4)	6 (31.6)
HPV testing (True)	14 (73.7)	5 (26.3)

Table 8.	Follow-	Up Care	e Sub-Sca	le
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# **In-Depth Interviews**

# Health Belief Model

Previous studies have used the HBM as a means of understanding screening behaviors,

including Pap test screening. This study aimed to not be limited to an existing public health

theory, but did use the central constructs of the HBM (Behavioral Perceptions, Perceived Threat,

and Cues to Action) as a starting point for the grounded theory approach. Table 9 summarizes

key points and representative statements based on the HBM constructs.

Construct	Theme	<b>Representative Statement</b>
Perceived Benefit	Taking Care of One's Self	"Just, it's good to get one now, even if I'm not
		having sex with anybody, I still feel like I should
		go get one, just to be on the safe side."
		[Age 25, Some College]
	Basic Part of Women's	"Just because it's something that women should
	Health	do."
		[Age 27, Some College]
	Knowing What's Going	"I want to know what's going on down there. I
	On With Your Body	can't speak for everybody, but I think everybody wants to know what's going on with their own
		vagina."
		[Age 36, Less Than High School]
	Early Detection	"I think you can know what's going on with
		your body, and, if there's a chance for cervical
		cancer or anything, that maybe they will catch it
		early, so they can do whatever they got to do so
		it won't spread or it won't be as deadly as most
		people who don't take Paps."
	Madiana (ad Das Durasiana	[Age 33, Some College]
	Motivated By Previous	I would rather them do whatever they need to
	Abramal Day Smaar)	do so we can figure out why the Pap was
	Abnormal Pap Smear)	abnormal, as opposed to just waiking around
		[A co 25. Lich School Croducto]
Demosived	Dain and Dhysical	[Age 55, High School Graduate]
Perceived	Pain and Physical Discomfort	It's just too painful for me. Like being raped is
Darriers	Disconnon	what it reels like, someouty is just, like,
		Invacing my privacy and it's just nun un.
		[Age 25, Some Conege]

 Table 9. HBM Constructs and Related Responses

Perceived	Embarrassing and	"It's, I mean, of course it's a little uncomfortable
Barriers	Awkward	because you got somebody you don't know, you
Cont'd		know, in your private area."
		[Age 41, Less than High School]
	Fear of Bad News or	"Just a little bit freaked out because, I don't
	Another Diagnosis	know, no more initials, you know? I got
	-	enough."
		[Age 35, High School Graduate]
	Intimidating	"I just hate it. It's just uncomfortable and I hate
		everything, I hate everything about it. I hate the
		instruments, I hate sitting up there, I hate the hot
		light. I just hate the whole thing."
		[Age 33, Some College]
	Not a Priority	"I think the barrier would be, especially in the
		African American community, it just really isn't
		of high importance, you know? I think we are
		the barriers, I mean, self is the barrier, because
		the service is there, it's accessible."
		[Age 35, High School Graduate]
	Few Logistical Barriers	"Transportation, gas is high right now. That is
		always an issue, but as far as I'm concerned, I
		can always call the number for transportation on
		my medical card, so that is not an issue, getting
		to the doctor for me."
		[Age 44, High School Graduate]
	No Barriers	Um, I don't, I don't see any barriers. There's
		nothing hard about getting it."
		[Age 27, Some College]
Perceived	HIV Increases Risk	"In my mind, HIV makes me more vulnerable to
Susceptibility		other things, so now I'm learning to stay on top
		of everything." [Age 35, 2001 HIV Diagnosis,
	Durani and Altan and al Dan	Previous Abnormal Pap Smear]
	Previous Abnormal Pap	The abnormal pap smear opened my eyes to
	Smear	ake more, taking better care of mysell. [Age
		25, 2011 HIV Diagnosis, Previous Adhorman
	Not Poing Screened	r ap Silical] "I mean the needle who will be more at right are
	Not being Screened	the women who don't go to the destor and got
		Pap smears. That is very important because you
		won't even know if you have HDV or not if you
		don't go get a Pan smear " [ $\Delta$ ge 28 2004 HIV
		Diagnosis Previous Abnormal Pan Smearl
		Diagnosis, i tovious Autoiniai i ap Silicai

# Table 9. HBM Constructs and Related Responses Cont'd

Perceived Susceptibility Cont'd	Lifestyle Choices Family History of Cancer	"They are more at risk if they are, if they're not taking care of themselves as far as eating habits and smoking, drinking, doing drugs, and things like that. But then on the other hand, they're not at risk if they're not doing those things," Age 44, 2006 HIV Diagnosis, No Abnormal Pap Smear "Cancer runs in my family so they check me extremely careful. If cancer runs in your family, you're probably more at higher risk then, you know, like another." [Age 41, 1993 HIV Diagnosis, Previous Abnormal Pap Smear]
Perceived Severity	More Testing after Abnormal Pap Smear	"They have to get like a biopsy, they have to get a colposcopy or something like that." [Age 28, Previous Abnormal Pap Smear, Received Follow-Up Care Immediately]
	Early Detection Important for Treating Cervical Cancer	"Like I said, from what I've heard thus far, the earlier it's detected, you know, the earlier they can treat. I think once it's untreated, then it can cause other things, even death. It may not be curable, but it's treatable." [Age 35, Previous Abnormal Pap Smear, Received Follow-Up Care within 6 Months]
	Oncology Treatments (Chemotherapy, Surgery, Radiation)	"I think that they either have to have a hysterectomy or have to get chemotherapy or will go through those treatments. I don't necessarily think cervical cancer, I don't think, is the leading cancer that causes women's death." [Age 35, Previous Abnormal Pap Smear, Received Follow-Up Care Immediately]
	Would Handle Cervical Cancer Diagnosis Like HIV	"Really it wouldn't affect me no more than what's already going on, I just want to make sure it's something that can get treated and don't get worse. It would mean I have to get myself checked more often." [Age 27, Previous Abnormal Pap Smear, Received Follow-Up Care Immediately]
	Cervical Cancer Diagnosis Would Lead to Depression	"I'd probably be devastated. I'd probably just go down and just, I already don't have a lot of friends, but the few friends I have, my coworkers, I'd probably quit working and just stay home." [Age 25, Previous Abnormal Pap Smear, Received Follow-Up Care Immediately]

# Table 9. HBM Constructs and Related Responses Cont'd

Cues to	Healthcare Provider	"Normally the doctor'll ask me at my visits since
Action		I see her so often, and she'll be like, 'Is it time?'
		or take a look in my chart, and normally they'll
		tell me when it's time for my Pap and then do it
		there in the office so I don't have to see a
		separate doctor or anything to get my Pap."
		[Age 35, Some College]
	Reminder Call from	"One thing that I have noticed with the medical
	Doctor's Office	people, that they have started emailing patients
		now about their appointments or they will have
		their nurses make calls to the patients to remind
		them that they have an appointment."
		[Age 44, High School Graduate]
	Personal Calendar	"I usually like to have a visual where I can see
	Reminders	my appointment on the calendar or have it in my
		cell phone to notify me when it's time to go to
		the doctor."
		[Age 44, High School Graduate]
	Certain Time of Year	"Well, for me, I just know that I was diagnosed
		with HIV in June so I know around that time of
		year I have to get a Pap."
		[Age 33, Some College]
	Symptoms	"And then like, if I feel like I'm itching or
		burning or something down there, I can just
		always walk in the doctor and tell them I need to
		see the nurse and then they'll, I'll tell them
		what s wrong and then I can get a Pap smear
		even when it ain t time for me to get a Pap
		smear.
		[Age 41, Less 1 nan High School]

# Table 9. HBM Constructs and Related Responses

# What psychosocial, cultural, contextual, and organizational factors influence

# HIV-positive women's engagement in cervical cancer screening?

# **Psychosocial Factors**

General Lack of Knowledge. Insights from the interviews largely reflect the findings

from the Knowledge of Pap Testing survey administered with the Participant Questionnaire.

Overall, the women had limited knowledge of Pap smears, often misunderstanding its purpose,

what it tests for, and what the results mean. "I don't know if I need the Pap smear or what the Pap smear does and everything," [Age 38, Some College]. Several of the women seemed to equate it with testing for sexually transmitted diseases in general. For instance, one participant said, "Yeah, so I had to take a Pap, and they take, they called me within three days letting me that I had gonorrhea, and I knew there was something because when I peed, it was burning," [Age 41, Les than High School]. However, this misinformation did not appear to keep the women from following through with Pap test screening. Although they were not entirely sure about the purpose of the Pap smear, the participants still saw it as a basic part of women's health.

**Benefits Outweigh Barriers.** While they may not have had detailed knowledge about the purpose of the Pap smear, the participants felt the benefits of Pap smears outweighed the barriers. The most common barrier, mentioned by 13 of the 19 participants, was pain. One woman went so far as to compare the pain and physical discomfort of a Pap smear to rape, saying, "Like being raped is what it feels like, somebody is just like invading my privacy and it's just... nuh uh," [Age 25, Some College].

In addition to physical pain, emotional discomfort was discussed as well, particularly the embarrassment and awkwardness of having a relative stranger "down there". Still, although the women did not enjoy the experience, they felt staying healthy and knowing what is going on with their bodies was worth the pain. One woman put it this way, "I think I'm more willing to get one now than I was before, because I hate taking Pap smears, I hate the whole thing, but I know it'll help my health and, if something's going wrong, they'll find out," [Age 33, Some College].

Another emotional barrier to having a regular Pap smear could be the fear of bad news or another diagnosis in addition to HIV. This type of fear is not uncommon among people who have already faced difficult diagnoses, whether HIV, cancer, or a chronic illness. The women in this study appreciated this issue: "Me, myself, my mind; afraid that it might come out abnormal would be the reason why, me thinking that there is going to be something wrong would be the only reason I wouldn't go get it," [Age 25, Some College]. However, they also recognized the importance of early detection if something is found; one participant summed it up this way, "Well, my feelings about the Pap smear basically is, they are looking for something, to help keep me healthy, that is the main thing and that is the reason why I go and get it… Benefits to it are preventative measures, mostly in making sure that everything is intact and the way it needs to be with the family body, and if anything does come up, it's caught in time for treatment," [Age 44, College Graduate].

Interestingly, few traditional logistical barriers to care were mentioned by participants. While some acknowledged that transportation could be an issue, they were aware of available resources to use or, worst case, said they would reschedule. "Transportation, gas is high right now. That is always an issue, but as far as I'm concerned, I can always call the number for transportation on my medical care, so that is not an issue, getting to the doctor for me, getting picked up from the doctor's office is not an issue as far as transportation is concerned," [Age 44, High School Graduate]. A couple of women specifically brought up issues of access related to insurance and availability, but felt there were enough clinics offering the service to keep it from being a problem anymore. For the women in this study, maintaining their health, keeping up with medical care, and early detection of any issues, all of which they saw as benefits to regular Pap test screening, were highly important, and overshadowed any physical, mental, or logistical barriers.

### **Cultural Influences**

Limited Role of Social Support. Most of the women indicated they did not discuss Pap smears with anyone outside of healthcare professionals, but if they did talk to anyone else, it was their partner. The reason given for this was that things related to Pap smears are too personal to talk about with family and friends. "Huh uh, nobody but my doctor. Because it ain't nobody's business but my doctor, me and my doctor. Whatever goes on, yeah, me, my doctor, and my partner," [Age 41, Less than High School]. Actually, the same was true for other types of screenings as well; the participants knew about those from medical providers, or maybe from television advertisements or the internet. While talking about it, one participant seemed to realize how heavily she relied on her doctor, saying, "My doctor, she always, you know, about the glucose and the diabetes class, she's always the one that, because she checks for everything, so she's always the one that kind of keeps me abreast of the screenings I should have, the vaccines I should have, so I just, it's sad to say, but I just completely 100% trust her to kind of keep me healthy," [Age 35, High School Graduate].

However, most participants described having a strong support system, maybe not large in number but close-knit. These were family members, such as parents, siblings, significant others, or even children, and friends, and they were very encouraging of the women to stay on top of their health, especially with regard to HIV. "My family. My family and my fiancée, they're very supportive. They tell me, um, 'I'm proud of you', 'you're doing good', 'keep taking your medicine', 'keep going to the doctor and let me know what's going on with you,'" [Age 41, Less than High School].

It would appear then that the issue is not a lack of social support related to Pap test screening, but rather that it plays a limited role, even while support is provided for HIV and overall health. One participant expressed this sentiment well when she said:

"So I have a team as far as that's concerned, as far as just overall general health and trying to keep myself healthy, lose some weight, try to lower my glucose levels, stuff like that. But I don't know, I just don't, I'm sure if I tell them about the Pap smear, they'll probably remind me of that too, I just think some things are a little too personal. Like we can talk about the weight, but we're not going to talk about that it's time to check my vagina, now I don't want to talk about that so..." [Age 35, High School Graduate].

Participants were asked specifically if their church offered any support in regards to their health, and Pap test screening in particular. Not surprisingly, churches did not discuss or provide information on HPV, cervical cancer, or Pap smears, even if they offered health fairs or had other forms of health ministries. "Not really, you know, they may have a health fair every now and then, but they tend to steer away from a lot of stuff, so truth be told, and they did a health fair just a couple of months ago, I don't remember seeing nothing about Pap smears or the importance of Pap smears," [Age 35, High School Graduate]. Some churches did have prayer ministries and make hospital and home visits to sick people in need. "They do, they send prayers to the peoples who's been in the hospital or been sickly or whatever," [Age 41, Less than High School].

