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Barriers to Cervical Cancer Screening among Enrollees in Georgia's Women's Health Medicaid Program: A Qualitative Analysis

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ABSTRACT

Barriers to Cervical Cancer Screening among Enrollees in Georgia's Women's Health Medicaid Program: A Qualitative Analysis

By Robert J. Greathouse

Background: In the United States, cervical cancer is the 14th most common cause of cancer death among women, causing an estimated 4,000 deaths per year. Prevention efforts centered on early detection and treatment of precancerous lesions have the potential to drastically improve cervical cancer death rates. Despite the availability of government-subsidized cervical cancer screening services, Pap test rates among low income, uninsured/underinsured, and ethnic minority women remain considerably below those of the general population.

Objective: The purpose of this study was to explore the barriers that inhibit low income, uninsured or underinsured women from accessing cervical cancer screening services. Comparisons of such barriers between African American and Caucasian women are of particular interest, in order to ascertain whether each group experiences similar types of barriers, and to understand which barriers are more influential within each group.

Methods: The data consisted of 25 interview transcripts of African American and Caucasian women with cervical pre-cancer or invasive cervical cancer who were currently or previously enrolled in the Georgia Women's Health Medicaid Program. The transcripts were coded using MAXqda 10 software, and the data were analyzed using the content analysis approach. Descriptive analyses were prepared for the factors that both aided and hindered women's ability to seek cervical cancer screening.

Findings: Three key factors were identified that influenced women's cervical cancer screening behaviors: the importance of education about HPV screening, the HPV vaccine, and the link between HPV and cervical cancer, patient perceptions of quality of care in their interactions with providers, and cultural or personal beliefs that influenced women's ability to comprehend and internalize the need for screening services. The first and third key factors were experienced differently by African American and Caucasian women, while both groups expressed similar sentiments relative to the second key factor.

Discussion: The study's findings may be useful in strengthening community outreach, secondary screening, and prevention efforts targeted at underserved women, in order to achieve improved cancer and chronic disease outcomes. These efforts will be of increasing importance in light of the expansion of Medicaid envisioned in the Patient Protection and Affordable Care Act.

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1.0 INTRODUCTION

1.1 Background and Problem Statement

Cervical cancer is the second highest cause of cancer mortality among women worldwide, largely due to the lack of population-based routine screening and treatment modalities in the developing world.[1] Before the introduction of the Papanicolaou, or Pap, test in the 1950's, cervical cancer was the foremost cause of cancer death among American women as there was no method for screening high grade precursors.[2] Since the introduction of organized cervical cancer screening programs in the United States in the1950's and 1960's, the cancer mortality rate has dropped considerably. Cervical cancer is currently the 14th most common cause of cancer death for women in the United States.[3] Each year, approximately 4,000 women in the United States die from cervical cancer.[4] Deaths caused by cervical cancer are highly preventable, as the development of invasive cervical cancer from precancerous lesions is relatively slow. The growth period for precancerous lesions to develop into invasive cervical cancer can take up to 10 years.[5] Hence, secondary prevention efforts focused on the detection and treatment of precancerous lesions, such as routine Pap test screening, have the potential to dramatically improve cervical cancer death rates. Pap test screening programs are estimated to have reduced cervical cancer deaths in the U.S. by up to 70% in some studies.[6]

Despite standardized national recommendations, the number of women receiving routine Pap tests in the United States is insufficient. As a component of its "Healthy People 2020" initiative, the U.S. Department of Health and Human Services set a goal of increasing to 93% the proportion of women aged 21 to 65 who received cervical cancer screening within the past three years.[7] Data from the 2010 National Health Interview Survey (NHIS)

highlighted the shortfalls in cervical cancer screening nationwide. Only 83% of women in the general population with no hysterectomy had received a Pap test within the past 3 years, considerably less than the "Healthy People 2020," target of 93%.[8]

In an effort to close gaps in cervical and breast cancer screening rates among underserved women, the United States Congress created the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) in 1991. The NBCCEDP obligates federal funds to states for the provision of free cancer screening, diagnostic tests, and public education and outreach; in the case of cervical cancer, services provided through the program include Pap tests, colposcopies, diagnostic evaluations (e.g. cervical cryotherapy, punch biopsies etc.), and referrals for treatment services.[9] The NBCCEDP's intended beneficiaries, in terms of cervical cancer screening services, are low-income, uninsured/underinsured, and minority women aged 18-64. Eligibility criteria for women receiving free screening services through NBCCEDP, although dependent on state implementation, generally include: absence of, or minimal health insurance coverage, lack of a primary care provider, and incomes at or below 250% of the Federal Poverty Level.[10] While progress has been made in narrowing gaps in cervical cancer screening in the two decades since the establishment of the NBCCEDP, disparities in screening among underserved women persist. In 2005, for instance, more than 34% (3.1 million women) of NBCCEDP-eligible women did not receive recommended Pap tests from NBCCDCP or any other screening source.[11]

Despite the expansion of free cervical cancer screening services targeted to minority women through the NBCCEDP, disparities in cervical cancer screening and risk exist among ethnic minorities, particularly African Americans, persist. In 2005, data from the "Healthy People 2010" initiative revealed that 80% of African American women had received a Pap

test in the past 3 years; this screening rate was 10% below the stated objective of 90% of women from all populations having had a Pap test within the past 3 years.[12] Further, African American women have the second highest risk of developing cervical cancer among all ethnic minorities, behind only Hispanic women.[13] Data from treatment studies also suggests that African Americans are less frequently treated for cervical cancer.[13] A decisive factor driving these disparities is the ability of underserved populations to access screening, appropriate follow-up of abnormal Pap test results, and treatment services. Nonadherence to screening and follow-up may result in later stages of diagnosis, in turn resulting in increased morbidity and mortality. Barriers to accessing screening services may be broadly classified into the following three categories: personal/cultural, socioeconomic, or institutional barriers.[13] Specific examples of these barriers among ethnic minorities that are recurrent in the literature include: fatalistic attitudes regarding cancer, a lack of knowledge about cervical cancer, beliefs that a Pap test is unnecessary unless one is ill, and administrative processes in establishing healthcare.[14] The majority of the literature on African American women's barriers to cervical cancer has focused on socioeconomic or institutional barriers; few published studies exist that examine this group's personal/cultural barriers. Few studies have sought to understand these barriers specifically among NBCCEDP's target audience.

1.2 Purpose Statement

The purpose of this study is to explore the barriers that inhibits low income, uninsured or underinsured women from accessing cervical cancer screening services. The comparison of these barriers among groups, specifically African American and Caucasian women, is of particular interest, in order to understand whether these two groups experience such barriers at equal levels of intensity, or whether certain types of barriers are more

influential among either group. A qualitative approach will be useful in collecting rich narrative material on women's health beliefs and health behaviors concerning cancer screening. This data will assist in discovering important underlying themes and patterns of relationships in order to construct the recurrent barriers experienced by these two groups, as well in supporting drawing comparisons between the two study groups. Armed with a deeper understanding of these barriers, secondary prevention programs such as the NBCCEDP can perform targeted outreach to this underserved population to increase use of screening services.

1.3 Specific Aims

I. To explore the barriers that inhibit low income, uninsured or underinsured women from accessing cervical cancer screening services.

II. To compare the experiences of these barriers among African American and Caucasian women.

1.4 Significance Statement

Since the establishment of the NBCCEDP in 1991, the United States federal government has devoted considerable financial and human resources to improve cervical cancer screening rates among underserved women. Although the program has made inroads in providing screening and diagnostic services to its priority population of low income, uninsured/underinsured, and minority women, recent research reveals that screening disparities still exist among program-eligible women.

A qualitatively focused inquiry into the barriers that these underserved women face in engaging in, or completing, cervical cancer screening will discover the specific causes that hamper these women from accessing the free screening services offered by the NBCCEDP. In this study, women with precancerous lesions or cervical cancer diagnoses and who were

currently or previously enrolled in a state NBCCEDP program, namely Georgia's Women's Health Medicaid Program, are interviewed about their prior cervical cancer screening history. The information obtained from these interviews provides a unique and insightful perspective on cervical cancer screening behavioral patterns among women who are low income, uninsured/underinsured, and at increased risk for developing cervical cancer or its precursors. Armed with this knowledge, NBCCEDP grantees and participating providers will be able to develop improved recruitment strategies to tackle these impediments to screening among its marginalized target population. These recruitment strategies can educate women on the importance of cervical cancer screening, heighten risk perceptions, and hopefully motivate women to complete screening exams on a routine basis. Improvements in cervical cancer screening resultant from these recruitment strategies will assist in preventing needless cervical cancer deaths.

2.0 LITERATURE REVIEW

2.1 Cervical Cancer Facts and Statistics

Cervical cancer is a significant cause of global mortality among women aged 15 years and above. From 1980 to 2010, global cervical cancer incidence increased from an estimated 378,000 cases per year to 454,000 cases per year, a 0.6% annual rate of increase.[15] Cervical cancer death rates, which have declined in recent years, still indicate that cervical cancer is a prominent threat to women of reproductive age; in 2010, cervical cancer killed 200,000 women worldwide.[1] In the United States, the American Cancer Society estimates that in 2012, 12,170 new cases of invasive cervical cancer will be diagnosed, and 4,220 women will die from cervical cancer.[16] The association between cervical cancer incidence and screening is stark; the benefits of regular cervical cancer screening include early stage of invasive disease at diagnosis and reduced incidence through detection and treatment of cervical pre-

cancer (pre-cancerous changes in cervical cells).[17] Indeed, when cervical cancers are detected at an early stage, five-year survival rates are above 90%.[2] Thus, both regular cervical cancer screening and stage at diagnosis are contributing factors to improved cervical cancer outcomes and survival.