**Disconnect Between Health and Spirituality.** Although results from the participant questionnaires indicated most of the women, nearly 85%, felt their religious beliefs were very important to them, many did not see the connection between these beliefs and their health, seeing them as two separate, even opposing, aspects of their lives. Many of the women discussed

believing in the healing power of prayer: "I mean, I pray all day, every day, whew, man, it ain't a word that don't come out of my mouth that doesn't say 'Lord please, help me and give me strength'. I believe God is my higher power and He is the reason I am here. It ain't because of medicine, it was like some of the medicine, but it's because of Him I'm here," [Age 37, Less than High School]. While acknowledging belief in God's ability to heal and in the power of prayer, a few of the women had been able to reconcile these beliefs in conjunction with western medicine. One participant resolved it this way: "To me, I'm like, 'Yeah, that's right, faith without works is death,' and I do understand that I can't sit here and continue to pray to God about healing me from HIV or diabetes or whatever it is; I can sit here and pray about this diabetes all day, but what good is it if I'm praying about it and still eating a box of cupcakes?" [Age 35, High School Graduate].

Although it seems contradictory given they were generally engaged in medical care, some of the participants expressed a "Let go, let God" sentiment. "No, I just 'Let go, let God'. Let God, put everything in the Lord's hands and He's going to work it out," [Age 41, Less than High School]. This mentality emphasizes the distinction some participants saw between their health and their religious beliefs, which could be justification to some women for not engaging in traditional medical care. One woman recognized the dichotomy, saying,

"Well, if I went strictly by my religious beliefs, I would just completely rely on God to heal and fix everything, and don't get me wrong, I know He's able to do all things, but I also know that He blesses us with physicians and other people to help us keep a healthy us, so uh, I know people that use this certain scripture to apply to, you know, faith, uh, you're healed by His stripes. I don't doubt that, but I know if I don't, if I don't take this medication or if I don't get these different screenings, healing by the stripes is very irrelevant at that point, you know?" [Age 35, High School Graduate].

Still, a handful of participants did consider their faith to be motivation for staying healthy, including regular engagement in Pap test screening. "It helps me to stay positive. It's helped me to take my medicine. It's helped me to just get up, to just go and be motivated, it's motivation," [Age 36, Less than High School]. One participant said she owed it to God to keep up with her health because of all the good He had brought to her life: "The lifestyle that I used to live, and God done changed me from the inside out and changed my whole lifestyle, you know, I'm a true believe that only God did it, I didn't do it, so if he did this for me then why I can't do this for myself, keep myself health?" [Age 41, Less than High School].

# **Contextual Considerations**

**HIV as a Facilitator.** Half of the women said having HIV made them want to take better care of themselves, actually serving as motivation for them to keep up with annual Pap test screening. The women recognized the vulnerability associated with being immune-compromised due to HIV, and wanted to stay healthy. Additionally, as mentioned previously, the women saw Pap smears as a basic part of women's health and understood that early detection of a problem is better for treatment. "Yes, it makes me want one more frequently to keep, to make sure I'm healthy," [Age 41, 1999 HIV Diagnosis]. One participant admitted she did not keep up with cervical cancer screening before HIV: "And to be honest I didn't really start getting regular Pap smears until I became HIV-positive," [Age 35, 2001 HIV Diagnosis].

#### **Organizational Dynamics**

**Reliance on Healthcare Provider.** The women's healthcare providers largely served as the women's cue to action for Pap test screening. Nearly all of the participants had their Pap smears scheduled for them or incorporated into their routine HIV care appointments. "Normally she'll [the doctor] ask me at my visits since I see her so often, and she'll be like, 'Is it time?' or take a look in my chart, and normally they'll tell me when it's time for my Pap and then do it there in the office so I don't have to see a separate doctor or anything to get my Pap," [Age 35, Ryan White Participant, 3 Doctor Visits Per Year]. In addition, the doctor's office would call, text, or email to remind the women of their upcoming appointments a few days in advance, allowing them to easily confirm or reschedule if needed. "One thing that I have noticed with the medical people, that they have started emailing patients now about their appointments or they will have their nurses make calls to the patients to remind them that they have an appointment," [Age 44, Ryan White Participant, 3 Doctor Visits Per Year]. In short, the healthcare providers essentially served as Cues to Action for the women to engage in regular Pap test screening.

The women described having a good relationship with the doctor who performed their most recent Pap smear. Most of these providers were female and they were described as nice, informative, and helpful. They were concerned with the women's comfort, and explained the step-by-step process of the exam. "It was very comfortable, I like it that she explained to me what she was doing, um, you know, she, she kind of talked me through, you know," [Age 35, Ryan White Participant, 3 Doctor Visits Per Year]. Several of their women received comprehensive care through their healthcare provider, so their Pap smears were incorporated into their regular HIV appointments. There was an established, trusted relationship between patient and provider. "I mean, I wouldn't change, I wouldn't want to change because that's my doctor and I've been seeing her for awhile, so I'm comfortable with seeing her," [Age 41, Ryan White Participant, 3 Doctor Visits Per Year]. In terms of health, the providers were the participants' main source of social support, especially for sexual and reproductive health. At least one participant recognized this issue, vocalizing the sentiment this way: "Yeah, she [the doctor] reminds me, and I hate that because I know I'm supposed to be on top of it and I rely on her to remind me, be like, 'Hey, it's that time,' because am I really, really excited about the Pap smear? No," [Age 35, Ryan White Participant, 3 Doctor Visits Per Year].

#### Intersectionality

Public health issues never occur in a vacuum, and this study sought to examine Pap test screening among HIV-positive women in the Mid-South through psychosocial, cultural, contextual, and organizational lenses. The major themes identified within each socioecological layer have been described, but it is also necessary to consider how they interact together. The participants in this study were engaged in regular Pap test screening, just as they kept up with their HIV care. In fact, the two were often done in conjunction with each other, and in partnership with an established, trusted healthcare provider. Not only did the women rely on their doctors to schedule their appointments, but they also kept these appointments largely in following doctors' orders. While they knew of Pap test screening as an important part of women's healthcare, they lacked specific knowledge of the relationships between HPV, cervical cancer, and Pap smears; however, this did not keep them from complying with current guidelines. Being HIV-positive seemed to have a large influence on this compliance because the women recognized their increased vulnerability from being immune-compromised and so were motivated to keep up with preventive healthcare measures. From this perspective, the benefits of Pap test screening far outweighed its disadvantages.

#### **CHAPTER 4: DISCUSSION**

This study aimed to answer two research questions: 1.) What psychosocial, cultural, contextual, and organizational factors influence HIV-positive women's engagement in cervical cancer screening? and 2.) How do these factors intersect with each other to affect HIV-positive women's engagement in cervical cancer screening? Through one-on-one interviews, participants discussed their thoughts on and experiences with cervical cancer screening, with a demographic questionnaire and knowledge survey providing background information. Several interesting themes across multiple socioecological levels emerged from the data, including the factors that guided women's engagement with Pap test screening. In addition to identifying such facilitators and barriers, this research also attempted to examine their interactions.

#### What psychosocial, cultural, contextual, and organizational factors influence

# HIV-positive women's engagement in cervical cancer screening?

#### **Psychosocial Factors**

Psychosocial questions for the one-on-one interviews asked participants about their personal experiences with Pap test screening and were based on constructs from well-known public health theories, such as the HBM. The HBM is a good and stable predictor for both screening and treatment behaviors because it considers both perceptions of disease as well as beliefs about health behaviors, rather than just one or the other, to be motivators for taking action (Carpenter, 2010; Tanner-Smith & Brown, 2010). Drawing from the HBM, the women in this study were asked what advantages and disadvantages, benefits and barriers exist to engaging in Pap test screening for themselves and women in general. They also discussed how much they worry about cervical cancer, how an abnormal Pap smear or cervical cancer diagnosis would impact their life, and what cues trigger or remind them to get a Pap smear.

**Knowledge.** Although knowledge alone does not motivate people's decision-making, it does lay the foundation for beliefs and perceptions; thus, it is generally considered necessary but not sufficient for motivating a particular health behavior (DiClemente, 1989; Fisher & Fisher, 1992). In the present study, participants' knowledge of Pap test screening and its relationship to HPV and cervical cancer were assessed through both Brietkopf et al's (2005) Knowledge of Pap Screening survey and interview discussions. Much of the literature, regardless of the sample being studied, suggests women have limited knowledge regarding HPV, cervical cancer, and Pap test screening (Daley et al., 2013; Friedman & Shepeard, 2006; Kobetz et al., 2010; Montgomery et al., 2010; Mosavel & El-Shaawari, 2007; Nardi et al., 2016; Nolan et al., 2014). This finding is consistent throughout the research, with little to no disparities found among different age, race, or socioeconomic groups.

In Brietkopf et al's (2005) research validating the measure used in this study, the average score for the entire sample of 338 Texas women was 8.7 out of a possible 20. Breaking the average scores down by race, White women scored the highest with 10.2, African American women were next 8.4, and Hispanic women scored the lowest with 7.4. Interestingly, scores did not differ based on Pap screening history, but lower socioeconomic status was associated with a lower score. The women in the current study were African American and low income, but had an overall mean score of 12.3, higher than any average in Brietkopf et al's study (2005). Comparing the women in this study with African American women in Brietkopf et al's study (2005), the same was true of the Purpose and Symptoms subscores, with means being 2.8 vs 1.7 and 3.7 vs

2.1, respectively. However, the participants in Brietkopf et al's (2005) study scored higher on the Abnormal Pap Smear subscore than did the women in this study, 2.5 vs 2.1. Brietkopf and colleagues (2005) did not report scores for the Follow-Up subscale. The women in the two studies were similar, but the participants in the present study were likely more aware of their health and motivated to gain health-related knowledge given their HIV status.

In their meta-analysis, Wong and colleagues (2018) found that inadequate knowledge of HPV transmission and cervical cancer prevention were common among women living with HIV. Although the women in the study presented here also had limited knowledge on the subject, it did not appear to keep them from engaging in regular Pap test screening. At least one other study has reported this same phenomenon, and found knowledge to be positively correlated with self-efficacy and benefits, while having a negative relationship with perceived barriers (Lambert et al., 2015).

**Benefits versus Barriers.** For the women in this study, the leading benefit of engaging in Pap test screening was staying on top of their health and knowing what was happening with their body; conversely, the most commonly mentioned barrier was pain, both physical and emotional. The issues of physical pain and emotional discomfort associated with Pap test screening are not unique to HIV-positive women (Duffett-Leger et al., 2008). Beyond simply identifying perceived benefits and barriers to Pap test screening, the findings in this study also demonstrated that the pain and discomfort associated with Pap smears does not necessarily keep women from engaging in this screening behavior. This notion has been previously demonstrated in a study of HIV-positive women in Texas; in their study, Fletcher, Buchberg, and colleagues

(2014) found that pain was described as the primary barrier to Pap smears and subsequent testing, but that nearly 80% of their participants still had a Pap smear in the last year.

Regarding emotional discomfort, one of the most salient descriptions from a participant in this study was the comparison of the Pap smear to being raped. While this may simply be hyperbole, it nevertheless raises concern that screening examinations may actually be traumatic for patients. In a study of the experience of a Pap smear among women with a history of trauma or abuse, all but one indicated having an emotional response during the exam (Ackerson, 2012). Specifically, the perception of being "forced" to have the test, undressing, putting feet in stirrups, and insertion were the most traumatic aspects of the test. However, many attempted to control their emotions and still receive a Pap smear versus one-quarter who stated they avoided Pap test screening altogether. Also interesting, almost none of the participants had discussed their previous trauma with their doctor. The issue of emotional discomfort is particularly concerning for women living with HIV/AIDS because they may be at greater risk than the average woman of experiencing intimate partner violence (Phillips et al., 2014). Lichtenstein (2005) found the women in his study attributed intimate partner violence to their acquisition of HIV.

Participants in this study also discussed the fear of having some type of diagnosis, whether an abnormal result, HPV, or even cervical cancer, and this on top of already being diagnosed with HIV. As mentioned previously, this concern is not unique to HIV-positive women; fear of an undesirable result is common for any test, and especially for those who have already faced a difficult diagnosis (Aranda-Naranjo et al., 2005; Nolan et al., 2014; Studts, Tarasenko, & Schoenberg, 2013). While fear of an abnormal Pap test result or another diagnosis certainly existed, participants in this study still recognized the importance of early diagnosis for treatment and best outcomes.

Oftentimes, barriers to Pap test screening are logistical in nature, such as transportation, cost, accessing care, etc (Andrasik et al., 2008; Daley et al., 2013; Studts et al., 2013). However, these traditional barriers were generally non-issues for participants in this study. This could be related to the large proportion of the sample who were enrolled in the Ryan White program, which provides medical case management, comprehensive care, primary care coverage, and transportation, among other services. Multiple studies have demonstrated the efficacy of the services provided by the Ryan White program, which directly translates to improved HIV outcomes (Diepstra et al., 2016; Hirschhorn et al., 2009; Irvine et al., 2014; Lopez, Shacham, & Brown, 2018). However, Ryan White participants may still have unmet needs; one study found that 90% of women, compared to 76% of men, received medical case management through Ryan White and two-thirds of all participants had access to a directory of services and resources, but nearly half of the participants still had at least one unmet need, with the top four being dental care, housing, transportation, and food (Kenagy et al., 2003). Similarly, the 2012 Comprehensive Needs Assessment for the Memphis TGA found 43% of PLWHA had an unmet need related to comprehensive medical care, with higher disparities in the rural versus urban counties (Pichon et al., 2012).

#### **Cultural Influences**

Culture is a shared system of values, beliefs, behaviors, social patterns, and other customs, and has a significant impact, whether consciously or subconsciously, on an individual's health (Steele-Moses et al., 2009). An individual's social network describes their system of relationships and social support, both their characteristics and functions (Heaney & Israel, 2008). The one-on-one interviews in this study asked participants to not only identify who they talk with about Pap smears, cervical cancer, HIV, and their health in general, but also what is said between them.

**Social Support.** There are many types of social support, from received and perceived (Dukel-Schetter & Skokan, 1990) to emotional, informational, and tangible (Cohen et al., 1985). This study largely focused on the latter, asking the women who talks to them and gives them information about health-related matters. Social support also comes from either formal sources, such as healthcare providers, or informal sources, including family and friends (Heaney & Israel, 2008). Most of the women in this study had a support system of informal sources in place to help them and encourage them with HIV care and their overall health. Social support on this level, however, had limited influence on the participants' engagement with Pap test screening because the subject was deemed too personal and intimate. Thus, the women relied more on formal sources of social support, specifically their healthcare providers, to discuss such matters.

Other studies have demonstrated similar findings, with social support having a borderline, minor, or mediating role on sexual health behaviors (Clum, Chung, Ellen, & The Adolscent Medicine Trials Network for HIV/AIDS Interventions, 2009; Documet et al., 2015). Nearly two-thirds of the participants in the study presented here indicated they were single, but some did mention discussing their gynecological health with their sexual partners, although the exact nature of these relationships was not necessarily known. The association between cervical cancer screening and marital status has been examined, with cervical cancer screening being significantly higher among married women (83.9%) compared to their never married (78.7%)

and divorced/ widowed/ separated (75.1%) counterparts (Hanske et al., 2016). Alternatively, other studies have shown that significant others may discourage women from having Pap smears because of jealousy, the intimate nature of the test, and abusive control (Leite et al., 2016; Phillips et al., 2014; Williams et al., 2015). More research is needed to determine the role significant others and sexual partners might have on influencing an HIV-positive woman's engagement with Pap test screening.

**Religiosity.** Religiosity is another important aspect of culture, especially for African Americans (Holt et al., 2017). As a construct, religiosity is multidimensional and encompasses both religion and spirituality, from the quantitative aspect of service attendance to more qualitative beliefs about the power of prayer (Szaflarski, 2013). In this study, the women were asked what religion, if any, they identify with and how important their religion is to them on the demographic questionnaire. They were also asked to discuss how their spiritual beliefs influence their health, including HIV status and Pap test screening, in the one-on-one interviews.

The women in this study had mixed feelings about if or how their religious and spiritual beliefs influenced their health. The literature on this subject is similarly mixed (Wigfall et al., 2012). For instance, in their prospective, long-term study of the association between religion and HAART adherence among HIV-positive patients at a San Diego clinic, Vyas, Limneos, Qin, and Mathews (2014) found those whose beliefs gave their lives meaning, connected them to a higher being and humanity, and influenced their recovery were more likely to achieve 90% adherence. In contrast, those who believed God created all things in the universe, that God will not His turn back on them, and who had higher attendance of religious services, were less likely to have 90% adherence. Qualitative studies have demonstrated that people living with HIV/AIDS for several

years see it as a spiritual journey, and that spirituality, rather than organized religion, can help with coping, provide social support, and decrease stress, pain, and depression (Dalmida et al., 2012; Emlet, Harris, Pierpaoli, & Fulotte, 2017; Slomka, Lim, Gripshover, & Daly, 2013). In their meta-analysis of religious beliefs and HIV, Szaflarski (2013) found spirituality to be multidimensional, having a direct influence on health and quality of life as well as mediating health behaviors, optimism, and social support; additionally, religious beliefs helped people living with HIV cope with stressors, particularly stigma and prejudice, in part through the power of prayer and meditation.

# **Contextual Considerations**

To fully understand the uptake of Pap test screening among African American, HIVpositive women in the Mid-South, the perspective from which the participants view the behavior must be considered. This context encompasses not only the physical, environmental qualities of a community, but also the social and cultural aspects (Berkman, 2009; Krieger, 2001). Stokols (1996) lists five potential roles of the environment in relation to health: Transmitter of Diseases, Stressor, Source of Safety or Danger, Enabler of Healthy Behaviors, or Provider of Health Resources. Specifically, this study sought to examine cervical cancer screening in the context of living with HIV.

**Fatalism.** Much of the literature indicates fatalistic beliefs related to chronic diseases, including HIV/AIDS, may disengage people from screenings and healthcare because they believe some negative outcome associated with the condition is inevitable (Eastwood et al., 2015; Hotz, 2015; Jones, Frohwirth, & Blades, 2016; Marlow, Ferrer, Chorley, Haddrell, & Waller, 2018; Steward, Koester, Myers, & Morin, 2006; Vanderpool, Dressler, Stradtman, &

Crosby, 2015; Vu, Azmat, Radejko, & Padela, 2016;). However, the opposite was true for women in this study, where being HIV-positive actually served as a facilitator for engaging in Pap test screening, and this notion was supported by at least one other study (Bynum et al., 2016). Drew and Schoenberg (2011) have deconstructed Fatalism, describing the term as a catchall that actually masks complex life constraints and fear of change. Through case studies of cervical cancer screening among Appalachian women, they demonstrate fatalistic health beliefs and issues of choice and control exist on a continuum of active pursuit versus active restraint, from seeking out information and biomedical services to ambivalence or submission to healthcare authorities. Research on the role of fatalism in HIV-positive women's engaging in other health screening is limited and warrants more attention. Self-esteem may be used as a measure of confidence, especially in terms of overcoming obstacles. One study of young HIVpositive women between the ages of 17 and 24 years old found a wide range of self-esteem; some had high self-esteem and said HIV had no impact on their life goals and dreams, while others had become less hopeful and felt less good about themselves since their diagnosis (Hosek et al., 2012).

#### **Organizational Dynamics**

The healthcare system itself has an influence on an individual's health behaviors, with past experiences positively or negatively affecting future engagement. These organizational-level factors may be related to the clinic and setting itself, such as location, appointment availability, and waiting time, or to the healthcare providers and staff who interact with patients. Patient– provider relationships have the potential to reduce health system failures among patients with low health literacy (Wigfall et al., 2017). Thus, the interview discussion in this study asked

participants not only about their experience with Pap smear exams at their clinic, including scheduling, setting and mood, hospitality of staff, obtaining results, etc., but also their relationships with their healthcare provider.

**Healthcare Providers.** In this study, healthcare providers were essential to facilitating Pap test screening, from tracking when the participants were due for a Pap smear to automatically scheduling appointments and referrals. This likely explains the high rate of Pap screening adherence among the participants; all of the women indicated they had received a Pap smear within a year of their interview date, and all of those who had had an abnormal Pap result said they received follow-up care within a year. This phenomenon conflicts with other literature on distrust of healthcare providers and the medical system among people of color (Driscoll, 2016; Mattocks et al., 2017; Nolan et al., 2014). However, there are numerous examples within the literature of how the relationship a patient has with his/her healthcare provider can either positively or negatively influence engagement in HIV care (Hawk et al., 2017; Landovitz, Desmond, Gildner, & Leibowitz, 2016; Slomka et al., 2013;), as well as Pap test screening for women (Ackerson, 2012; Nonzee et al., 2015; Peralta, Holaday, & Hadoto, 2017).

While it is certainly beneficial for the women in this study to have positive relationships with their healthcare providers, total reliance on their doctors to keep them engaged in Pap test screening could be problematic. For instance, participants may not schedule or keep Pap smear appointments if their providers did not do it for them (Hawk et al., 2017; Wigfall et al., 2017). In their study of more than 1,300 HIV-positive patients at an urban, academic medical center, Flickinger and colleagues (2013) found participants who had positive relationships and communication with their providers were more likely to keep their appointments and achieve retention in care. Thus, the high rate of compliance with regular Pap test screening in this study may be fragile, potentially declining if the patient – provider relationship were to break down.

#### **Intersection of Cervical Cancer Screening Influences**

Intersectionality as a framework seeks to understand the impact of multiple marginalized identities on individuals. The concept was first discussed in terms of African American women, who experience both racial discrimination and sexual biases (Perry, Harp, & Oser, 2013), but also experience them simultaneously, with the combined impact having more weight than the two separately (Lewis, Williams, Peppers, & Gadson, 2017). Researchers are starting to utilize the intersectionality framework to examine health outcomes among African American women. For instance, one study assessed how simultaneously experiencing sexism and racism affected African American women's health (Lewis et al., 2017). They found participants whose selfconcept was less grounded in their gender and racial identity were more likely to disengage from society as a coping strategy, which negatively affected both their mental and physical health. Williamson, Mahmood, Kuhn, and Thames (2017) sought to examine the intersection of race, discrimination, depression, and HIV status among women, and identified a 3-way interaction does exist between social adversity, HIV status, and race. There was a direct relationship between discrimination and depression for HIV-positive African American women, but not for HIV-negative African American women nor White women regardless of HIV status.

One study examined how cultural and structural factors influence Pap test screening among Latina women in Los Angeles, and identified several predictors, including structural barriers, fatalism, attending religious services, perceived susceptibility, perceived costs, and cues to action from a healthcare provider (Chen, Moran, Frank, Ball-Rokeach, & Murphy, 2018). Similarly, the women in the present study were motivated to engage in Pap test screening by the belief that the benefits of Pap smears outweigh the costs, perceived susceptibility due to their HIV-positive status, and cues to action from healthcare providers. That the subjects of this study are women, that they are African–American, and that they are situated in Memphis are all crucial to understanding the dynamics of their faith, their health-seeking behaviors, and the particular ways in which they narrate the meanings of their bodies (Hotz, 2015).

#### **Strengths and Limitations**

A major strength of this study, and qualitative methods in general, is that the results are grounded in the data itself. Findings from this study emerged from the participants' descriptions of their experiences and have been reported using the participants' own words. Additionally, the interview guide was designed to discuss facilitators and barriers to Pap test screening across multiple socioecological levels, from individual to cultural to organizational. The qualitative nature of this study and reflexivity of the interview guide also allowed for discussions of intersectionality, forming a more complete representation of Pap test screening among this population.

One distinct quality of this study is its concentration on HIV-positive women. Much of the international HIV research is focused on meeting the needs of women, sex workers, and preventing mother-child transmission, but this is not always the case in the United States, where the focus is largely on men who have sex with men (MSM) and the transgender community. This study examines a common women's health behavior from the unique perspective of women living with HIV, a complex, often-stigmatized condition. However, the inclusion criteria for this study limited the pool of potential participants, which led to the relatively small sample size of 19. Still, this size is not unusual for qualitative research, and the point of saturation, when no new themes were emerging from the data, was met (Creswell, 2007).

All of the participants in study were engaged in HIV care and in compliance with Pap test screening guidelines, which provided for thick description of this subpopulation's experiences. However, other perspectives may not be represented, including HIV-positive women who are not engaged in regular care and those who do not receive basic women's healthcare. In an effort to recruit a wider sample of the population, social services agencies as well as healthcare clinics posted study flyers and allowed in-person representatives to meet with potential participants. Advertisements were also sent electronically through related email distribution lists.

Regarding data collection and analysis, both have limitations involving the number of researchers. Multiple researchers conducted interviews with participants, meaning that, while the same overall collection methods were utilized, there may have been variability in styles. All interviewers completed CITI training, reviewed the study protocol and interview guide, and listened to interview recordings. Grounded theory methods of analysis were employed, including open, axial, and selective coding, but reliability may have been increased if multiple researchers independently coded the data then came together to develop a consensus. Nevertheless, the findings of this study should be considered reliable because the participants' own words are used to explain the emerging themes.

#### **Future Research**

To the author's knowledge, this is the first study of its kind to be conducted with this population and in the Mid-South region, making its findings important not only for local public health practitioners and interventions, but also other researchers in the field. While this research provides a unique insight into this issue, more research is needed. Specifically, it would be beneficial to reach HIV-positive women who were not as actively engaged in care as the participants in this sample. Additionally, it may of interest to further examine differences between women who have had an abnormal Pap smear result and those who have not. One barrier mentioned in this study was emotional pain, and other literature indicates sexual abuse and intimate partner violence may influence the uptake of Pap test screening. More research on this connection between emotional trauma and cervical cancer screening, or even other screenings, is warranted. The religiosity factor deserves more exploration, specifically differences in religion and spirituality. Similar studies could be done on anal Pap test screening and HIV-positive transwoman. As HIV is now considered a chronic disease, it may be necessary to assess other preventive health and screening behaviors, such as mammography, colonoscopies, diabetes, and heart disease.

The findings presented here provide insight into what motivates some HIV-positive women to engage in annual Pap test screening. The qualitative methods employed here allow for more in-depth information beyond simply a list of facilitators and barriers. This study could provide public health practitioners with a deeper understanding of women's engagement in cervical cancer screening compliance. Healthcare providers may apply these results to improve their relationships and communication with patients, especially considerations of physical and emotional pain. They may also be more aware of patients' possible lack of knowledge or sources of information, and help to educate women on HPV and cervical cancer.

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#### Conclusions

The purpose of this study was to explore the motivations, facilitators, and barriers to annual Pap test screening among HIV-positive women in the Mid-South. To achieve this end, psychosocial, cultural, contextual, and organizational factors were considered, as well as the intersections among them. Participants in this study were generally in compliance with Pap test screening guidelines, even though their knowledge of it was limited. Interestingly, their HIV status largely helped facilitate this compliance because participants were aware of their increased vulnerability from being immune-compromised. They also had established relationships with their healthcare providers, who were able to schedule, or even perform, Pap smears for them. Although most participants had strong support systems, Pap test screening was not something they discussed; however, their significant others, family, and friends encouraged them about their health overall. Although more research is needed, the results of this study could provide insight for public health interventions to increase knowledge about HPV and cervical cancer, awareness of the purpose and availability of Pap smears, and uptake of Pap test screening.