Cervical cancer is staged clinically, based on a doctor's physical examination in conjunction with additional tests, rather than through an examination of surgical findings. The gold standard for staging cervical cancer is the International Federation of Gynecology and Obstetrics (FIGO) staging system. The FIGO staging system classifies cervical cancer stages on a scale using Roman numerals from I to IV, with each stage being further subdivided into two sub-stages, sub-stage A or B (i.e. Stage IA/IB, Stage IIA/IIB, etc.). The primary FIGO stages correspond with the spread of cervical cancer from the cervix to neighboring areas of the female reproductive system or other areas of the body; the sub-stages, meanwhile, document the amount of cancer found at each stage, and/or the extent of the cancer's spread and where it is found. Stage I denotes cancerous cells confined to the cervix only, while the sub-stages measure the amount of cancer found in the cervix, from 3 to 5 millimeters deep (Stage IA) to 4 centimeters or smaller (Stage IB). Stage II refers to cancerous cells that have spread beyond the cervix, but not to the pelvic wall (tissues lining the area of the body between the hips) or the lower third of the vagina. Stage II's sub-stages measure the amount of cancer that has spread beyond the cervix, and indicate where the cancer has spread. In the first sub-stage (Stage IIA), the cancer has spread beyond the cervix to the upper two-thirds of the vagina, but has yet to spread to the tissues around the uterus. Stage IIA itself is further subdivided into Stages IIA1 and IIA2, based on tumor size; the tumor in Stage IIA1 is 4 centimeters or smaller, while the tumor in Stage IIA2 is larger than 4 centimeters. In the second sub-stage of Stage II (Stage IIB), the cancer has spread beyond

the cervix to the tissues around the uterus. Stage III denotes that the cancerous cells have spread to the lower third of the vagina, and/or to the pelvic wall, and/or have cause kidney problems. Stage III's sub-stages signify where the cancer is found, either in the lower third of the vagina, but not the pelvic wall (Stage IIIA), or to the pelvic wall and/or to the ureters (tubes that connect the kidneys to the bladder) causing kidney damage (Stage IIIB). Stage IV indicates cancerous cells that have spread from the cervix to the bladder, rectum, or other areas of the body, while the sub-stages of this advanced stage indicate where the cancer is found, either at the bladder or rectum (Stage IVA) or other areas of the body, such as the liver or lungs (Stage IVB).[18] Cervical cancer stage at diagnosis and survival rates share an inverse relationship, underscoring the necessity of early detection and treatment of the disease for positive prognoses.

The development of cervical cancer is associated with a multitude of risk factors, many of which are preventable, unlike risk factors for many other cancers. The most important risk factor for cervical cancer is Human Papilloma Virus (HPV) infection. HPV is a group of over 100 related viruses, of which some cause a type of growth called a "Papilloma," more commonly referred to as warts. Although warts are a common symptom of HPV, the virus does not always produce symptoms among infected persons; in fact, an individual may have the virus for years, and subsequently pass it on, without ever knowing he/she was infected. HPV infections among women occur mainly at younger ages, and are less common in women older than 30.[2] Certain kinds of sexual behaviors increase women's risk of acquiring HPV genital infection, including: early sexual debut, having multiple sexual partners (or having a partner with many sex partners), and having sex with uncircumcised men. Although the aforementioned sexual behaviors increase risk of HPV infection, HPV

may be transmitted simply via skin-to-skin contact with an area of the body infected with HPV.

The link between HPV infection and development of cervical cancer is well-documented. Some estimates have suggested that 93% of invasive cervical cancers worldwide are caused by HPV.[19] Such a strong association between HPV and cervical cancer has led researchers to declare that continual infection of the cervix with high-risk strains of HPV is a precursor in the development of cervical cancer. This assertion is given credence by the finding that two strains of HPV, HPV 16 and 18, are the cause of 70% of all cervical cancers.[20] Cervical infections with HPV typically are cleared or suppressed within 1 to 2 years of exposure; those infections that continue beyond this timeframe are strongly associated with a diagnosis of cervical pre-cancer.

Besides HPV infection, another significant risk factor in the development of cervical cancer is smoking. Women who smoke are twice as likely as non-smokers to develop cervical cancer. While the exact mechanism causing the relationship between smoking and cervical cancer is unknown, two noteworthy causal mechanism have been identified: tobacco-related chemical carcinogens damaging the DNA of cervix cells and contributing to the development of cervical cancer, and tobacco exposure negatively affecting markers of immune system functioning and response, thus making the immune system less effective in combating HPV infections.[21] Furthermore, nicotine and tobacco-specific carcinogens have been identified in the cervical mucus of smokers, clearly underlining the detrimental association between smoking behaviors among women and cervical cancer.[9]

Another important risk factor is family history of cervical cancer. Women who have a first-degree relative with a history of cervical cancer are 2 to 3 times more likely to develop invasive cervical cancer than women with no such family history.[22] Some researchers posit

that familial connections to cervical cancer development may be due to an inherited condition making affected women less able to combat HPV infections than their peers. However, despite this hypothesis, it is currently inconclusive as to whether this particular risk factor is a result of genetic predispositions or shared environmental exposures and lifestyle factors.

Alongside the risk factors discussed previously, another risk factor for cervical cancer is use of oral contraceptives. Findings showing an association between oral contraceptive use and cervical cancer have been controversial. Nonetheless, evidence exists that long-term use of oral contraceptives increases the risk of cancer of the cervix. Generally, this evidence implies that risk of cervical cancer increases as the duration of oral contraceptive use increases; this association is especially true among women who test positive for high-risk cervical HPV strains. Compared with women who never used oral contraceptives, women who used oral contraceptives for 5-9 years, and tested positive for high-risk cervical HPV strains, were twice as likely to develop cervical cancer; women who used oral contraceptives for ten years or longer were four times more likely to develop cervical cancer.[23] Moreover, women reporting use of oral contraceptives within the past 5 years were nearly three times more likely to develop cervical cancer compared to women who never used such contraceptives, while a similar level of risk was observed among women who began using oral contraceptives before age 20.[11] It is important to note, however, that a degree of heterogeneity of results exists among studies examining the association between oral contraceptives and cervical cancer that adjust for HPV status.

Apart from knowledge of the risk factors for cervical cancer, it is critical for women to recognize the warning signs for cervical cancer in order to initiate action for early detection and treatment. Women with pre-cancers or early cervical cancers may not have

any signs or symptoms of the disease. These signs and symptoms normally occur in advanced cervical cancers, wherein the cancer becomes invasive and spreads to neighboring tissues. Symptoms indicative of cervical cancer include: abnormal vaginal bleeding, such as after vaginal sexual intercourse, abnormal vaginal discharge, for instance bleeding after menopause, or pain during intercourse.[24]

2.2 Screening Tests, Policies, and Programs

Cervical cancer is easily detected before the disease becomes symptomatic via screening programs. The primary screening test for cervical cancer, the Papanicolaou Test, often referred to as the "Pap test," or "Pap Smear," has contributed greatly to the precipitous decline in cervical cancer mortality which occurred during the latter half of the twentieth century. From 1946 to 2000, the US age-standardized cervical cancer mortality rate is estimated to have declined by 76%, primarily due to the introduction of the Pap test in 1941.[25] A Pap test is a procedure employed to collect cervical cells for cytology testing, or examination of cells under a microscope to diagnose cancers and/or pre-cancers. During a Pap test, a small spatula is used to scrape a sample of cells and mucus from the surface of the cervix nearest the vagina. Thereafter, a small brush or cotton swab collects samples from the endocervix (the portion of the cervix nearest to the uterus). Lastly, the collected samples are prepared for microscopic examination through two primary methods, including: placement of the smear samples directly onto a glass microscopic slide prior to laboratory testing (referred to as "Conventional Cytology"), or suspension of the smear sample in a special preservative liquid prior to laboratory testing under microscope (termed "Liquid-based Cytology," or a liquid-based Pap test).[2]

Pap test screening is universally recommended as the primary means to detect cervical cancer by the three preeminent U.S.-based public health organizations that

standardized nationwide cervical cancer screening guidelines in 2003. These three organizations, American Cancer Society (ACS), the American College of Obstetricians and Gynecologists, and the United States Preventive Services Task Force (USPSTF), collectively recommend that cervical screening begin 3 years after sexual debut, but no later than age 21. The point of contention between these three organizations concerns the frequency and discontinuation of cervical cancer screening. The USPSTF recommends that women be screened on at least a triennial basis. The ACS and the ACOG, meanwhile, recommend that women less than 30 years old be screened on an annual basis if a conventional Pap test is used; the ACS extends this screening interval to a biennial basis if a liquid-based Pap test is used. For women older than 30, both the ACS and the ACOG propose that screening may occur on a biennial or triennial basis if a woman has three consecutive negative Pap tests. In terms of screening discontinuation, the USPSTF contends that women 65 years old or above should discontinue screening, while the ACS recommends discontinued screening at age 70 for women with 3 or more documented, consecutive, normal Pap tests and no abnormal Pap tests within the past 10 years. The ACOG, on the other hand, recommends assessing individual risk factors, such as multiple concurrent sexual partners, before discontinuing screening.[21]

Laboratory findings from Pap tests are reported using a system known as the Bethesda System. The three categories of findings employed by the Bethesda System include: Negative for intraepithelial lesions or malignancies (meaning no cancerous signs, pre-cancerous changes, or significant abnormalities were discovered), Epithelial cell abnormalities (confirming that cervical or vaginal cells display changes that might be cancer or a pre-cancerous condition), which is further sub-divided into the following classes- Atypical squamous cells (ASCs), including Atypical squamous cells of uncertain significance

that look abnormal but cannot be definitely diagnosed as pre-cancerous via microscopic examination, and Squamous intraepithelial lesions (SILs) that are divided into High-grade SILs (necessitating treatment and more likely to develop into cancer) and Low-Grade SILs, both of which may be treated prior to invasive cancer development and require additional follow-up testing, Squamous cell carcinoma, indicating that a woman is likely to have invasive squamous cell cancer, Adenocarcinoma (cancers of the glandular cells, i.e. endocervix, uterus, etc.), and finally Atypical glandular cells (when glandular cells look abnormal but cannot definitively be termed cancerous); lastly, the final category in the Bethesda system is Other malignant neoplasms, used to identify potentially problematic endometrial cells.[26] The importance of Pap tests cannot de understated; screening tests conducted every 3 years among women aged 20 to 64 have been shown to reduce the cumulative incidence of invasive cervical cancer by 91% according to estimates from the USPSTF. Regular Pap tests allow the detection of pre-cancers that can then be observed, followed, and treated before they progress to invasive cervical cancer thus halting the development of invasive cervical cancer entirely.

Annually, an estimated 3,644 deaths from cervical cancer could be prevented if every woman in the United States received the appropriate and recommended screening services.[27] In addition to its mortality benefit, early detection of cervical cancer through Pap test screening has the added benefit of reducing the considerable economic burden associated with cervical cancer. Direct annual healthcare costs in the US associated with HPV, cervical cancer screening, follow-up of abnormal Pap tests, treatment of invasive cervical cancer, and other associated costs are estimated at US$4 billion; this estimate includes annual costs of $300-400 million attributed to management and treatment of invasive cervical cancer.[28] Similarly, the impact of cervical cancer on productivity loss to the US labor market is

staggering. A recent study that quantified the societal burden due to HPV-associated cancers through estimates of productivity losses from premature cancer mortality, inclusive of factors such life expectancy, labor force participation rate, and values for household productivity (e.g. child care, food preparation, home maintenance, etc.), measured in 2003 US dollar rates, found that cervical cancer-related productivity costs were estimated at US$1.8 billion, or $US541, 576 per death.[29] Besides the cost savings early detection of cervical cancer contributes to productivity levels, early detection of cervical cancer via Pap tests also decreases treatment costs borne by government-administered public health programs such as Medicaid. Recent research analyzing the costs of cervical cancer treatment among Medicaid beneficiaries indicates that there is a direct relationship between stage of cancer at the time of diagnosis, and total treatment costs. Findings from a study examining North Carolina Medicaid recipients demonstrated that 12 months post-diagnosis, the average cost of treatment for cervical cancer that was diagnosed at stage 0 was $6,347. In contrast, the average cost of treatment for cervical cancer 12 months post-diagnosis that was initially diagnosed at stage 4 was $83,494.[10] Hence, the added value of early detection via expanded screening rates is undeniable, both in terms of lives saved and cost-effectiveness.

Recognizing the need to expand screening services for cervical cancer and precancerous lesions to underserved populations, in 1990 Congress passed the Breast and Cervical Cancer Mortality Prevention Act; this public law subsequently created the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) the following year. The goal of the NBCCEDP is to reduce breast and cervical cancer morbidity and mortality among low-income, uninsured/underinsured, and minority women aged 18-64 (for cervical cancer services), through the provision of free cancer screening, diagnostic tests, and public education and outreach. Cervical cancer screening services offered through NBCCEDP

include Pap tests, colposcopies, diagnostic evaluations (e.g. cone biopsies, endocervical scraping, etc.), and referrals for treatment services.[10] The program is administered by the Centers for Disease Control and Prevention's (CDC) Division of Cancer Prevention and Control through cooperative agreements with state government, Native American tribes, and US territory grantees. Recipients of NBCCEDP funds as of 2003 include all 50 US states, the District of Columbia, 6 US territories, and 14 Native American and Alaska Native tribes and tribal organizations.[30] Each NBCCEDP grantee allocates supplemental funding to the program and establishes eligibility criteria that determine women who comprise the program's beneficiary pool. Women who receive free screening services through NBCCEDP typically meet the following eligibility criteria that are standardized across most US states: have little or no health insurance, lack a primary care provider, and have incomes at or below 250% of the Federal Poverty Level.[11]

Despite the implementation of NBCCEDP nationwide, disparities in screening rates and availability persist. From 2004-2006, only 9% (775,312 of 8.9 million women aged 18-64) of NBCCEDP-eligible women received NBCCEDP-funded Pap tests nationwide. In 2005 more than 34% (3.1 million women) of NBCCEDP-eligible women did not receive recommended Pap tests from NBCCDCP or any other screening source.[12] During the same time period 16,947 late-stage cervical cancer cases (5.2 per 100,000 women) were diagnosed in women 20 years or older.[31]

Adoption of NBCCEDP in the state of Georgia occurred in 1994.[32] The program is referred to in the state currently as the Breast and Cervical Cancer Program (BCCP), or simply the Cancer Screening Program. The program's previous name was BreasTest and More. Georgia women who seek to qualify for free screening services through the BCCP must meet all of the following criteria: household incomes less than 200% of the Federal

Poverty Level, not possess insurance for cancer screening, or be underinsured and not eligible for either Medicare or Medicaid assistance, and lastly be between the ages of 18-64 (with special emphasis on women aged 40-64).[24] Another priority population of the BCCP is women who have a five year gap since their last Pap test, as this population segment has been deemed high-risk by the CDC. Mirroring the disparities apparent in the national NBCCEDP, Georgia's BCCP has also fallen short in maximizing screening rates. During the 2007 calendar year, over 94,000 Pap tests were performed by the BCCP, out of 384,000 women statewide who met the program's eligibility criteria. Therefore, only 25% of eligible women in the program's target age group of 40-64 received cervical cancer screening and diagnostic services through BCCP.[24] This shortfall in screening rates has largely been attributed to federal underfunding of the state program.

Seeking to redress the lack of coverage of treatment costs for conditions diagnosed through NBCCEDP in its authorizing legislation, Congress passed the National Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) in 2000. This act catalyzed a disease-specific expansion of Medicaid, allowing states to extend Medicaid coverage to women for the duration of their treatment who met the following preconditions: be uninsured, 65 years old or younger, and screened for and diagnosed with breast or cervical cancer through NBCCEDP.[33] The program is administered through an interagency consortium of government partners, including the CDC, Centers for Medicare and Medicaid Services (CMS), state Medicaid directors, and directors of state and Native American/Alaska Native tribal grant programs.[25] Since the passing of its authorizing legislation, all 50 US states and the District of Columbia have enacted BCCPTA, firmly entrenching a previously optional publicly-funded health insurance program.[34]

Although the BCCPTA was enacted with the express purpose of expanding breast and cervical cancer treatment to most at risk populations, initial evidence regarding the impact of the act on treatment outcomes at the national level has been mixed. A study utilizing longitudinal NBCCEDP surveillance data (from 1995-2005) to estimate the impact of the BCCPTA on the timing of definitive cervical cancer diagnoses and treatment initiation within the program's first five years yielded heterogeneous results. Positive findings from the study indicate a 12.8% reduction in the average number of days to definitive cervical cancer diagnosis for white women (ranging from four to six days across age groups).[26] On the contrary, negative findings from the study include significant increases of 60.6% for Black and 39.3% for Hispanic women, in the average time between diagnosis of cervical dysplasia or cancer and initiation of treatment (ranging from 7-15 days across age groups for both races), along with a 9% decrease in the probability that Black women would initiate treatment within 60 days of a cervical diagnosis.[26] While the impacts of the BCCPTA on time to enrollment outcomes at the national level have been heretofore mixed, comparable outcomes examined at the state level have been more promising.

Georgia enacted its version of the BCCPTA program, the Women's Health Medicaid Program (WHMP) in 2001.[35] The state's implementation of the program revised the BCCPTA's coverage options to include uninsured women screened for and diagnosed with breast or cervical cancer through non-NBCCEDP participating providers as eligible enrollees in WHMP. Eligibility criteria for WHMP were harmonized to correspond to the eligibility criteria for Georgia's Breast and Cervical Cancer Program.