# Works Cited

Abercrombie, P.D. (2003). Factors Affecting Abnormal Pap Smear Follow-Up among HIV-Infected Women. *Journal of the Association of Nurses in AIDS Care*, 14(3): 41 - 54.

Ackerson, K. (2010). Personal Influences that Affect Motivation in Pap Smear Testing among African American Women. *Journal of Obstetric, Gynecology and Neonatal Nursing*, 39(2): 136 – 146.

Ackerson, K. (2011). Interactive Model of Client Health Behavior and Cervical Cancer Screening of African-American Women. *Public Health Nursing*, 28(3): 271 – 280.

Ackerson, K. (2012). A History of Interpersonal Trauma and the Gynecological Exam. *Qualitative Health Research*, 22(5): 679 – 688.

Ahdieh, L., Klein, R.S., Burk, R., Cu-Uvin, S., Schuman, P., Duerr, A., Safaeian, M., Astemborski, J., Daniel, R., and Shah, K. (2001). Prevalence, Incidence, and Type-Specific Persistence of Human Papillomavirus in Human Immunodeficiency Virus (HIV)-Positive and HIV-Negative Women. *The Journal of Infectious Diseases*, 184(6): 682 – 690.

Aizer, A.A., Chen, M.H., McCarthy, E.P., Mendu, M.L., Koo, S., Wilhite, T.J., Graham, P.L., Choueiri, T.K., Hoffman, K.E., Martin, N.E., Hu, J.C., and Nguyen, P.L. (2013). Marital Status and Survival in Patients with Cancer. *Journal of Clinical Oncology*, 31(31): 3869 – 3876.

Anderson, J.R., Paramsothy, P., Heilig, C., Jamieson, D.J., Shah, K., and Duerr, A. (2006). Accuracy of Papanicolaou Test among HIV-Infected Women. *Clinical Infectious Diseases*, 42(4): 562 – 568.

Andrasik, M.P., Rose, R., Pereira, D., and Antoni, M. (2008). Barriers to Cervical Cancer Screening among Low-Income HIV-Positive African American Women. *Journal of Health Care for the Poor and Underserved*, 19(3): 912 – 925.

Aranda-Naranjo, B., Barini-Garcia, M., and Pines, E.W. (2005). "I Can't Deal with One More Piece of Bad News": The Voices of Women Living with HIV Infection in an Inner City Gynecology Clinic. *The Journal of Multicultural Nursing & Health*, 11(1): 84–92.

Badial, R.M., Dias, M.C., Stuqui, B., Melli, P.P., Quintana, S.M., Bonfim, C.M., Cordeiro, J.A., Rabachini, T., Calmon, M., Provazzi, P.J.S., and Rahal, P. (2018). *Medicine*, 97(14): 1 – 6.

Baranoski, A.S., Horburgh, C.R., Cupples, L.A., Aschengrau, A., and Stier, E.A. (2011). Risk Factors for Non-Adherence with Pap Testing in HIV-Infected Women. *Journal of Women's Health*, 20(11): 1635 – 1643.
Baranoski, A.S. and Stier, E.A. (2012). Factors Associated with Time to Colposcopy after Abnormal Pap Testing in HIV-Infected Women. *Journal of Women's Health*, 21(4): 418 – 424.

Baumgartner, L.M. and David, K.N. (2009). Accepting Being Poz: The Incorporation of the HIV Identity into the Self. *Qualitative Health Research*, 19(12): 1730 – 1743.

Benard, V.B., Thomas, C.C., King, J., Massetii, G.M., Doria-Rose, V.P., and Saraiya, M. (2014). Vital Signs: Cervical Cancer Incidence, Mortality, and Screening – United States, 2007 – 2012. *Morbidity and Mortality Weekly Report*, 63(44): 1004 – 1009.

Berkman, L.F. (2009). Social Epidemiology: Social Determinants of Health in the United States: Are We Losing Ground? *Annual Review of Public Health*, 30: 27 – 41.

Breitkopf, C.R., Pearson, H.C., and Breitkopf, D.M. (2005). Poor Knowledge Regarding the PapTest among Low-Income Women Undergoing Routine Screening. *Perspectives on Sexual and Reproductive Health*, 37(2): 78 – 84.

Bynum, S.A., Wigfall, L.T., Brandt, H.M., Julious, C.H., Glover, S.H., and Hebert, J.R. (2016). Social and Structural Determinants of Cervical Health among Women Engaged in HIV Care. *AIDS Behavior*, 20: 2101 – 2109.

Callahan, T.L. and Caughey, A.B. (2007). Cervical Neoplasia and Cervical Cancer. In *Blueprints: Obstetrics and Gynecology* (4<sup>th</sup> ed., pp. 296-307). Baltimore, MD: Lippincott Williams & Wilkins.

Carpenter, C.J. (2010). A Meta-Analysis of the Effectiveness of Health Belief Model Variables in Predicting Behavior. *Health Communication*, 25: 661–669.

Cates, J.R., Brewer, N.T., Fazekas, K.I., Mitchell, C.E., and Smith, J.S. (2009). Racial Differences in HPV Knowledge, HPV Vaccine Acceptability, and Related Beliefs among Rural, Southern Women. *Journal of Rural Health*, 25(1): 93 – 97.

Chen, N.N.T., Moran, M.B., Frank, L.B., Ball-Rokeach, S.J., and Murphy, S.T. (2018). Understanding Cervical Cancer Screening among Latinas through the Lens of Structure, Culture, Psychology, and Communication. *Journal of Health Communication*, 23(7): 661–669.

Chin-Hong, P.V. and Palefsky, J.M. (2005). Human Papillomavirus Anogenital Disease in HIV-Infected Individuals. *Dermatologic Therapy*, 28: 67 – 78.

Clum, G., Chung, S.E., Ellen, J.M., and The Adolescent Medicine Trials Network for HIV/AIDS Interventions. Mediators of HIV-Related Stigma and Risk Behavior in HIV Infected Young Women. *AIDS Care*, 21(11): 1455 – 1462.

Cohen, S., Mermelstein, R., Kamarck, T., and Hoberman, H.M. (1985). Measuring the Functional Components of Social Support. In Sarason, I.G. (Ed.), *Social Support: Theory, Research, and Applications* (pp. 73 – 94). Netherlands: Springer.

Corbin, J. and Strauss, A. (1990). Grounded Theory Research: Procedures, Canons, and Evaluative Criteria. *Qualitative Sociology*, 13(1): 3 - 21.

Creswell, J.W. (2007). *Qualitative Inquiry and Research Design: Choosing among Five Approaches* (2<sup>nd</sup> ed., pp. 147-176). Thousand Oaks, CA: Sage Publications, Inc.

Curry, C.L., Sage, Y.H., Vragovic, O., and Stier, E.A. (2012). Minimally Abnormal Pap Testing and Cervical Histology in HIV-Infected Women. *Journal of Women's Health*, 21(1): 87 – 91.

Daley, E., Perrin, K., Vamos, C., Hernandez, N., Anstey, E., Baker, E., Kolar, S., and Ebbert, J. (2013). Confusion about Pap Smears: Lack of Knowledge among High-Risk Women. *Journal of Women's Health*, 22(1): 67 – 74.

Dalmida, S.G., Holstad, M.M., Dilorio, C., and Laderman, G. (2012). The Meaning and Use of Spirituality among African American Women Living with HIV/AIDS. *Western Journal of Nursing Research*, 34(6): 736 – 765.

Denny-Smith, T., Bairan, A., and Page, M.C. (2005). A Survey of Female Nursing Students' Knowledge, Health Beliefs, Perceptions of Risk, and Risk Behaviors Regarding Human Papillomavirus and Cervical Cancer. *Journal of the American Academy of Nurse Practitioners*, 18: 62 – 69.

DiClemente, R.J. (1989). Prevention of Human Immunodeficiency Virus Infection among Adolescents: The Interplay of Health Education and Public Policy in the Development and Implementation of School-Based AIDS Education Programs. *AIDS Education and Prevention*, 1(1): 70 - 78.

Diepstra, K.L., Rhodes, A.G., Bono, R.S., Patel, S., Yerkes, L.E., and Kimmel, A.D. (2017). Comprehensive Ryan White Assistance and Human Immunodeficiency Virus Clinical Outcomes: Retention in Care and Viral Suppression in a Medicaid Nonexpansion State. *Clinical Infectious Diseases*, 65(4): 619 – 625.

Digney, S.A., Morrell, K.R., Montgomery, M.A., and Pichon, L.C. (2013). *Covariates of Papanicolaou Test Screening among HIV-Positive Women Receiving Outpatient Medical Care from the Memphis Transitional Grant Area Ryan White Part A Program*. Presented at the Society of Behavioral Medicine Conference held April 23<sup>rd</sup> to 26<sup>th</sup>, 2014, Philadelphia, PA.

Documet, P., Bear, T.M., Flatt, J.D., Macia, L., Trauth, J., and Ricci, E.M. (2015). The Association of Social Support and Education with Breast and Cervical Cancer Screening. *Health Education and Behavior*, 42(1): 55 – 64.

Draucker, C.B., Martsolf, D.S., Ross, R., and Rusk, T.B. (2007). Theoretical Sampling and Category Development in Grounded Theory. *Qualitative Health Research*, 17(8): 1137 – 1148.

Drew, E.M. and Schoenberg, N.E. (2011). Deconstructing Fatalism: Ethnographic Perspectives on Women's Decision Making about Cancer Prevention and Treatment. *Medical Anthropology Quarterly*, 25(2): 164 – 182.

Driscoll, S.D. (2016). Barriers and Facilitators to Cervical Cancer Screening in High Incidence Populations: A Synthesis of Qualitative Evidence. *Women and Health*, 56(4): 448 – 467.

Duffett-Leger, L.A., Ledourneau, N.L., and Croll, J.C. (2008). Cervical Cancer Screening Practices among University Women. *Journal of Obstetrics, Gynecology and Neonatal Nursing*, 37: 572 – 581.

Dunkel-Schetter, C. and Skokan, L.A. (1990). Determinants of Social Support Provision in Personal Relationships. *Journal of Social and Personal Relationships*, 7(4): 437 – 450.

Eastwood, E.A., Fletcher, J., Quinlivan, E.B., Verdecias, N., Birnbaum, J.M., and Blank, A.E., (2015). Baseline Social Characteristics and Barriers to Care from a Special Projects of National Significance Women of Color with HIV Study: A Comparison of Urban and Rural Women and Barriers to HIV Care. *AIDS Patient Care and STDs*, 29(S1): S4 – S10.

Emlet, C.A., Harris, L., Pierpaoli, C.M., and Furlotte, C. (2018). "The Journey I Have Been Through": The Role of Religion and Spirituality in Aging Well Among HIV-Positive Older Adults. *Research on Aging*, 40(3): 257 – 280.

Erwin, D.O., Johnson, V.A., Trevino, M., Duke, K., Feliciano, L., and Jandorf, L. (2007). A Comparison of African American and Latina Social Networks as Indicators for Culturally Tailoring a Breast and Cervical Cancer Education Intervention. *Cancer*, 109(2 Suppl): 368 – 377.

Fisher, J.D. and Fisher, W.A. (1992). Changing AIDS Risk Behavior. *Psychological Bulletin*, 111(3): 455 – 474.

Fletcher, F.E., Buchberg, M., Schover, L.R., Basen-Engquist, K., Kempf, M.C., Arduino, R.C., & Vidrine, D.J. (2014). Perceptions of Barriers and Facilitators to Cervical Cancer Screening among Low-Income, HIV-Infected Women from an Integrated HIV Clinic. *AIDS Care*, 26(10): 1229 – 1235.

Fletcher, F.E., Vidrine, D.J., Tami-Maury, I., Danysh, H.E., King, R.M., Buchberg, M., Arduino, R.C., and Gritz, E.R. (2014). Cervical Cancer Screening Adherence among HIV-Positive Female Smokers in a Comprehensive HIV Clinic. *AIDS Behaviors*, 18(3): 544 – 554.

Flickinger, T.E., Saha, S., Moore, R.D., and Beach, M.C. (2013). Higher Quality Communication and Relationships are Associated with Improved Patient Engagement in HIV Care. *Journal of Acquired Immune Deficiency Syndrome*, 63(3): 362 – 366.

Friedman, A.L. and Shepeard, H. (2007). Exploring the Knowledge, Attitudes, Beliefs, and Communication Preferences of the General Public Regarding HPV: Findings from CDC Focus Group Research and Implications for Practice. *Health Education and Behavior*, 34(3): 471 – 485.

Gamarra, C.J., Paz, E.P., and Griep, R.H. (2009). Social Support and Cervical and Breast Cancer Screening in Argentinean Women from a Rural Population. *Public Health Nursing*, 26(3): 269 – 276.

Guilfoyle, S., Franco, R., and Gorin, S.S. (2007). Exploring Older Women's Approaches to Cervical Cancer Screening. *Health Care for Women International*, 28: 930 – 950.

Hanske, J., Meyer, C.P., Sammon, J.D., Choueiri, T.K., Menon, M., Lipsitz, S.R., Noldus, J., Nguyen, P.L., Sun, M., and Trinh, Q.D. (2016). The Influence of Marital Status on the Use of Breast, Cervical, and Colorectal Cancer Screening. *Preventive Medicine*, 89: 140 – 145.

Hawk, M., Coulter, R.W.S., Egan, J.E., Friedman, M.R., Meanley, S., Fisk, S., Watson, C., and Kinsky, S. (2017). Exploring the Healthcare Environment and Associations with Clinical Outcomes of People Living with HIV/AIDS. *AIDS Patient Care and STDs*, 31(12): 495 – 503.