Annually from 2003-2007, 390 cervical cancer cases were detected in the state of Georgia.[24] Due to the expansion of Medicaid coverage in Georgia through the WHMP, access to and continuity of care has greatly increased for the state's cervical cancer cases. A

recent study scrutinizing patterns of Medicaid disenrollment among women with breast or cervical cancer (pre- and post-implementation of the BCCPTA in Georgia) from 1999-2004 indicated that disenrollment rates declined 50% for women with breast and cervical cancers during the timeframe.[36] As recipients of Georgia's BCCPTA-sponsored Medicaid program must be actively enrolled in treatment, these findings indicate that stable coverage may contribute to improved continuity of care and consequent treatment outcomes for breast or cervical cancer patients. Further, a related study comparing the likelihood of Medicaid enrollment in a given month between 1999-2004 (pre- and post-BCCPTA enactment) in a breast/cervical group to a cancer control group, as well as time to enrollment (measured in months) for individuals eventually enrolling in the state's Medicaid program produced complimentary positive findings. This study's results noted that of 1,000 women with local or later stages of cervical cancer, the number enrolling in the Georgia Medicaid program increased by 3.4 due to BCCPTA. Further, the time between cancer diagnosis and enrollment was shortened by 7 to 8 months.[37]

Given that screening services provided through NBCCEDP are reaching a relatively small portion of the program's eligible population, it is worthwhile to examine the nature and extent of barriers to cervical cancer screening among underserved populations.

2.3 Cervical Cancer Screening Barriers

Despite the recently observed declines in cervical cancer incidence and mortality, stark inequalities persist within discrete populations within the United States. Some estimates indicate that African Americans are twice as likely, while Hispanics are two to three times more likely to develop invasive cervical cancer than non-Hispanic Whites. Other high-risk populations include women with lower incomes and education levels, the uninsured or underinsured, and members of ethnic minorities or immigrant groups.[38] One of the most

critical factors underlying such disparities is the ability to access screening and appropriate follow-up services for abnormal Pap test results. Noncompliance with screening and follow-up recommendations results in suboptimal outcomes that can negatively affect a cervical cancer patient's prognosis. Divergence from prescribed screening and follow-up procedures may lead to later stage at diagnosis, which consequently can result in increased morbidity and mortality. The ability to access care is dependent on a set of interacting factors that oftentimes present challenges to individual women seeking care. The literature on barriers to cervical cancer screening has classified potential barriers into three overarching categories, namely: cultural and personal barriers, socioeconomic barriers, and institutional barriers.[13]

Culture may be operationally defined as a worldview that encompasses an individual's or community's shared communication system, similarities in physical and social environments, common beliefs, values, and traditions, and similarities in lifestyle, attitude, perceptions, and behavior.[13] In terms of cancer healthcare seeking behaviors, culture may influence an individual's capability to understand and internalize the need to seek or accept cancer care and perceptions related to the likelihood of developing cancer. Further, culture may affect one's capacity to understand information on cancer and screening, since culture is a key determinant of beliefs and perceptions regarding cancer. Cultural beliefs may give rise to the oft-noted phenomenon of cancer fatalism (i.e. the perception that a cancer diagnosis is a death sentence), while personal factors may involve competing life priorities such as income generation, work, or familial responsibilities, that moderate the importance of cancer screening in comparison.[32,13] Prominent iterations of cultural barriers identified in the literature include: lack of accurate cancer information; underutilization of cancer information (if available) due to literacy, language, or cultural concerns; cultural beliefs regarding cancer

and cancer fatalism that obstruct individuals from seeking care; lack of community support for screening activities; and cultural perceptions of quality care.[32]

Moving from the simple delineation of these cultural barriers, recent research has attempted to link specific cultural or personal phenomena that act as barriers to screening with specific populations. A recent study conducted in three inner-city hospitals in Chicago and New York City investigated the association between cultural barriers, health beliefs, and Pap test use patterns among African American and Hispanic women newly diagnosed with invasive cervical cancer. Cultural barriers reported by the African American women who had never received a Pap test included: the belief that cancer was the result of bad luck, and the desire to not be informed they had cancer.[13] A qualitative study conducted among middle-aged African American and Hispanic women enrolled in community health centers in New York City elicited cultural barriers to cervical, breast, and colorectal cancer screening. The main cultural barrier to cervical cancer screening cited by the women in this study was a perception that screening tests were unnecessary if in good health or not experiencing symptoms indicative of ill health.[13] Further, a qualitative study conducted among Florida direct healthcare service providers described the cultural and personal barriers that impeded their clients' ability to access cervical screening services.[30] Cultural barriers described in this study include community-based fears of deportation and mistrust of the health system and physicians, and perceptions that cancer diagnoses are a curse or death sentence. Personal barriers described in the study include lack of finances to cover everyday expenses (i.e. child care, transportation and gas, rent, etc.) necessitating a choice between basic essentials and preventive health care, as well as low levels of literacy that hamper completion of enrollment forms and reading of appointment reminder cards.[30]

These studies' findings on cultural and personal barriers are supported by recent reviews of the literature evaluating factors that inhibit decisions by minority women to obtain cervical cancer screening. One such review, focusing on African American and Hispanic women, enumerated the following cultural and personal barriers among African American women: the belief that not knowing if cancer is present is better than such knowledge, the tendency to term health prevention as unnecessary unless symptoms are present, beliefs that cancer treatments are worse than the disease itself, the inability of an individual to reduce the risk of cancer, a belief that cutting into a cancer makes it spread, and a belief that an individual has little to no self-efficacy in minimizing their risk of cancer .[13] Another review focusing on minority women described the following personal barriers to cervical cancer screening: discomfort at a doctor's touch, embarrassment, and fear of pain.[31]

As opposed to cultural barriers, socioeconomic barriers are not based on belief systems, traditions, or worldviews, but on measures of economic and educational attainment. Socioeconomic status, as a concept, may be defined as a composite measure that typically incorporates the following three closely-related elements: economic status as measured by income level, social status as measured by educational attainment, and professional status measured by occupation.[13] One's economic status may hinder access to medical insurance, or the ability to cover incurred medical costs. Poor socioeconomic status is also associated with suboptimal physical and social environments, inadequate information and knowledge, risk-promoting lifestyles, and lack of insurance or being underinsured. Individuals with low socioeconomic status are likely to have less correct information and knowledge, are less likely to undergo cancer screening tests, and are less likely to be informed of abnormal screening and diagnostic results in a timely manner.[32] The most common markers for socioeconomic status that have been utilized in the literature concerning cervical cancer

screening barriers include: income, poverty level, educational status, and residence in socioeconomically disadvantaged areas. Prominent barriers noted in the literature include health insurance status, problems of paying for services, and lack of screening facilities.[13,32]

Recent research has attempted to quantify the relationship between socioeconomic status and cervical cancer screening adherence. A study that investigated factors associated with failure to obtain cervical and breast cancer screening among inner-city African American women who received a culturally appropriate multimedia educational intervention found that failure to obtain Pap tests post-intervention was significantly associated with insurance status. Women with private insurance were more likely to be screened than those covered by Medicaid, Medicare, or who were uninsured ($p \leq 0.01$).[13] Interestingly, this study did not find education, income, or employment to be associated with post-intervention screening among the study population. However, even in studies conducted among women with health insurance plans, other socioeconomic factors are associated with failure to receive cervical cancer screening. For instance, a recent study utilizing medical record review of women diagnosed with invasive cervical cancer between 1995-2000 covering approximately 8 million people found that failure to receive a Pap test was associated with living in areas of high poverty (OR=1.72, 95% CI=1.11-2.67) or possessing lower education (OR=1.52, 95% CI=1.07-2.16).[13] The findings from these studies are supported by reviews of the literature examining the underlying factors in cervical cancer screening disparities. One such review states that one's socioeconomic position is a better indicator of cervical cancer screening rates than race or ethnicity; ultimately making the assertion that women from low socioeconomic backgrounds face significant barriers to cervical screening services.[13] Another recent review, citing data from the 2000 Behavioral Risk Factor Surveillance Survey linked with state-specific NBCCEDP data, indicated that low income

and lack of medical insurance were significant barriers to Pap test screening among Hispanic and African American women, and also cited low levels of education as reliable indicators for screening nonadherence.[31]

In comparison to socioeconomic barriers, institutional barriers are structural in nature, and primarily deal with organized systems and structures, such as the healthcare system. Institutional barriers may therefore be broadly defined as barriers that represent the larger systems factors that constrain and impact women's screening options.[30] With respect to cervical cancer screening, institutional barriers may inhibit access to care, negatively impact the provider-patient relationship, or jeopardize access to and engagement with a usual source of care. Notable institutional barriers identified by the literature include: failure of physician to recommend screening, financial issues that affect patient access to care, poor provider-patient relationships, and limitations on screening and treatment services.[32]