Head, K.J. and Cohen, E.L. (2012). Young Women's Perspectives on Cervical Cancer Prevention in Appalachian Kentucky. *Qualitative Health Research*, 22(4): 476–487.

Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB). (2008). *HAB HIV Core Clinical Performance Measures: Adult/ Adolescent Clients Group 2*. Online Available: <a href="http://hab.hrsa.gov/deliverhivaidscare/clinicalguide11/pdf/p07-cg/habgrp2pms082.pdf">http://hab.hrsa.gov/deliverhivaidscare/clinicalguide11/pdf/p07-cg/habgrp2pms082.pdf</a>

Health Resources and Services Administration, HIV/AIDS Bureau. (2010). *Going the Distance: The Ryan White HIV/AIDS Program, 20 Years of Leadership, a Legacy of Care.* Rockville, MD: Health Resources and Services Administration.

Heaney, C.A. and Israel, B.A. (2008). Social Networks and Social Support. In Glanz, K., Rimer, B.K. and Viswanath, K. (Eds.), *Health Behavior and Health Education: Theory, Research and Practice* (pp. 189-210). San Francisco, CA: Jossey-Bass.

Hirschhorn, L.R., Landers, S., McInnes, D.K., Malitz, F., Ding, L., Joyce, R., and Cleary, P.D. (2009). Reported Care Quality in Federal Ryan White HIV/AIDS Program Supported Networks of HIV/AIDS Care. *AIDS Care*, 21(6): 799 – 807.

Holt, C.L., Roth, D.L., Huang, J., Park, C., and Clark, E.M. (2017). Longitudinal Effects of Religious Involvement on Religious Coping and Health Behaviors in a National Sample of African Americans. *Social Science Medicine*, 187: 11 – 19.

Hosek, S., Brothers, J., Lemos, D., and the Adolescent Medicine Trials Network for HIV/AIDS Interventions. (2012). What HIV-Positive Young Women Want from Behavioral Interventions: A Qualitative Approach. *AIDS Patient Care and STDs*, 26(5): 291–297.

Hotz, K.G. (2015). "Big Momma Had Sugar, Imma Have It Too" Medical Fatalism and the Language of Faith among African-American Women in Memphis. *Journal of Religion and Health*, 54: 2212 – 2224.

Irvine, M.K., Chamberlin, S.A., Robbins, R.S., Myers, J.E., Braunstein, S.L., Mitts, B.J., Harriman, G.A., and Nash, D. (2015). Improvements in HIV Care Engagement and Viral Load Suppression Following Enrollment in a Comprehensive HIV Care Coordination Program. *HIV/AIDS*, 60(2): 298 – 310.

Jones, R.K., Frohwirth, L.F., and Blades, N.M. (2016). "If I Know I am on the Pill and I Get Pregnant, It's an Act of God": Women's Views on Fatalism, Agency, and Pregnancy. *Contraception*, 93(6): 551 – 555.

Kang, S.H., Bloom, J.R., and Romano, P.S. (1994). Cancer Screening among African-American Women: Their Use of Tests and Social Support. *Annual Review of Public Health*, 84: 101 – 103.

Keller, M.J., Burk, R.D., Xie, X., Anastos, K., Massad, L.S., Minkoff, H., Xue, X., D'Souza, G., Watts, D.H., Levine, A.M., Castle, P.E., Colie, C., Palefsky, J.M., and Strickler, H.D. (2012). Risk of Cervical Pre-Cancer and Cancer among HIV-Infected Women with Normal Cervical Cytology and No Evidence of Oncogenic HPV Infection. *Journal of the American Medical Association*, 308(4): 362 – 369.

Keller, M.J., Burk, R.D., Massad, L.S., Eltoum, I.E., Hessol, N.A., Castle, P.E., Anastos, K., Xie, X., Minkoff, H., Xue, X., D'Souza, G., Flowers, L., Levine, A.M., Colie, C., Rahangdale, L., Fischl, M.A., Palefsky, J.M., and Strickler, H.D. (2015). Cervical Precancer Risk of HIV-Infected Women Who Test Positive for Oncogenic Human Papillomavirus Despite a Normal Pap Test. *HIV/AIDS*, 61(10): 1573 – 1581.

Kenagy, G.P., Linsk, N.L., Bruce, D., Warnecke, R., Gordon, A., Wagaw, F., and Densham, A. (2003). Service Utilization, Service Barriers, and Gender among HIV-Positive Consumers in Primary Care. *AIDS Patient Care and STDs*, 17(5): 235 – 244.

Kobetz, E., Kornfeld, J., Vanderpool, R.C., Rutten, L.J.F., Parekh, N., O'Bryan, G., and Menard, J. (2010). Knowledge of HPV among United States Hispanic Women: Opportunities and Challenges for Cancer Prevention. *Journal of Health Communication*, 15: 22 – 29.

Krefting, L. (1991). Rigor in Qualitative Research: The Assessment of Trustworthiness. *The American Journal of Occupational Therapy*, 45(3): 214 – 222.

Krieger, N. (2001). Theories for Social Epidemiology in the 21<sup>st</sup> Century: An Ecosocial Perspective. *International Journal of Epidemiology*, 30: 668 – 677.

Lambert, C.C., Chandler, R., McMillan, S., Kromrey, J., Johnson-Mallard, V., and Kurtyka, D. (2015). Pap Test Adherence, Cervical Cancer Perceptions, and HPV Knowledge among HIV-Infected Women in a Community Health Setting. *Journal of the Association of Nurses in AIDS Care*, 26(3): 271 – 280.

Landovitz, R.J., Desmond, K.A., Gildner, J.L., and Leibowitz, A.A. (2016). Quality of Care for HIV/AIDS and for Primary Prevention by HIV Specialists and Nonspecialists. *AIDS Patient Care and STDs*, 30(9): 395 – 408.

Leite, F.M.C., Amorim, M.H.C., Primo, C.C., and Gigante, D.P. (2016). Violence Against Women and Cervical Cancer Screening: A Systematic Review. *Journal of Clinical Nursing*, 26: 2126–2136.

Lekas, H.M., Siegel, K., and Schrimshaw, E.W. (2006). Continuities and Discontinuities in the Experiences of Felt and Enacted Stigma among Women with HIV/AIDS. *Qualitative Health Research*, 16(9): 1165 – 1190.

Lewis, J.A., Williams, M.G., Peppers, E.J., and Gadson, C.A. (2017). Applying Intersectionality to Explore the Relations Between Gendered Racism and Health among Black Women. *Journal of Counseling Psychology*, 64(5): 475 – 486.

Lichtenstein, B. (2005). Domestic Violence, Sexual Ownership, and HIV Risk in Women in the American Deep South. *Social Science and Medicine*, 60: 701 – 714.

Liu, G., Sharma, M., Tan, N., and Barnabas, R.V. (2018). HIV-Positive Women Have Higher Risk of Human Papilloma Virus Infection, Precancerous Lesions, and Cervical Cancer. *AIDS*, 32(6): 795 – 808.

Lodi, C.T., Michelin, M.A., Lima, M.I., Teixeira, N.C., Adad, S.J., Murta, E.F., and Melo, V.H. (2011). Factors Associated with Recurrence of Cervical Intraepithelial Neoplasia after Conization in HIV-Infected and Non-Infected Women. *Archives of Gynecology and Obstetrics*, 284: 191 – 197.

Logan, J.L., Khambaty, M.Q., D'Souza, K.M., and Menezes, L.J. (2010). Cervical Cancer Screening among HIV-Infected Women in a Health Department Setting. *AIDS Patient Care and STDs*, 24(8): 471–475.

Lopez, J.D., Shacham, E., and Brown, T. (2018). The Impact of the Ryan White HIV/AIDS Medical Case Management Program on HIV Clinical Outcomes: A Longitudinal Study. *AIDS and Behavior*, 22: 3091 – 3099.

Marlow, L.A.V., Ferrer, R.A., Chorley, A.J., Haddrell, J.B., and Waller, J. (2018). Variation in Health Beliefs Across Different Types of Cervical Screening Non-Participants. *Preventive Medicine*, 111: 204 – 209.

Massad, L.S., Fazzari, M.J., Anastos, K., Klein, R.S., Minkoff, H., Jamieson, D.J., Duerr, A., Celentano, D., Gange, S., Cu-Uvin, S., Young, M., Watts, H., Levine, A.M., Schuman, P., Harris, T.G., and Strickler, H.D. (2007). Outcomes after Treatment of Cervical Intraepithelial Neoplasia among Women with HIV. *Journal of Lower Genital Tract Disease*, 11(2): 90 – 97.

Massad, L.S., Pierce, C.B., Minkoff, H., Watts, D.H., Darragh, T.M., Sanchez-Keeland, L., Wright, R.L., Colie, C., and D'Souza, G. (2014). Long-Term Cumulative Incidence of Cervical Intraepithelial Neoplasia Grade 3 or Worse after Abnormal Cytology: Impact of HIV Infection. *International Journal of Cancer*, 134(8): 1854 – 1861.

Mattocks, K.M., Gilbert, C., Fiellin, D., Fiellin, L.E., Jamison, A., Brown, A., and Justice, A.C. (2017). Mistrust and Endorsement of Human Immunodeficiency Virus Conspiracy Theories among Human Immunodeficiency Virus- Infected African American Veterans. *Military Medicine*, 182: e2073 – e2079.

McLeroy, K.R., Bibeau, D., Steckler, A., and Glanz, K. (1988). An Ecological Perspective on Health Promotion Programs. *Health Education Quarterly*, 15(4): 351 – 377.

Miles, M.S., Isler, M.R., Banks, B.B., Sengupta, S., and Corbie-Smith, G. (2011). Silent Endurance and Profound Loneliness: Socioemotional Suffering in African Americans Living with HIV in the Rural South. *Qualitative Health Research*, 21(4): 489 – 501.

Montgomery, K., Bloch, J.R., Bhattacharya, A., and Montgomery, O. (2010). Human Papillomavirus and Cervical Cancer Knowledge, Health Beliefs, and Preventative Practices in Older Women. *Journal of Obstetrics, Gynecology and Neonatal Nursing*, 39(3): 238 – 249.

Mosavel, M. and El-Shaarawi, N. (2007). "I Have Never Heard That One": Young Girls' Knowledge and Perception of Cervical Cancer. *Journal of Health Communication*, 12: 707 – 719.

Moyer, V.A. (2012). Screening for Cervical Cancer: U.S. Preventive Services Task Force Recommendation Statement. *Annals of Internal Medicine*, 156(12): 880 – 891.

Nardi, C., Sandhu, P., and Selix, N. (2016). Cervical Cancer Screening among Minorities in the United States. *The Journal for Nurse Practitioners*, 12(10): 675 – 682.

Nolan, J., Renderos, T.B., Hynson, J., Dai, S., Chow, W., Christie, A., and Mangione, T.W. (2014). Barriers to Cervical Cancer Screening and Follow-Up Care among Black Women in Massachusetts. *Journal of Obstetrics, Gynecology and Neonatal Nursing*, 43(5): 580 – 588.

Nonzee, N.J., Ragas, D.M., Luu, T.H., Phisuthikul, A.M., Tom, L., Dong, X.Q., and Simon, M.A. (2015). Delays in Cancer Care among Low-Income Minorities Despite Access. *Journal of Women's Health*, 24(6): 506 – 514.

Ogunwale, A.N., Coleman, M.A., Sangi-Haghpeykar, H., Valverde, I., Montealegre, J., Jibaja-Weiss, M., and Anderson, M.L. (2016). Assessment of Factors Impacting Cervical Cancer Screening among Low-Income Women Living with HIV-AIDS. *AIDS Care*, 28(4): 491 – 494.

Peralta, A.M., Holaday, B., and Hadoto, I.M. (2017). Cues to Cervical Cancer Screening among U.S. Hispanic Women. *Hispanic Health Care International*, 15(1): 5 – 12.

Perry, B.L., Harp, K.L.H., and Oser, C.B. (2013). Racial and Gender Discrimination in the Stress Process: Implications for African American Women's Health and Well-Being. *Sociological Perspectives*, 56(1): 25 – 48.

Phillips, D.Y., Walsh, B., Bullion, J.W., Reid, P.V., Bacon, K., and Okoro, N. (2014). The Intersection of Intimate Partner Violence and HIV in U.S. Women: A Review. *Journal of the Association of Nurses in AIDS Care*, 25(1S): S36 – S49.

Pichon, L.C., Morrell, K., Digney, S.A., Montgomery, M., and Asemota, A. (2012). *The 2012 Memphis Transitional Grant Area (TGA) Ryan White Part A Comprehensive Needs Assessment.* Memphis, TN; The University of Memphis School of Public Health, Memphis TGA Ryan White Part A Program, Shelby County Health Department Epidemiology Section.

Potter, E.C., Allen, K.R., and Roberto, K.A. (2018). Agency and Fatalism in Older Appalachian Women's Information Seeking about Gynecological Cancer. *Journal of Women and Aging*, DOI: <u>https://doi.org/10.1080/08952841.2018.1434951</u>.

Prado, G., Feaster, D.J., Schwartz, S.J., Pratt, I.A., Smith, L., and Szapocznik, J. (2004). Religious Involvement, Coping, Social Support, and Psychological Distress in HIV-Seropositive African American Mothers. *AIDS and Behavior*, 8(3): 221 – 235.

Rahangdale, L., Samquist, C., Yavari, A., Blumenthal, P., and Israelski, D. (2010). Frequency of Cervical Cancer and Breast Cancer Screening in HIV-Infected Women in a County-Based HIV Clinic in the Western United States. *Journal of Women's Health*, 19(4): 709 – 712.