Contemporary research attempts to describe the association between institutional barriers and cervical cancer screening discrepancies. A study using nationally representative data from the 2000 National Health Interview Survey to examine whether women received physician recommendations to get Pap tests found that among 2,310 women reporting not receiving a Pap test, 10.3% reported that "the doctor didn't order it" (95% CI=8.7%-12.0%). Likewise, the study reported that among women who had a doctor visit within the past year but did not receive a Pap test, 86.7% reported that their doctor had not recommended a Pap test in the previous year (95% CI=84.5%-88.6%).[13] Another study that examined the correlates of adherence to cervical cancer screening guidelines among African American and Hispanic public housing residents in Los Angeles found that 29% of the study sample (n=230) reported that no health care provider had ever informed them that they needed a cervical cancer screening test. The study further reported that continuity of care was

strongly associated with obtaining a Pap test, as study subjects that reported lack of continuity of care were up to four times less likely to report having had cervical screening within the past year.[13] Results from recent reviews of the literature confirm and expand upon these study findings. A recent comprehensive review found that having a regular physician or usual source of care was associated with increased cervical cancer screening rates. This review also noted that cervical cancer screening failures were reported to have occurred in 30%-69% of insured women over a three year screening period.[13] Another recent literature review enumerated the various forms of health access barriers, including: long wait times at health clinics, lack of transportation, no family support, lack of available child care, and difficulty obtaining an appointment (for individuals in managed care).[31]

Hence, while the NBCCEDP has introduced free or reduced cervical cancer screening programs into local health departments and other public healthcare providers, and increases in Pap test screening rates have occurred, these programs are still only reaching a portion of eligible individuals. Pap test rates among underserved, socioeconomically disadvantaged women remain persistently low when compared to the general population. An analysis of the barriers discussed above that are exhibited within such populations may shed light on why these screening rates remain low. Currently, very few studies have been published that document the cultural beliefs and personal perceptions of African American women regarding cervical cancer that act as barriers to screening. The majority of research concerning cultural and personal barriers conducted among minority women has focused on Hispanics, as Hispanic women tend to have lower rates of screening than African American women. African American women, however, tend to be screened less as they grow older, by which time the risk of cervical cancer increases. An exploration of the barriers inhibiting these African American women from accessing cervical cancer screening services would

assist state-run NBCCEDP programs, such as Georgia's BCCP, to better target their outreach efforts to a reach priority groups, such as women aged 40-64. The research on socioeconomic and institutional barriers to screening has tended to focus on either women with private insurance, or women who were uninsured. Very little research on these two types of barriers has been conducted among recipients of publicly-funded health insurance programs, such as the Women's Health Medicaid Program. Further, research on barriers to screening among "underserved and socioeconomically disadvantaged" women has tended to refer to such women as a homogenous group when enumerating specific barriers. Only a relatively few studies have attempted to explain whether underserved women of different racial backgrounds experience the same types of barriers to cervical cancer screening. A qualitative study of the barriers to cervical cancer screening among enrollees of Georgia's WHMP program will be useful in attempting to fill these knowledge gaps in the public health literature. A qualitative approach will be useful in collecting rich narrative material on women's health beliefs and health behaviors concerning cancer screening. This data will assist in discovering important underlying themes and behavioral patterns. Such an approach will be helpful in gaining emergent understanding and drawing comparisons between groups of the thematic barriers to screening that exist among this special population.

3.0 METHODOLOGY

3.1 Introduction

This study utilized qualitative methods, namely in-depth interviews, and qualitative data analysis techniques to accomplish its specific aims. Data analyzed for this study was collected in the qualitative component of a larger mixed methods study investigating the timing of important events, such as diagnosis, Medicaid enrollment, and treatment among

African American and Caucasian women with breast cancer, cervical pre-cancer or cervical cancer who enrolled in Georgia's Women's Health Medicaid Program. This larger study was funded by a grant from the American Cancer Society (grant number RSGT-05-004-01-CPHPS) to the study investigators based at Emory University's Rollins School of Public Health, namely: Dr. E. Kathleen Adams (Principal Investigator), Dr. Karen Andes (Co-Principal Investigator), and Mrs. Sarah Blake (Co-Principal Investigator). Prior to the commencement of the larger study, human subjects approval was sought and granted by Emory University's Institutional Review Board. The present study, and the views expressed herein, is not necessarily representative of views held by the funding agency.

The qualitative portion of the mixed methods study interviewed two discrete groups: women, who had experienced episodes breast cancer or cervical cancer or its precursors, and physicians, particularly radiologists, oncologists, and surgeons, who actively served women with the aforementioned conditions. The study in question only draws upon the interviews with women diagnosed with cervical cancer or precancerous lesions.

3.2 Population and Sample

The population eligible for participation in the in-depth interviews was African American or Caucasian women who currently (at time of interview) or previously were enrolled in the Georgia WHMP. In order for these women to enroll in WHMP, they must satisfy all of the following eligibility criteria: have household incomes less than 200% of the Federal Poverty Level, not possess insurance for cancer screening, or be underinsured and not eligible for either Medicare or Medicaid assistance, and be between the ages of 18-64. It is not a necessity for these women to be screened for and diagnosed with cervical cancer through NBCCEDP-participating providers to enroll in WHMP.

Recipients of Medicaid in Georgia, including WHMP enrollees, are required to register with one of three Care Management Organizations (CMOs). The three Georgia Medicaid CMOs are WellCare, Amerigroup Community Care, and Peach State Health Plan. Study staff partnered with representatives of each CMO to recruit women to participate in in-depth interviews through mailers and offers of cash incentives ($50).

The sampling frame for the larger qualitative study was 64-72 women with breast and cervical cancer, evenly distributed by cancer diagnosis. This sampling frame was further stratified by race (African American or Caucasian) and area of residence (urban or rural); area of residence was based on the county where interviewees resided. Based on the lower estimate of 64 interviews, the study strata were broken out as shown below:

	BREAST CANCER INTERVIEWS		**CERVICAL CANCER INTERVIEWS**	
	Urban	**Rural**	**Urban**	**Rural**
African American	**8**	**8**	**8**	**8**
Caucasian	**8**	**8**	**8**	**8**

Due to difficulties in recruiting African American women residing in rural areas with cervical cancer diagnoses, the sample for this study is less than that envisioned in the larger study. This study's sample includes the interview transcripts of 25 WHMP-enrolled women with cervical cancer, or cervical dysplasia. The women ranged in age from 19 to 60 years. In terms of cancer diagnoses, 10 (40% of the study sample) of the women were diagnosed with invasive cervical cancer, and 15 (60% of the study sample) were diagnosed with a form of cervical dysplasia. This study's strata is broken out as follows:

	CERVICAL CANCER INTERVIEWS	
	Urban	**Rural**
African American	**8**	**1**
Caucasian	**8**	**8**

3.3 Research Design

The in-depth interviews utilized a "life history" approach in interviewing 64-72 women about their breast or cervical cancer episodes and WHMP enrollment. These interviews focused on six key "moments" in the cancer episodes, specifically: suspicion or fear of a problem, seeking cancer screening, receipt of cancer diagnoses, making treatment decisions and subsequent receipt of treatment, and obtaining follow-up care. Each interviewee was asked to explain their cancer history, focusing on the screening, diagnostic, treatment, and follow-up services received, location where these services were accessed, and notably the barriers they faced or perceived as they advanced through these processes. Additionally, interviewees were asked to depict both the personal and system factors that influenced their decisions regarding screening, diagnosis, treatment, and follow-up care, in order to capture explicit barriers and facilitators in each woman's cancer episode.

3.4 Instruments

Upon their successful recruitment to participate in the study, interviewees were invited to participate in face-to-face in-depth interviews with Emory-affiliated study interviewers to elicit their cancer experiences. These in-depth interviews lasted between one and two hours, and were audio-recorded using digital audio recorders with the consent of the interviewee. Prior to the commencement of each interview, informed consent was obtained by each participating woman through the review and discussion of the study's

informed consent policies with the study interviewers, as laid out in the informed consent form (Appendix A). This document, prepared by two of the study's Co-Investigators, Dr. Karen Andes and Mrs. Sarah Blake, explained the purpose of the study, the procedures utilized to maintain confidentiality of study records, the study incentive ($50 per interviewee), and the process of withdrawal from the study. Informed consent was obtained verbally, and documented via the interviewee's signature, and affirmed via the signature of individual conducting the informed consent discussion, normally the study interviewer.

The conduct of the in-depth interviews with women diagnosed with cervical cancer or cervical dysplasia was guided by a semi-structured interview guide (Appendix B) designed to capture data on the aforementioned six key "moments" of the women's cancer experiences. This guide, also prepared by Dr. Karen Andes and Mrs. Sarah Blake, was also designed to capture social and behavioral factors that affect the women's outcomes which were not amenable to quantitative data collection instruments or empirical measures, such as levels of fear, distrust of the medical system, and family history of cancer. Furthermore, this guide was drafted to assess the barriers these women experienced in advancing through the "life history" of their cervical pre-cancer or cancer. Sample questions from the guide included: Suspicion-When did you first suspect that something was wrong?; Screening-When did you get tested/screened? What was that like?; and Diagnosis-What was it like hearing that you had cancer?

3.5 Data Analysis

The present study utilized 25 interview transcripts of WHMP-enrolled women with cervical cancer, or cervical dysplasia for the purposes of analysis. These transcripts were removed of all personally identifiable information and assigned a pseudonym for each interviewee. Each transcript selected for analysis needed to include the following

information: discussions of beliefs about health and cancer, information about seeking (or failing to seek) cancer screening tests, i.e. Pap tests, and discussions of challenges in obtaining cancer care and facilitators that assist in overcoming such challenges.