Raiford, J.L., Wingood, G.M., and DiClemente, R.J. (2007). Correlates of Consistent Condom Use among HIV-Positive African American Women. *Women & Health*, 46(2/3): 41 - 58.

Rao, D., Andrasik, M.P., and Lipira, L. (2018). HIV Stigma among Black Women in the United States: Intersectionality, Support, Resilience. *American Journal of Public Health*, 108(4): 446–448.

Saghari, S., Ghamsary, M., Marie-Mitchell, A., Oda, K., and Morgan, J.W. (2015). Sociodemographic Predictors of Delayed versus Early Stage Cervical Cancer in California. *Annals of Epidemiology*, 25: 250 – 255.

Schlect, N.F., Burk, R.D., Palefsky, J.M., Minkoff, H., Xue, X., Massad, L.S., Bacon, M., Levine, A.M., Anastos, K., Gange, S.J., Watts, H., Da Costa, M.M., Chen, Z., Bang, J.Y., Fazzari, M., Hall, C., and Strickler, H.D. (2006). Variants of Human Papillomavirus 16 and 18 and Their Natural History in Human Immunodeficiency Virus-Positive Women. *Journal of General Virology*, 86: 2709 – 2020.

Sharpe, P.A., Brandt, H.M., and McCree, D.H. (2006). Knowledge and Beliefs about Abnormal Pap Test Results and HPV among Women with High-Risk HPV: Results from In-Depth Interviews. *Women & Health*, 42(2): 107 – 133.

Silva, I.T., Griep, R.H., and Rotenberg, L. (2009). Social Support and Cervical and Breast Cancer Screening Practices among Nurses. *Revista Latino-Americana de Enfermagem* 17: 514 – 521.

Silverberg, M.J., Schneider, M.F., Silver, B., Anastos, K.M., Burk, R.D., Minkoff, H., Palefsky, J., Levine, A.M., and Viscidi, R.P. (2006). Serological Detection of Human Papillomavirus Type 16 Infection in Human Immunodeficiency Virus (HIV)-Positive and High-Risk HIV-Negative Women. *Clinical and Vaccine Immunology*, 13(4): 511 – 519.

Slomka, J., Lim, J.W., Gripshover, B., and Daly, B. (2013). How Have Long-Term Survivors Coped with Living with HIV? *Journal of the Association of Nurses in AIDS Care*, 24(5): 449–459.

Smeltzer, S., Yu, X., Schmeler, K., and Levison, J. (2016). Abnormal Vaginal Pap Test Results after Hysterectomy in Human Immunodeficiency Virus-Infected Women. *Obstetrics and Gynecology*, 128(1): 52 – 57.

Starks, H. and Brown Trinidad, S. (2007). Choose Your Method: A Comparison of Phenomenology, Discourse Analysis and Grounded Theory. *Qualitative Health Research*, 17(10): 1372 – 1380.

Steele-Moses, S.K., Russell, K.M., Kreuter, M., Monahan, P., Bourff, S., and Champion, V.L. (2009). Cultural Constructs, Stage of Change, and Adherence to Mammography among Low-Income African American Women. *Journal of Health Care for the Poor and Underserved*, 20(1): 257 – 273.

Steward, W.T., Koester, K.A., Myers, J.J., and Morin, S.F. (2006). Provider Fatalism Reduces the Likelihood of HIV-Prevention Counseling in Primary Care Settings. *AIDS and Behavior*, 10(1): 3 - 12.

Stokols, D. (1996). Translating Social Ecological Theory into Guidelines for Community Health Promotion. *American Journal of Health Promotion*, 10(4): 282 – 298.

Studts, C.R., Tarasenko, Y.N., and Schoenberg, N.E. (2013). Barriers to Cervical Cancer Screening among Middle-Aged and Older Rural Appalachian Women. *Journal of Community Health*, 38: 500 – 512.

Szaflarski, M. (2013). Spirituality and Religion among HIV-Infected Individuals. *Current HIV/AIDS Reports*, 10(4): 324 – 332.

Tanner-Smith, E.E. and Brown, T.N. (2010). Evaluating the Health Belief Model: A Critical Review of Studies Predicting Mammographic and Pap Screening. *Social Theory and Health*, 8(1): 95 – 125.

Tello, M.A., Jenckes, M., Gaver, J., Anderson, J.R., Moore, R.D., and Chandler, G. (2010). Barriers to Recommended Gynecologic Care in an Urban United States HIV Clinic. *Journal of Women's Health*, 19(8): 1511 – 1518.

Valente, T.W. (2012). Network Interventions. Science, 337(6): 49 – 53.

Vanderpool, R.C., Dressler, E.V.M., Stradtman, L.R., and Crosby, R.A. (2015). Fatalistic Beliefs and Completion of the HPV Vaccination Series among a Sample of Young Appalachian Kentucky Women. *Journal of Rural Health*, 31: 199 – 205.

Vu, M., Azmat, A., Radejko, T., and Padela, A.I. (2016). Predictors of Delayed Healthcare Seeking among American Muslim Women. *Journal of Women's Health*, 25(6): 586 – 593.

Vyas, K.J., Limneos, J., Qin, H., and Mathews, W.C. (2014). Assessing Baseline Religious Practices and Beliefs to Predict Adherence to Highly Active Antiretroviral Therapy among HIV-Infected Persons. *AIDS Care*, 26(8): 983 – 987.

Vyavaharkar, M., Moneyham, L., Corwin, S., Saunders, R., Annang, L., and Tavakoli, A. (2010). Relationships Between Stigma, Social Support, and Depression in HIV-Infected African American Women Living in the Rural Southeastern United States. *Journal of the Association of Nurses in AIDS Care*, 21(2): 144 – 152.

Walker, D. and Myrick, F. (2006). Grounded Theory: An Exploration of Process and Procedure. *Qualitative Health Research*, 16(4): 547 – 559.

Wigfall, L., Rawls, A., Sebastian, N., Messersmith, A., Pirisi-Creek, L., Spiryda, L., Williams, E.M., Creek, K., and Glover, S.H. (2012). HPV High Risk and Protective Behaviors: The Effects of Religious Affiliation. *Journal of Religion and Health*, 51: 1325 – 1336.

Wigfall, L.T., Bynum, S.A., Friedman, D.B., Brandt, H.M., Richter, D.L., Glover, S.H., and Hebert, J.R. (2017). Patient-Provider Communication with HIV-Positive Women about Abnormal Pap Test Results. *Women and Health*, 57(1): 19 – 39.

Williams, M., Moneyham, L., Kempf, M.C., Chamot, E., and Scarinci, I. (2015). Structural and Sociocultural Factors Associated with Cervical Cancer Screening among HIV-Infected African American Women in Alabama. *AIDS Patient Care and STDs*, 29(1): 13 – 19.

Williamson, T.J., Mahmood, Z., Kuhn, T.P., and Thames, A.D. (2017). Differential Relationships Between Social Adversity and Depressive Symptoms by HIV Status and Racial/ Ethnic Identity. *Health Psychology*, 36(2): 133 – 142.

Wong, J.P.H., Vahabi, M., Miholjcic, J., Tan, V., Owino, M., Li, A.T.W., and Poon, M.K.L. (2018). Knowledge of HPV/ Cervical Cancer and Acceptability of HPV Self-Sampling among Women Living with HIV: A Scoping Review. *Current Oncology*, 25(1): e73 – e82.

Yoo, W., Kim, S., Huh, W.K., Dilley, S., Coughlin, S.S., Partridge, E.E., Chung, Y., Dicks, V., Lee, J.K., and Bae, S. (2017). Recent Trends in Racial and Regional Disparities in Cervical Cancer Incidence and Mortality in United States. *PLoS ONE*, 12(2): 1 – 13.

## **APPENDIX A: RECRUITMENT FLYER**



## **APPENDIX B: INTERVIEW GUIDE**

A Pap smear is a common procedure for cervical cancer screening in women. It is performed by a gynecologist and involves a small brush that scrapes cells off a woman's cervix to test them for any abnormalities. You're here today to talk about your thoughts and experiences with Pap smears. There are no right or wrong answers, your opinion is what matters to me, so please feel free to share whatever you are comfortable with sharing. I'll be recording our discussion today, but everything you say will be kept private and your identity will not be revealed. This discussion should take around an hour and you'll receive a \$10 Kroger gift card for your participation. Do you have any questions or concerns before we get started?

- Tell me about your experience(s) with Pap test screening.
  - How has having HIV affected your decisions about getting a Pap smear?
  - What are your feelings about getting a Pap smear?
  - What is a Pap smear?
  - What is getting a Pap smear like for you?
  - Have you ever had a bad experience getting a Pap smear?
- As best you can recall, describe step-by-step your last Pap smear appointment.
  - How did you schedule the appointment?
  - How was it when you got to the appointment?
  - What was the doctor like?
  - How did you get the results?
  - How was your last appointment compared to other appointments?
- What do you think of your risk of getting cervical cancer?
  - How much do you worry about getting cervical cancer?
  - Is there anything you think puts you at more/less risk for cervical cancer?
  - Why do you think some people might be at more/less risk for cervical cancer?
- What do you think happens to someone who has an abnormal Pap smear?
  - How would having an abnormal Pap affect you?
  - What would it mean to you to have an abnormal Pap smear?
- What do you think happens to someone with cervical cancer?
  - How would you feel if you were diagnosed with cervical cancer?
  - How would having cervical cancer affect you?

- What are the benefits of getting a Pap smear every year?
  - Why would you get a Pap smear?
  - What are some reasons you might decide to get a Pap smear?
- What are the barriers to getting a Pap smear every year?
  - Why would you not get a Pap smear?
    - What are some disadvantages to getting a Pap smear?
    - What are some things you worry about when getting a Pap smear?
  - What are some things that make it hard for you to get a Pap smear?
    - What are some challenges you might face in getting a Pap smear?
    - Is there anything in particular that makes it difficult to get a Pap smear?
- What are some cues that might help you get a Pap smear every year?
  - What are some things that make it easy for you to get a Pap smear?
  - Is there anything in particular that helps you get a Pap smear?
  - Is there anything that triggers it's time to get a Pap smear for you?
- Who talks to you about cervical cancer screening? What do they say?
  - Is there anyone who tells you or reminds you to get a Pap smear? If so, what do they say?
  - Who do you talk about ways to staying healthy? What do they say?
  - Is there anyone who talks to you about preventative health behaviors, like screening? If so, what do they say?
- How do your religious or spiritual beliefs influence your cervical cancer screening practices?
  - What does your church tell you about getting an annual Pap smear?
  - Why do you think churches don't talk about Pap smears?
  - In what ways does your church influence your beliefs about preventative screenings?
  - Does your church do health fairs or anything else to promote healthy behaviors?
     Why or why not?
  - How do your religious or spiritual beliefs influence your health?

## **APPENDIX C: PARTICIPANT QUESTIONNAIRE**

**Instructions:** The following questions are about your background and health status.

- 1. How old are you? \_\_\_\_\_ (If not between ages 18 to 45 years old, stop interview.)
- 2. What is your gender? (If not Female with a Cervix, stop interview.)

Female with a Cervix	☐ Male	☐ Transgender	Other
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- 3. What race do you most identify with? (If not Black or African American, stop interview).
  - Black or African American
  - □ White or Caucasian
  - Asian
  - American Indian or Alaska Native
  - □ Native Hawaiian or Pacific Islander
  - □ Other: \_\_\_\_\_
- 4. What is your ethnicity?
  - □ Hispanic/ Latino □ Non-Hispanic/ Latino
- 5. What is your current relationship status?
  - □ Single
  - Steady Partner But Not Living Together
  - □ Married/ Living with Partner
  - □ Widowed
  - Separated/ Divorced
- 6. What county do you live in?
  - □ Shelby County, TN
  - □ Fayette County, TN
  - □ Tipton County, TN
  - Desoto County, MS
  - □ Tunica County, MS
  - □ Tate County, MS
  - □ Marshall County, MS
  - $\Box$  Crittenden County, AR
  - Other: \_\_\_\_\_

- 7. What best describes your current living situation?
  - $\Box$  I own the home I live in
  - $\Box$  I rent the home I live in
  - $\Box$  I am staying with family/ friends
  - $\Box$  I live in a car or other vehicle
  - □ I live in a shelter
  - $\Box$  I live on the streets
  - Other: \_\_\_\_\_
- 8. What is the highest level of school you have completed?
  - □ Less than High School
  - □ High School or GED
  - Some College or Vocational School
  - □ College Graduate (Bachelors Degree)
  - Graduate Degree (Masters, Doctorate, MD, PhD)
- 9. What is your current job situation?
  - □ Working Full-Time
  - □ Working Part-Time
  - $\Box$  Working Off and On
  - □ Unemployed (Looking for Work)
  - Unemployed (Not Looking for Work)
  - Homemaker
  - Student
  - Other: \_\_\_\_\_
- 10. What is your annual household income?
  - □ \$0 \$5,000
  - □ \$5,001 \$10,000
  - \$10,001 \$15,000
  - \$15,001 \$20,000
  - □ \$20,001 \$30,000

- \$30,001 \$40,000
- \$40,001 \$50,000
- \$50,001 \$60,000
- □ \$60,001 or Higher

11.	What	religion	do	you	most	identify	with?
-----	------	----------	----	-----	------	----------	-------

	Baptist Catholic Church of God in Chr (COGIC)	rist		Disciples of Christ (DOC) Non-Denominational Agnostic/ Atheist Other:
12. How in	nportant would you sa	y religion is in your life	e?	
	Not at all important			
	A little important			
	Somewhat important			
	Very important			
13. Have y	ou ever been diagnose Yes	ed with HIV? (If No or	Don't I	Know, stop interview.) n't Know
14. What y	vear were you first diag	gnosed with HIV?		
15. How so diagno	oon after you were dia sis?	gnosed with HIV did y	ou go te	o see a doctor about your HIV
	Immediately			
	Within 6 Months			
	Within a Year			
	Longer than 1 Year			
	I Have Not Seen a Do	octor for HIV		
	Don't Remember			
	Other:			
16. Have y	ou ever been diagnose	ed with AIDS?		
	Yes	🗌 No	🗌 Do	n't Know
17. Have y	ou had any of the follo	owing in the last 12 mo	nths?	
	CD4 Counts (If yes,	what was it?		)
	Viral Load Test (If	yes, what was it?		)
	HIV Medication (AR	V)		

18. How often have you received HIV care in the past 12 months?

16. HOW OIL	ten nave you received	i m v care m me p	ast 12 months?	
	have not been to an	HIV care visit in the	he past 12 months	
	l Time			
	2 Times			
	3 Times			
	4 or More Times			
19. What ty	pe of health insuranc	e do you have?		
	Private	-	□ No Insurance	
	Medicaid/ TennCare		□ Other:	
	Medicare			
20. Do you	participate in the Rya	an White program?		
	res		Don't Know	
21. Have yo	ou had a Pap smear in	the past 3 years? (	(If No or Don't Know, stop interview.)	
	Yes	□ No	Don't Know	
22. What ye	ear was your last Pap	smear?		
23. Have yo	ou ever had an abnorr	nal Pap smear?		
	Yes		Don't Know	
24. How so	on after your abnorm	al Pap smear did y	ou follow-up with a doctor?	
	Immediately			
	Within 6 Months			
	Within a Year			
	Longer than 1 Year			
	Have Not Seen a Do	octor for Follow-U	р	
	Don't Remember			
	Other:			

## 25. <u>Have you ever...?</u>

	Yes	No	Don't Know
a. Been diagnosed with HPV			
b. Been diagnosed with pre-cancer cells in your cervix			
c. Been diagnosed with cervical cancer			
d. Received an HPV vaccine, such as Gardasil or Cervavix			

**Instructions:** The following questions about Pap test screening. Indicate whether each statement is true or false. (Interviewer: Read each statement and place a check mark or an X in the box beside the answer the participant thinks is correct.)

1. The purpose of the Pap smear test is to:

	True	False	Don't Know
a. Check your ovaries			
b. Scrape cells to look for cancer			
c. Treat cancer			
d. Test for sexual disease			
e. Check your urine			

2. Symptoms of an abnormal Pap smear are:

	True	False	Don't Know
a. Vaginal itching/ irritation			
b. Pain with sexual intercourse			
c. A frequent need to urinate			
d. Unnoticeable/ no symptoms			
e. Unusual vaginal spotting/ bleeding			
f. Genital warts			

3. If you have an abnormal result on the Pap test:

	True	False	Don't Know
a. You should tell your partner			
b. It means you have cancer			
c. The problem could go away on its own			
d. You may need more frequent Pap smears			

4. Follow-up for an abnormal Pap smear can involve:

	True	False	Don't Know
a. A blood test			
b. Biopsy			
c. Another Pap smear test			
d. Colposcopy			
e. HPV testing			

## Thank you!

For Internal Use Only:	
Interviewer Initials:	
Gift Card #:	

## **APPENDIX D: ELIGIBILITY SCREENING TOOL**

	Uniqu	e Identifier:	
Thank	you for calling about the	Pap smear study. Let's make	e sure you're eligible to participate.
1.	How old are you?	(Exclude if <18 or >4.	5 years old*)
2.	What is your gender?		
	☐ Female with a Ce (Exclude*)	ervix 🗌 Male (Exclu	ide*)
3.	What race do you most i	dentify with?	
	□ Black or African	American	
	□ White or Caucas	ian (Exclude*)	
	☐ Asian (Exclude*	)	
	□ American Indian	or Alaska Native (Exclude*)	)
	□ Native Hawaiian	or Pacific Islander (Exclude <sup>3</sup>	*)
	Other:	(Exclud	le if not Black/ African American*)
4.	Have you ever been diag	gnosed with HIV?	
	☐ Yes	□ No (Exclude*)	Don't Know (Exclude*)
5.	Have you ever had a Pap	o smear in the past 3 years?	
	☐ Yes	□ No (Exclude*)	Don't Know (Exclude*)
*[Exc	lusion Script]: I am sorry,	but you need to	to participate. Thank you for
your in	nterest in this research stu	dy. Do you have any question	ons?
sched	iled.	ble to participate in this study	y! Let's get your interview
Senea	Interview Date:	Inter	view Time:
	Interview Location:		
	Partic	ipant's Contact #:	

## **APPENDIX E: INFORMED CONSENT FORM**



Institutional Review Board

315 Administration Bldg. Memphis, TN 38152-3370 Office: 901.678.2705 Fax: 901.678.2199

INFORMED CONSENT

#### Pap Test Screening Experiences of HIV-Positive Women

INVESTIGATORS: Siri A. Digney, MS; The University of Memphis School of Public Health Latrice C. Pichon, PhD, MPH; The University of Memphis School of Public Health

<u>STUDY PURPOSE:</u> You are being asked to participate in a research study. The purpose of the study is to better understand your experiences with getting a Pap smear. You are eligible to participate because you have selfidentified as a black woman between the ages of 18 and 45 living with HIV and you've had a Pap smear in the past 3 years.

<u>PROCEDURES</u>: You will first complete a participant questionnaire that will ask you about your background, health history and Pap smear knowledge. Next, a trained researcher will facilitate the interview discussion, which will last approximately 45 minutes to 1 hour. You will be asked to share your thoughts, beliefs and experiences related to getting a Pap smear. The interview will be audio taped so that what you say is correctly recorded. If you do not agree to be audio taped, you may not participate.

POTENTIAL RISKS: Potential risks of participating in this interview may include feeling uncomfortable with answering sensitive questions. To reduce these minimal risks, your confidentiality will be protected and you will be allowed to refuse to answer any questions that are uncomfortable to you.

VOLUNTARY NATURE OF PARTICIPATION: Participation in this study is voluntary. You may refuse to answer any questions and you may stop participating at any time without any consequences.

BENEFIT'S OF THE STUDY: Potential benefits of your participation may include knowing that what you share could help improve Pap smear experiences of other HIV-positive women.

CONFIDENTIALITY: The information collected from you will not link your name to anything you say during the interview. Only a unique identifier, not your name, will be used on transcripts and surveys. The answers you give will be kept private. You will not be identified in any publications from this study. Audiotapes will be used to transcribe and code the data, but only the research team will have access to the data, which will be stored in a locked file cabinet or on a password-protected computer in a locked office. Records will be kept confidential to the extent provided by federal, state and local law.

INCENTIVES: To thank you for your time and effort, you will receive a \$10 Kroger gift card for your participation. If you should decide to end the interview early, you will still receive the \$10 Kroger gift card for you time. The researcher does not have funds budgeted for compensation for injury, damages or other expenses.

ADDITIONAL INFORMATION: If you have any questions about the research, you may contact Mrs. Siri Digney at (901)678-1689 or Dr. Latrice Pichon at (901)678-1675. If you have questions about your rights as a participant in the study, you may contact the Administrator for the Institutional Review Board for the Protection of Human Subjects at The University of Memphis at (901)678-2533.

Unique identifier of person agreeing to take part in the study

Date

Name of [authorized] person obtaining informed consent

Date

IRB #: 3117 Expiration Date: 2/6/15

Page 1 of 1

### **APPENDIX F: CERVICAL CANCER BROCHURE**

# **Cervical** Cancer

There are five main types of cancer that affect a woman's reproductive organs: cervical, ovarian, uterine, vaginal, and vulvar. As a group, they are referred to as gynecologic (GY-neh-kuh-LAH-jik) cancer. (A sixth type of gynecologic cancer is the very rare fallopian tube cancer.)

This fact sheet about cervical cancer is part of the Centers for Disease Control and Prevention's (CDC) *Inside Knowledge*: Get the Facts About Gynecologic Cancer campaign. The campaign helps women get the facts about gynecologic cancer, providing important "inside knowledge" about their bodies and health.





#### What is cervical cancer?

Cancer is a disease in which cells in the body grow out of control. Cancer is always named for the part of the body where it starts, even if it spreads to other body parts later.

When cancer starts in the cervix, it is called cervical cancer. The cervix is the lower, narrow end of the uterus. The cervix connects the vagina (the birth canal) to the upper part of the uterus. The uterus (or womb) is where a baby grows when a woman is pregnant.



Cervical cancer is the easiest gynecologic cancer to prevent with regular screening tests and followup. It also is highly curable when found and treated early.

#### Who gets cervical cancer?

All women are at risk for cervical cancer. It occurs most often in women over age 30. Each year, approximately 12,000 women in the United States get cervical cancer.

The human papillomavirus (HPV) is the main cause of cervical cancer. HPV is a common virus that is passed from one person to another during sex. At least half of sexually active people will have HPV at some point in their lives, but few women will get cervical cancer.

#### What are the symptoms?

Early on, cervical cancer may not cause signs and symptoms. Advanced cervical cancer may cause bleeding or discharge from the vagina that is not normal for you, such as bleeding after sex. If you have any of these signs, see your doctor. They may be caused by something other than cancer, but the only way to know is to see your doctor.

www.cdc.gov/cancer/knowledge 1-800-CDC-INFO

Are there tests that can prevent cervical cancer or find it early?

There are two tests that can either help prevent cervical cancer or find it early:

 The Pap test (or Pap smear) looks for precancers, cell changes, on the cervix that can be treated, so that cervical cancer is prevented. The Pap test also can find cervical cancer early, when treatment is most effective. The Pap test is recommended for women aged 21-65 years old.

The Pap test only screens for cervical cancer. It does not screen for any other gynecologic cancer.

 The HPV test looks for HPV the virus that can cause precancerous cell changes and cervical cancer.

Inside Knowledge is an initiative that supports the Gynecologic Cancer Education and Awareness Act of 2005, or Johanna's Law, which was unanimously passed by the U.S. House and Senate in December of 2006, and signed into law in January 2007.

## When should I get tested for cervical cancer?

The Pap test is one of the most reliable and effective cancer screening tests available. You should start getting regular Pap tests at age 21. If your Pap test results are normal, your doctor may say that you will not need another Pap test for three years.

The HPV test can be used to screen for cervical cancer along with the Pap test in women aged 30 years and older. It also is used to provide more information when women aged 21 years and older have unclear Pap test results.

If you are age 30 or older, you may choose to have an HPV test along with the Pap test. If the results are normal, your chance of getting cervical cancer in the next few years is very low. Your doctor may then say that you can wait up to five years for your next screening.

For women aged 21-65, it is important to continue getting a Pap test as directed by your doctor—even if you think you are too old to have a child or are not having sex anymore. However, your doctor may tell you that you do not need to have a Pap test if either of these is true for you:

- You are older than 65 and have had normal Pap test results for several years.
- You have had your cervix removed as part of a total hysterectomy for non-cancerous conditions, like fibroids.

#### What raises a woman's chance of getting cervical cancer?

Almost all cervical cancers are caused by HPV. You are more likely to get HPV if you started having sex at an early age, or if you or your partner have had sex with several others. However, any woman who has ever had sex is at risk for HPV.

There are many types of HPV. Usually HPV will go away on its own, but if it does not, it may cause cervical cancer over time.

In addition to having HPV, these things also can increase your risk of cervical cancer:

- Smoking.
- Having HIV (the virus that causes AIDS) or another condition that makes it hard for your body to fight off health problems.
- Using birth control pills for a long time (five or more years).
- Having given birth to three or more children.

#### How can I prevent cervical cancer?

- Get the HPV vaccine. It protects against the types of HPV that most often cause cervical, vaginal, and vulvar cancers. It is given in a series of three shots. The vaccine is recommended for 11 and 12 year old girls. It is also recommended for girls and women aged 13 through 26 who did not get any or all of the shots when they were younger. (Note: The vaccine can be given to girls beginning at age 9.)
- See your doctor regularly for a Pap test that can find cervical precancers.
- Follow up with your doctor, if your Pap test results are not normal.
- Don't smoke.
- Use condoms during sex.\*
- Limit your number of sexual partners.

#### What should I do if my doctor says I have cervical cancer?

If your doctor says that you have cervical cancer, ask to be referred to a gynecologic oncologist—a doctor who has been trained to treat cancers like this. This doctor will work with you to create a treatment plan.

#### Where can I find free or low-cost Pap tests?

If you have a low income or do not have insurance, you may be able to get a free or low-cost Pap test through the National Breast and Cervical Cancer Early Detection Program. To learn more, call 1-800-CDC-INFO or visit www.cdc.gov/cancer/nbccedp.



#### Where can I find more information about cervical and other gynecologic cancers?

Centers for Disease Control and Prevention: 1-800-CDC-INFO or www.cdc.gov/cancer

National Cancer Institute: 1-800-4-CANCER or www.cancer.gov

CDC Publication #99-9123, Revised July 2012



U.S. Department of Health and Human Services Centers for Disease Control and Prevention



<sup>\*</sup> HPV infection can occur in both male and female genital areas that are covered or protected by a latex condom, as well as in areas that are not covered. While the effect of condoms in preventing HPV infection is unknown, condom use has been associated with a lower rate of cervical cancer.

## APPENDIX G: GENITAL HPV INFECTION FACT SHEET

## **Genital HPV Infection - Fact Sheet**



#### What is genital HPV infection?

Genital human papillomavirus (also called HPV) is the most common sexually transmitted infection (STI). There are more than 40 types of HPV that can infect the genital areas of males and females. These HPV types can also infect the mouth and throat.