The interview transcripts were entered into the textual data analysis software package, MAXqda (version 10). This program aids in the organizing of qualitative data through systematic indexing, annotation, and retrieval functions. Once the transcripts were entered into MAXqda, a set of deductive codes were defined, entered into MAXqda, and applied to the data. These codes represented the study objective of capturing the six key "moments" in the life history of the women's cancer experiences (e.g. suspicion, screening, diagnosis, treatment, follow-up care). Supplemental codes aimed to explore other aspects of the women's cancer stories or life experiences during their cancer episodes, such as cancer perceptions and beliefs, differential care received by providers based on socioeconomic variables (place of residence, race/ethnicity, level of education, etc.), social support extended to or provided by the interviewee, and enrollment in WHMP. The study in question utilized three of these codes for the purposes of data analysis and achievement of the study aims. These codes of interest were: Barriers/Facilitators, Cancer Perceptions/Beliefs, and Screening. Definitions for each of these codes are provided in the table below:

CODE NAME	DEFINITION
Barriers/Facilitators	Discussions of challenges in obtaining cancer care and things that help overcome such challenge. Includes discussions of quality of care. Excludes broader discussions of things that make it harder or easier to deal with cancer that are not related to access to care.
Cancer Perceptions/Beliefs	Discussions of beliefs about health and cancer, experiences with friends or family members' cancer, and how these perceptions and beliefs influence behaviors related to seeking care, making decisions, etc. Includes

	background knowledge, health education received, risk perceptions. Excludes straightforward discussions of medical interventions.
Screening	Discussions of screening such as Pap tests, mammography, breast self-exam, and post-treatment re-screening (mammography, Paps). Includes explicit discussions of not seeking screening and the reasons for this, as well as timelines. Excludes screening for other cancers (apart from breast/cervical) or conditions.

A detailed qualitative analysis of the interview transcripts was executed using elements of the content analysis approach, through the systematic retrieval and review of data categorized by each of the aforementioned three codes. The first preliminary data analysis step focused on the preparation of "mini summaries" for each of the three codes of interest per transcript, to summarize relevant data captured by the codes of interest. In the second preliminary data analysis step, the salient data contained in the "mini summaries" were organized into a summative table by transcript pseudonym and code to identify recurrent patterns of barriers to screening. The data contained in this table identified three thematic barriers to accessing cervical cancer screening services: 1-Lack of screening for HPV and poor uptake of the HPV vaccine and confusion on the relationship between HPV and cervical cancer, 2- Poor provider-patient relationships and negative perceptions of quality of care provided at health departments, and 3-Cultural and/or personal beliefs inhibiting access to cervical cancer screening services, including: believing cancer will self-correct, viewing cancer as a death sentence, fear of doctors, competing priorities, "illiteracy" concerning women's health issues, and lack of sexual promiscuity. Descriptive analyses were performed for each of these three barriers. In order to accurately represent the diversity of sentiments that both substantiated and refuted these barriers, data were indexed and within-

group comparisons were constructed per theme and racial group. Lastly, in order to draw comparisons between racial groups per barrier, between-group comparisons were constructed between the African-American and Caucasian cases.

3.6 Limitations

In this study, data on barriers to cervical cancer screening was collected from women with invasive cervical cancer or cervical dysplasia through in-depth interviews. As is common with in-depth interview data, generalizations about the results of this study cannot be extended to wider populations due to the small sample size for this study, and the purposive sampling method used. In order for such generalizations to be made, future research efforts should employ a larger, multi-state sample to investigate potential barriers to cervical cancer screening among NBCCEDP-eligible women.

Further, since the in-depth interviews were conducted either in the latter stages of the cancer experience, or after the conclusion of a woman's cancer experience, the data captured in the transcripts may be vulnerable to interviewees' recall bias, such as memory failures or misremembering of events. Hence, reporting of events in the cancer experience may be based on what the women think happened, rather than their actual experiences. However, data from this population offers a unique outlook on the cervical cancer screening behaviors of low income and underinsured/uninsured women at increased risk of cervical cancer.

Lastly, the data in this study may be subject to contextual effects that may affect data quality. These contextual effects include characteristics of the interviewer, interviewee's level of comfort with the interview format, or the interview's setting; these contextual effects may influence the responses provided by interviewees. Considerable efforts were made to

minimize the impact of these contextual effects through the informed consent process and the training provided to study interviewers.

Despite the limitations associated with this study, women were given the opportunity to explain their cervical cancer screening behaviors in an open-ended context and in their own words. Consequently, the data was richer in context due to the structuring of the in-depth interviews. For these reasons, this study provides insightful explanations of the reasons why women within this special population may falter in receiving cervical cancer screening.

4.0 RESULTS

4.1 Introduction

All of the women interviewed had begun receiving Pap tests on an annual or semi-annual basis at some point in the past, however many reported subsequent gaps in screening. Three key factors influenced cervical cancer screening behavior among interviewees. The first was the importance of education about HPV screening, the HPV vaccine, and the link between HPV and cervical cancer. Education on these three issues, provided primarily by physicians and coworkers, contributed to women's decisions related to HPV screening. When this education was lacking, it contributed to missed opportunities for HPV screening, thereby constricting the cervical cancer screening options of interviewees. Three main behavioral patterns were observed among women relative to the first key factor: the extensiveness of provider education on HPV and its relationship to cervical cancer, the provision of HPV screening as part of STD screening, and provider recommendations to receive the HPV vaccine.

The second factor influencing screening behaviors concerned patient perceptions of quality of care in their interactions with providers. Characteristics of patient-provider

interactions that contributed to perceptions of quality care included: attempts by providers to reassure and comfort women during their screening experiences, displays of empathy towards the women's conditions, and encouragement towards women to ask questions about their conditions, screening tests and results. Providers who exhibited these characteristics of quality care were instrumental in assisting women to deal with their diagnoses and move through the cancer care system. On the other hand, providers who did not exhibit these characteristics were viewed negatively by interviewees, who highlighted lax provider attitudes towards abnormal screening results, feelings of being "rushed," or discouraged from asking questions, and lack of detailed explanation of test results as important barriers.

The third factor consisted of cultural or personal beliefs that influenced women's ability to comprehend and internalize the need for screening services. Cultural beliefs included: beliefs that cervical cancer would "fix itself," that a cancer diagnosis was a "death sentence," and that Paps were unnecessary for women who "felt healthy" or were not sexually promiscuous. Personal beliefs that hindered screening included: being "too busy" for screening, having competing priorities (primarily work-related), and lacking insurance or finances to cover the cost of screening.

The experiences of women who encountered these barriers are recounted below, both in terms of their individual experiences and in terms of evident patterns among African American and Caucasian women.

4.2 Findings

Education on the link between HPV and cervical cancer

Roughly one quarter of the women interviewed (6 cases) were educated on HPV and its linkage to cervical cancer. Only one participant explicitly stated that she was tested for

HPV; five had either had physicians recommend the HPV vaccine or had requested it themselves. Within this group, the differences observed between the African American and Caucasian women suggest that Caucasian women may be more likely to seek information out on their own while African American women may rely more prevalently on information from providers.

The two African American women in this group had received education on the HPV-cervical cancer relationship from providers or coworkers; however this education came late in their screening timelines, long after receiving an initial abnormal Pap result. Both learned about the HPV vaccine from their physicians; neither had sought information on their own initiative nor requested the inoculation. One of these women had received two abnormal Pap results in 2006 and 2007, and was treated both times with cryotherapy procedures. On receiving a third abnormal Pap in 2009, she was referred to a new doctor for a LEEP procedure, who educated her about HPV and its connection to cervical cancer.

> She gave me, like, pamphlets about it and everything and told me that basically me having the cells that basically it was, you know, from HPV and everything…And she told me that sometimes, you know, possibly you can get it from, you know, it's passed, you know, can be passed during intercourse of course and sometimes if you had, like, untreated, I think she told me something about if you had untreated STDs that you may not have known about or anything, sometimes it can lead to having HPV sometimes. And then other times it could just be…your first, you know, experience, somebody passed it on to you or something…she kind of explained to me and have me some pamphlets about it. (162_CUA, 234)

Caucasian women in this group (4 cases) also received education on the HPV-cervical cancer relationship from their providers, but also sought information online. For these women, provider education occurred earlier in the screening timelines, typically directly after the receipt of their first or second abnormal Pap result. One such woman received a second abnormal Pap at age 21, after her earlier mild dysplasia had resolved on its own. This

provider discussed the cause of her abnormal Pap, educated her on the HPV-cervical cancer relationship, and recommended that she receive the HPV vaccine.

> She said, don't worry, it doesn't necessarily mean you have cancer. She said it could be that you have the HPV virus and that's why your Pap is abnormal. So I was curious and, you know, I asked her about it and she said that, well, she explained to me that it was an STD because, you know, she said it was an STD and I was like, I have an STD? I was like going crazy and, you know, she explained to me that anybody that has sex can get that, you know, and so I looked into that and I asked her to give me the Gardasil vaccine for that and she, I had the first 2 but I couldn't take the third one because I had a bad reaction to it. (151_CRW, 116)

Other women weren't initially educated by their providers, but researched their conditions online and learned about HPV's role in cervical cancer development. These women subsequently discussed HPV with their doctors, and some requested the HPV vaccine. One such woman had been getting annual Paps since age 14 and received her first abnormal Pap at age 26; her biopsy results confirmed three dysplasia sites. Upon receiving these results, she read up on her condition and learned of the connection with HPV. She spoke with her provider, requesting an HPV test and also the vaccine, although she was then over the recommended age to be vaccinated.

> I started reading up on it and started trying to figure out what was going on and, I mean, a lot of times, you know, people say that it was, comes from HPV and, you know, different things like that, and the thing is I'd never had an abnormal Pap and I'd never, and now, you know, they have the shot, the Gardasil which keeps you from getting anything, but see I was too old whenever that came out. I would have had to get all the series within like a few months because of my age when that came out. (148_CRW, 109)

In contrast, nearly half of the women interviewed (11 cases) were somewhat confused about the relationship between HPV and cervical cancer; they had not been tested for HPV nor vaccinated. Within this group, ten women received little or no education on

HPV and its relationship with cervical cancer. Where education was provided, it came in the form of pamphlets or passing conversations with doctors when discussing the results of abnormal Paps or other supplementary screening tests. In a few instances, women reported that their doctors told them that no screening test for HPV was available; in other instances, women were not offered the HPV test when screening for STDs. It is important to note that the standard STD screenings at Georgia county health departments, where the majority of the interviewees received screening, are Chlamydia, Gonorrhea, and Syphilis. HPV screening is seen as an adjunct to these three tests which may be administered when Pap results are inconclusive. In addition, these interviewees had not received the HPV vaccine, for several different reasons such as being above the targeted age range, being afraid of adverse reactions, thinking that the vaccine was "too new," and not personally knowing anyone who received the vaccine. Despite a history of routine cervical cancer screening, recurrence of abnormal Paps, and engagement with multiple types of providers, these women's stories highlight numerous missed opportunities to clarify the relationship between HPV and cervical cancer, screen for HPV, and provide the vaccine.

In a few (three) of these cases, women stated that their doctors did not mention HPV during screening, at diagnosis, or during treatment. When asked about HPV in their interviews, these women knew little about HPV, the connection between HPV and cervical cancer, or the existence of an HPV vaccine. If they had heard about HPV, they mentioned non-medical sources of information such as mass media or friends. Two of the three women in this group were African-American and had low levels of background knowledge on cervical cancer; these gaps remained despite their diagnosis and subsequent treatment of dysplasia or invasive cervical cancer. In one of these cases, a woman who hadn't had a normal Pap result since age 16 noted that by the time she had a hysterectomy at age 31, she

had seen multiple different providers and continued annual testing, yet had not been tested for HPV. She reported learning about HPV after her hysterectomy when discussing her condition with coworkers.

> I just heard about that about two months ago with some girls on my job, we did a little car wash, I was working up there at the little car wash for maybe a week or two and girls was talking about it then because I was telling them you know I had a hysterectomy, you know, and she asked me did anybody ever say something to me about it and I was like I don't even know what you're talking about I've never heard of that. I still don't know what it is really. (161_CUA, 459)

Finally, the remaining seven women in our sample of 25 had received some education from providers on HPV and cervical cancer; these predominantly Caucasian women were more proactive in their education about HPV, supplementing what providers told them with internet research. Among these women, confusion sometimes gave way to anger about not understanding how or why they had not been tested for HPV or offered the HPV vaccine during routine exams. One of these women who had had regular Paps and routine STD screening at the health department and received an abnormal Pap result at age 25 did not understand why she had not been tested for HPV.

> I was like, is HPV an STD or not? […] I was getting angry because I'm being told that I don't have an STD but I'm being told that I have an abnormal Pap. And I look online and an abnormal Pap says HPV. So I'm like, so there's no way that my Pap is or my abnormalness is from HPV because I don't have an STD…And I said, but I was tested for STDs and they said, yeah, but not HPV. It's like, but HPV is an STD right? And they're like, well, you know, I don't know, I mean maybe, maybe not but there's, there's really so many strands and it's really not considered an actual [STD] and I was like, I mean it was just so frustrating…with HPV, like, it's the masked thing that you never know if you have it or not unless something happens like this. (127_CUW, 89)

The interview data highlights the importance of in-depth provider education on HPV and its relationship to cervical cancer and pre-cancerous lesions. The stories of women who had incomplete or little education on HPV suggests that there were a series of missed opportunities during the screenings they did receive as part of their regular Pap smears or STD screenings. No doubt, these missed opportunities are closely related to perceptions of quality of care, discussed in the next section.

Quality of care

Nearly one-third (7 cases) of interviewees were satisfied with the quality of care they received from their providers during their screening experiences. Women praised providers who comforted and reassured them, were patient and empathetic, provided detailed explanations and were receptive to their questions. These attributes were expressed and valued by both African American and Caucasian interviewees. Patience and thoroughness were particularly valued.

> She helped me through this a lot too because you know she gave me confidence enough that they was going to fix me, they weren't going to let it take over my body. And so she really, she was really patient with me and made me feel secure. (120_CUA, 161)

> He's very thorough, he's always been the type of doctor, he's very easy going, he explains every little detail of what he is going to do because he wants his patients to understand…And he just sat down and explained what procedure he would have to do and what he was going to end up doing and what for me to expect when I got there, and what to expect after I got home after recovery. (129_CRW, 250)

The converse was also true; approximately one-third of interviewees (8 cases) reported unsatisfactory quality of care during their screening experiences. The provider attributes that characterized negative interactions included: reluctance to discuss patient questions, a perceived lack of empathy towards abnormal results, and an absence of detailed explanations

of test results. Again, these attributes were shared among both African American and Caucasian interviewees. In one such case, a woman described the lack of information provided as an issue of expertise.

> He really didn't […] you know, and that's the thing, and I don't know why these doctors do that. They never really explain to you in depth what everything, you know, it's like, I'm your doctor, trust me, but you're kind of, you pretty much go through it blind, you know." (154_CUA, 135)

Many interviewees transferred their beliefs about poor quality of care with providers employed by health departments onto the health departments as an institution, terming the overall quality of care provided by health departments as unsatisfactory. Again, women of both races conveyed such sentiments.

> My mamma says that, my brother's told me, you know, don't, you know, base your life on that, what they say, you know, because, I know because, and I see the type of people that come in there a lot, a lot of people use it because they keep having babies, and they really, really, really abuse all that, and just my grandma said, my mamma would tell me that, you know, it's just free healthcare, I mean, you don't expect a lot. (147_CUW, 359)

> How can you say it took you so long to find it when ya'll, when I've been having abnormal Pap smears for forever, you know if you done tested me and I have an abnormal Pap smear I feel like if you don't go to the next step and say 'Ok well we're going to test up for diseases, maybe that's why it's not coming back.' Ok you do that it's still not that then I think you should go deeper, don't just leave it, 'Ok well she ain't got no disease so I don't know what it is.' No, it's your job to find out what it is. And a result for you not doing that I had to have a hysterectomy at the age of 31. (161_CUA, 453)

Patient-provider relationships were judged based on a provider's ability to demonstrate the following attributes: providing reassurance and comfort to women during their screening experiences, displaying empathy towards women's abnormal results,

encouraging women to ask questions about their conditions, and providing thorough explanations of screening tests and results. When these characteristics were present, patients were able to more effectively deal with their cancer and move through the screening-diagnosis-treatment process. When they were not, however, the converse seemed to be true.

Cultural or personal beliefs

Roughly one-third of interviewees (8 cases) reported cultural or personal beliefs that may have inhibited their care-seeking behaviors. Cultural beliefs included: believing that cancer would "fix itself," equating cancer with a death sentence, having little education from female family members on women's health issues, and believing that Paps were unnecessary if one "felt healthy," or wasn't sexually promiscuous. Personal beliefs included: competing priorities (primarily work-related), being "too busy" for screening, and lacking finances to cover the cost of screening. While the personal beliefs expressed by African-American and Caucasian women were virtually the same, differences did exist among the cultural beliefs expressed by each group.

The African-American women within this group (4 cases) expressed both cultural and personal beliefs that were barriers to screening, although cultural beliefs were more prominent than personal beliefs. African-American women suggested that they thought the cancer would "fix itself," or conversely, they equated cancer with a death sentence. They also noted having a fear of doctors and needles and feeling "illiterate" on women's health issues due to a lack of education from female family members.

> I was too afraid to go because I knew what they were going to tell me, I wanted to go and I didn't want to go, and I kept telling myself you know I was a firm believer I would let it fix itself, it will go away if I don't touch it, if I don't mess with it it will fix itself, well it didn't fix itself. (118_CUA, 64)

> Growing up a child of the '50s, my mother and sister both being nurses, you know, whenever they mentioned cancer they'd say, 'oh, she has the "C,"' you know, and they would whisper it. And you knew it was a death sentence. And that's what I thought. (160_CUA, 55)

The Caucasian women in this group (4 cases) also expressed both cultural and personal beliefs, although compared to the African American women, they appeared to be on equal footing. For this group, cultural beliefs suggested that Paps were unnecessary if one "felt healthy" or wasn't sexually promiscuous. Personal beliefs centered on competing priorities and being "too busy" to access screening services, as well as financial constraints.