HPV can cause serious health problems, including genital warts and certain cancers. There is no certain way to tell who will develop health problems from HPV and who will not. In most cases HPV goes away by itself before it causes any health problems, and most people who become infected with HPV do not even know they have it.

HPV is not the same as herpes or HIV (the virus that causes AID5). Both viruses can be passed on during sex, but they have different symptoms and cause different health problems.

#### Who is at risk for HPV?

Anyone who is having (or has ever had) sex can get HPV. HPV is so common that nearly all sexually-active men and women get it at some point in their lives. This is true even for people who only have sex with one person in their lifetime.

#### How do people get HPV?

HPV is passed on through genital contact, most often during vaginal and anal sex. HPV may also be passed on during oral sex and genital-to-genital contact. HPV can be passed on between straight and same-sex partners—even when the infected person has no signs or symptoms.

Most infected persons do not realize they are infected, or that they are passing HPV on to a sex partner. A person can still have HPV, even if years have passed since he or she has had sexual contact with an infected person. It is also possible to get more than one type of HPV.

In rare circumstances, a pregnant woman with genital HPV can pass the HPV on to her baby during delivery.

#### What are the potential health problems caused by HPV?

Most people with HPV never develop symptoms or health problems. Most HPV infections (90%) go away by themselves within two years. But, sometimes, HPV infections will persist and can cause a variety of serious health problems. Health problems that can be caused by HPV include

- Genital warts (warts on the genital areas);
- Recurrent respiratory papillomatosis (RRP), a rare condition in which warts grow in the throat;
- Cervical cancer, cancer on a woman's cervix; and
- Other, less common, but serious cancers, including genital cancers (cancer of the vulva, vagina, penis, or anus), and a type of head and neck cancer called
  oropharyngeal cancer (cancer in the back of throat, including the base of the tongue and tonsils).

All cases of genital warts and RRP, and nearly all cases of cervical cancer, are caused by HPV. A subset of cancers of the vagina, vulva, anus, penis, and oropharynx, are caused by HPV.

The types of HPV that can cause genital warts are not the same as the types of HPV that can cause cancers.

#### Signs and symptoms of health problems caused by HPV:

Genital warts usually appear as a small bump or group of bumps in the genital area. They can be small or large, raised or flat, or shaped like a cauliflower. Healthcare providers can usually diagnose warts by looking at the genital area. Warts can appear within weeks or months after sexual contact with an infected partner—even if the infected partner has no signs of genital warts. If left untreated, genital warts might go away, remain unchanged, or increase in size or number. The types of HPV that can cause genital warts are not the same as the types of HPV that can cause cancers.

Cervical cancer usually does not cause symptoms until it is quite advanced. For this reason, it is important for women to get regular screening for cervical cancer. Screening tests can find early signs of disease so that problems can be treated early, before they ever turn into cancer.

Other cancers caused by HPV might not have signs or symptoms until they are advanced and hard to treat. Other HPV-associated cancers include some cancers of the vulva, vagina, penis, anus, and oropharynx.

RRP is a condition in which warts grow in the throat. RRP can occur in children (juvenile-onset) and adults (adult-onset). These growths can sometimes block the airway, causing a hoarse voice or trouble breathing.

#### How does HPV lead to health problems?

In most cases the virus goes away and it does not lead to any health problems. However, when the virus persists, or does not go away, HPV can cause normal cells to become abnormal and, most of the time you cannot see or feel these cell changes.

- Warts can appear within months after getting HPV.
- Cancer often takes years—even decades—to develop after a person gets HPV.

There is no certain way to know which people infected with HPV will go on to develop cancer or other health problems. However, persons with weak immune systems (including persons with HIV) may be less able to fight off HPV and more likely to develop health problems from it.

#### How common are HPV and health problems caused by HPV?

HPV (the virus): Approximately 79 million Americans are currently infected with HPV. About 14 million people become newly infected each year. HPV is so common that nearly all sexually-active men and women will get at least one type of HPV at some point in their lives.

Genital warts: About 360,000 persons in the U.S. get genital warts each year.

Cervical cancer: About 10,300 women in the U.S. get cervical cancer each year.

Other cancers that can be caused by HPV, including some vaginal, vulvar, penile, anal, and oropharyngeal cancers: Each year in the U.S., HPV is thought to cause an estimated – 2,100 vulvar cancers, – 1,500 anal cancers in men,

- 2,100 valvar cancers,
   500 vaginal cancers,
   600 penile cancers,
  - 1,700 oropharyngeal cancers in women,\*
  - and
  - 2,800 anal cancers in women, 6,700 oropharyngeal cancers in men.\*

\*Note: Other factors, notably tobacco and alcohol use, may also play a role with HPV to cause these cancers. About 21,000 of these cancers are potentially preventable by HPV vaccines.

> National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention Division of STD Prevention



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Recurrent respiratory papillomatosis (RRP) is very rare. It is estimated that about 820 children get juvenile-onset RRP every year in the U.S

#### What is the difference between HPV and HIV?

HPV is a different virus than HIV, and causes different health problems. HPV does not live in the blood cells, but rather lives on the skin. Also, whereas HIV can lead to AIDS, genital HPV can lead to genital warts and certain types of cancer. However, persons with HIV are more likely to get HPV and to develop health problems from HPV. This is especially true

#### Does HPV affect a pregnant woman and her baby?

Women who are pregnant can get infected with HPV. Usually these infections do not cause any problems. But sometimes

- HPV leads to genital warts, which can grow during pregnancy. Women with genital warts during the late stages
  of pregnancy are more likely to have children with warts in the throat, a condition called recurrent respiratory
  papillomatosis; however, this is a very rare condition.
- Pregnant women can develop cervical cell changes due to HPV. These changes can be detected through routine cervical cancer screening. Women should get routine cervical cancer screening, even during pregnancy.

#### Is there a test for HPV?

HPV tests are available to help screen women aged 30 years and older for cervical cancer. These HPV tests are not recommended to screen men, adolescents, or women under the age of 30 years. There is no general HPV test for men or women to check one's overall "HPV status." Also, there is not an approved HPV test to find HPV in the mouth or throat.

#### How can HPV be prevented?

#### There are several ways that people can lower their chances of getting HPV:

- HPV vaccines are recommended for 11- or 12-year-old boys and girls. HPV vaccines are safe and effective, and can protect males and females against some of the most common types of HPV that can lead to disease and cancer. HPV vaccines are given in three shots over six months; it is important to get all three doses to get the best protection. Boys and girls at ages 11 or 12 are most likely to have the best protection provided by HPV vaccines, and their immune response to vaccine is better than older women and men.
  - Girls and women: Two vaccines (Cervarix and Gardasil) are available to protect females against the types of HPV that cause most cervical cancers. One of these vaccines (Gardasil) also protects against most genital warts, and has been shown to protect against anal, vaginal, and vulvar cancers. Either vaccine is recommended for 11- and 12-year-old girls, and for females 13 through 26 years of age who did not get any or all of the shots when they were younger. These vaccines can also be given to girls beginning at 9 years of age.
- Boys and men: One vaccine (Gardasil) is available to protect males against most genital warts and anal who did not get any or all of the shots when they were younger. Gay, bisexual, and other men who have sex with men should receive the vaccine through age 26 years. Males 22–26 years of age may also get the vaccine.
- For those who choose to be sexually active, condoms may lower the risk of HPV. Condoms may also lower the risk of developing HPV-related diseases, such as genital warts and cervical cancer. To be most effective, condoms should be used with every sex act, from start to finish. HPV can infect areas that are not covered by a condom so condoms may not fully protect against HPV.
- People can also lower their chances of getting HPV by being in a faithful relationship with one partner; limiting their number of sex partners; and choosing a partner who has had no or few prior sex partners. But even people with only one lifetime sex partner can get HPV, and it may not be possible to determine if a person who has been sexually active in the past is currently infected. Because HPV is so common, and almost every sexually-active person will get HPV at some time in their lives, it is important to protect against the possible health effects of HPV.

#### Can people prevent health problems caused by HPV?

Yes, there are different prevention strategies for different health problems caused by HPV. HPV vaccines can prevent many diseases and cancers caused by HPV. In addition to vaccination, there are other ways to lower the risk of health problems caused by HPV.

A person can lower their risk of

- Cervical cancer by getting routine screening if they are a woman aged 21–65 years (and following up on any abnormal results);
- Oropharyngeal cancers by avoiding tobacco and limiting alcohol intake; and
- Genital warts by using condoms all the time and the right way.

#### Is there a treatment for HPV or health problems caused by HPV?

There is no treatment for the virus itself, but there are treatments for the health problems that HPV can cause:

- Gonital warts can be removed with treatments applied by the provider or the person himself/herself. No one treatment is better than another. Some people choose not to treat warts, but to see if they disappear on their own. If left untreated, genital warts may go away, stay the same, or grow in size or number.
- Corvical cancer is most treatable when it is diagnosed and treated early. Women who get routine Pap tests and follow up as needed can identify problems before cancer develops. Prevention is always better than treatment. For more information visit www.cancer.org.
- Other HPV-related cancers are also more treatable when diagnosed and treated early. For more information visit www.cancer.org
- Recurrent respiratory papillomatosis (RRP) can be treated with surgery or medicines. Curing RRP can sometimes require many treatments or surgeries over a period of years.



#### Where can I get more information?

#### STD Int

rmation ww.cdc.gov/std/ ccination rww.cdc.gov/vaccines/vpd-vac/hpv/.

r information www.cdc.gov/cancer/

cal Cancer Scree ervical/basic

nal Breast and Cervical Cancer Early n Program ww.cdc.gov/cancer/nbccedp/

CDC-INFO Contact Center 1-800-CDC-INFO (1-800-232-4636) TTY: (888) 232-6348

CDC National Prevention Information Network rw.cdcnpin.org/scripts/index.asp P.O. Box 6003 Rockville, MD 20849-6003 E-mail: inforcedenpin.org

nal HPV and Cervical Cancer Prever irce Center American Sexual Health lation (ASHA) ashastd.org/std-sti/hpv.html http://www.ash P. O. Box 13827 Research Triangle Park, NC 27709-3827 1-800-783-9877

## **IRB APPROVALS**

Mail - s	aogg@memphis.edu https://outlook.office.com/owa/?realm=memphis.edu&path=/mail/
	IRB Approval 3117
	Beverly Jacobik (bjacobik) on behalf of Institutional Review Board Tue 6/10/2014 8:54 AM
	To:Siri Alicia Digney (saogg) <saogg@memphis.edu>; Latrice C Pichon (lcpichon) <lcpichon@memphis.edu>;</lcpichon@memphis.edu></saogg@memphis.edu>
	Hello,
	The University of Memphis Institutional Review Board, FWA00006815, has reviewed and approved your submission in accordance with all applicable statuses and regulations as well as ethical principles.
	PI NAME: Siri Digney
	CO-PI: PROJECT TITLE, Don Tool Science Francisco CHIU Ducition Women
	FACULTY ADVISOR NAME (if applicable): Latrice Pichon
	IRB ID: #3117 APPROVAL DATE: 6/6/2014
	EXPIRATION DATE: 2/6/2015
	LEVEL OF REVIEW: Expedited Modification
	Please Note: Modifications do not extend the expiration of the original approval
	Approval of this project is given with the following obligations:
	<ol> <li>If this IRB approval has an expiration date, an approved renewal must be in effect to continue the project prior to that date. If approval is not obtained, the human consent form(s) and recruiting material(s) are no longer valid and any research activities involving human subjects must stop.</li> </ol>
	2. When the project is finished or terminated, a completion form must be completed and sent to the board.
	3. No change may be made in the approved protocol without prior board approval, whether the approved protocol was reviewed at the Exempt, Exedited or Full Board level.
	4. Exempt approval are considered to have no expiration date and no further review is necessary unless the protocol needs modification.
	Approval of this project is given with the following special obligations:
	I hank you,
	Ronnie Priest, PhD
	Institutional Review Board Chair
	The University of Memphis.
1 of 2	4/3/2010 10-21 AN

Mail - saogg@memphis.edu	https://outlook.office.com/owa/?realm=memphis.edu&path=/mail/
Note: Review outcomes will be communicated to the email address on file. This email should be considered an official	
communication from the UM IRB. Consent Forms are no longer being stamped as well. Please contact the IRB at IRB@memphis.edu if a letter on IRB letterhead is required.	

4/3/2019, 10:21 AM

2 of 2

Institutional Review Board Division of Research and Innovation Office of Research Compliance University of Memphis 315 Admin Bldg Memphis, TN 38152-3370

PI: Siri Ogg Co-Investigator: Advisor and/or Co-PI: Latrice Pichon Department: Social and Behavioral Sciences, unknown Study Title: Pap Test Screening Experiences of HIV-Positive Women IRB ID: PRO-FY2017-301 Submission Type: Renewal Level of Review:Expedited

IRB Meeting Date: Decision: Approved Approval Date: December 6, 2018 Expiration Date: December 6, 2019

Research Notes: Findings:

The IRB has reviewed the renewal request.

Approval of this project is given with the following obligations:

 If this IRB approval has an expiration date, an approved renewal must be in effect to continue the project prior to that date. If approval is not obtained, the human subjects consent form(s) and recruiting material(s) are no longer valid and any research activities involving human subjects must stop.

2. When the project is finished or terminated, a completion form must be completed and sent to the board.

No change may be made in the approved protocol without prior board approval, whether the approved protocol was reviewed at the Exempt, Expedited or Full Board level.

Exempt approval are considered to have no expiration date and no further review is necessary unless the protocol needs modification.

Thank you, James P. Whelan, Ph.D. Institutional Review Board Chair

#### The University of Memphis.

Note: Review outcomes will be communicated to the email address on file. This email should be considered an official communication from the UM IRB.