> Yeah, I'd, I had been wanting to do it but trying, you know, working forty hours a week, and we work 8-5. We couldn't go in early to make up hours, you know. And everybody was closed when I got off, you know, all the doctor's offices were the same, so I would have actually taken off time which would have been hours missed. And I just, I can't, that's something I just can't afford to do. (122_CRW, 110)

5.0 DISCUSSION

Few previous studies on barriers to cervical cancer screening have been conducted among enrollees of publicly-funded healthcare programs such as NBCCEDP or WHMP. Hence, little is known about why such programs designed to assist underserved, socioeconomically disadvantaged women persistently reach small percentages of the program eligible population. The use of qualitative methods in this study has produced rich narrative data on healthcare seeking behaviors and beliefs, whose analysis has provided key factors influential in the screening process of such women. The enumeration of these key factors serves to complement previous research efforts focused on barriers to screening among totally uninsured women, or women who possessed private insurance. Further, the utilization of qualitative methods was useful in determining whether the African American or Caucasian women in the sample experienced similar or different barriers to cervical cancer

screening. As previously noted, the existing literature on such barriers among "underserved and socioeconomically disadvantaged" women tends to conceptualize this group as monolithic, experiencing the same or similar types of barriers regardless of ethnic background. Only one finding within the present research supports this notion, namely the finding that both African American and Caucasian women reported identically similar attributes of providers that were used to judge patient-provider relationships. On the other hand, two of the study's findings indicated differences among African American and Caucasian women concerning screening barriers. The first of these findings highlighted the differences between the two groups on education concerning the HPV-cervical cancer relationship. African American women tended to have less background knowledge on cervical cancer than their Caucasian counterparts, and were more reliant on their provider's initiative to furnish them with information on HPV and cervical cancer. In contrast, Caucasian women were more likely to supplement provider information on HPV and cervical cancer with their own research, and were more likely to request additional screening measures such as HPV testing or the HPV vaccine. The second finding on cultural or personal beliefs underscored that cultural beliefs were more significant among African American women, while both types of beliefs were prominent among Caucasian women. Apart from the reasons described above, these findings are particularly germane to the current US federal public health policy and program environments, which are both in a state of transition in preparation for full implementation of the Patient Protection and Affordable Care Act. Specifically, these findings will be useful in formulating increasingly effective community outreach, secondary screening, and prevention efforts to reach larger numbers of underserved women, in order to achieve improved cancer and chronic disease outcomes,

through the act's envisioned expansion of Medicaid eligibility to all individuals with incomes equal to or below 133% of the Federal Poverty Line.

The finding that in-depth provider education on HPV and its relationship to cervical cancer and pre-cancerous lesions was critically important in preventing missed opportunities for education on the HPV-cervical cancer relationship, as well as HPV screening and inoculation provides an opportunity for Medicaid-participating providers to strengthen their prevention and behavior change efforts not only towards patients at risk for cervical cancer, but for other chronic diseases as well. One proposition to strengthen such efforts can be borrowed from the field of environmental health, namely the use of risk communication principles by providers when discussing the preventable nature of cervical cancer, the HPV-cervical cancer relationship, and the utility of the HPV vaccine. Risk communication, an interactive communication method that includes discussions about risk types and levels, is also designed to be participatory, involving discussants (i.e. patients) in making decisions that affect them, particularly in terms of developing plans to manage or minimize risks or risk behaviors. The use of risk communication would be useful in heightening risk perceptions among women most at-risk for cervical cancer, help such women to improve their decision-making regarding preventive measures (i.e. requesting the HPV vaccine), and help to minimize anxiety and confusion surrounding the HPV-cervical cancer relationship, or inconclusive Pap test results. In practice, the use of risk communication could also be beneficial for physicians when discussing other chronic conditions as well. Hence, Medicaid-providers would be well served to develop risk communication guidelines for its physicians to employ when discussing cervical cancer. These guidelines could then be pilot tested, refined, and broadened for use with other chronic diseases as well.

The finding on the attributes that women valued in their patient-provider interactions during screening experiences, which were integral in interpreting perceptions of quality of care, presents Medicaid decision makers with an opportunity to strengthen patient-provider interactions, and thus the delivery of care, system wide. Such patient-provider interactions could be improved not only for the small subset of patients seeking cancer screening services, but for all Medicaid patients. One way to improve such interactions may be to supplement the initial intake process, as well as the data stored in a patient's electronic medical records. An added "client profile" survey could be appended to existing Medicaid intake forms, to ascertain patient's preferences during interactions with their providers. The contents of this survey could be aligned with the critical attributes expressed by interviewees in this study (e.g. reassurance, comfort, showing empathy to problematic screening test results/diagnoses, patience in responding to patient questions, in-depth communication in explaining test results, treatment plans, etc.) to measure how important such attributes are from the patient's perspective when interacting with their provider. Areas of inquiry for the proposed survey could include: preferred methods of communication by providers, the patient's preferred level of involvement in health care decisions, and the optimal means of support delivered by providers. Critical data from this survey could then be included in an individual patient's electronic medical records, so that all Medicaid-participating providers, regardless of geographic location, could have access to such data to tailor their interactions with patients according to the patient's preferred specifications. Such data will thus help Medicaid-participating providers incorporate principles of patient-centered communication into their interactions with patients. This aggregated data could then be used by Medicaid officials to draft minimum standards for patient-provider interactions for all Medicaid providers, in an effort to improve the quality of care afforded to

patients. Such information may also be useful to Medicaid caretakers in determining reimbursement rates for Medicaid-participating providers, as the Patient Protection and Affordable Care Act changes the rationale for reimbursement from its previous justification based on number of patients served to its impending raison d'être based on quality of care.

Lastly, the finding on the cultural and personal beliefs expressed among this group that served to inhibit screening-related care-seeking behaviors presents Medicaid officials with an opportunity to develop joint government-community based organization coalitions at the state or local level; these coalitions can be utilized to implement culturally sensitive, community-based interventions and public awareness campaigns to overcome cultural and personal barriers to cancer screening among low-income women. These envisioned coalitions may increase cancer screening through the use of a case management approach to encourage early detection and treatment of chronic disease. Such coalitions can bring together relevant actors at the local level, such as state health departments, state-based cancer associations, local medical schools, and local cancer organizations. Community steering committees can then be formed to guide the operations of the coalition, with representation from Medicaid officials, healthcare providers, local government officials, and county or municipality residents. These coalitions can hire local residents in their areas of operation to work as lay health workers and provide case management services. Services provided by the lay health workers could include follow-up services for medical appointments, transportation assistance, and outreach education on early detection of chronic diseases, such as cervical cancer. This outreach education would be more effectual in overcoming cultural or personal barriers if the education provided incorporated key messages to address specific cultural or personal belief patterns; for instance, when working with African American audiences, such outreach education could address the notion of

cancer as a "death sentence," fear of doctors or needles, and the belief that cancerous conditions can self-correct. This form of education would be more effectual if at least a portion of the individuals hired as lay health workers were themselves cancer (or chronic disease) patients or survivors. Many of the women interviewed for this study expressed the need for more education on cervical health, and were motivated to get involved in their local communities as a result of their experiences. Hence, these women may be very amenable to acting as lay health workers under such an arrangement. One woman's sentiments about the need for such education are reflective of this phenomenon among cervical cancer survivors.

> "…I'm actually speaking to the [city newspaper], they're going to do a story on me, because January is cervical health awareness month, so I've become a big person on this and I believe you know, and I'm actually going to talk with the Health Department and see if they'll come, I'm speaking at a WOTEC meeting and educating women. I believe there's not enough education out there for women." (126_CUW, 380)

In fact, such a consortium was established in west Texas, in the El Paso area as well as in surrounding counties, which targeted a low-income population of Non-Hispanic White and Mexican American women. Through its use of the case management approach, this program increased the number of screenings for breast and cervical cancer by 85% in 3 years in its area of operation.[39]

In conclusion, the present study provides useful insights on the reasons why women eligible for enrollment into publicly-funded managed care do not seek routine cervical cancer screening services. This study has also identified three key factors that affect the receipt of such screening. The implications of this research will be useful in increasing the efficiency of chronic disease secondary screening programs for low income, underserved populations that will be expanded through the Healthcare Reform Act's provisions for Medicaid expansion. A question for future research efforts to address would be how barriers to

cervical cancer screening are affected by the expansion of Medicaid eligibility afforded by the implementation of the Patient Protection and Affordable Care Act.

6.0 APPENDIX A: INFORMED CONSENT FORM

Emory University Rollins School of Public Health

Consent to be a Research Subject

Women's Health Medicaid Program (WHMP) Enrollee Interview

Title: Expanding Medicaid Coverage and Time to Treatment: Effects by Race

Principal Investigator: E. Kathleen Adams, Ph.D.

Funding Source(s): American Cancer Society

Introduction and Purpose
You are being invited to participate in a research study on Georgia's breast and cervical cancer treatment program, known as the Women's Health Medicaid Program, or WHMP. I am asking you to participate because either you are currently enrolled in this program, or you were once enrolled in this program. Approximately 36 WHMP providers and 72 WHMP enrollees will be interviewed for this study.

Procedures
If you agree to participate, the interview will last between one to two hours. The interview will be conducted in person, at a location that is convenient to you. The overall purpose of the study is to learn about the experiences that both providers and patients have with the WHMP. For this interview, we are interested in learning about your experience as an enrollee in this program. In particular, we are interested in understanding your 'life history' with cancer. Talking about life histories means telling about your entire experience with your breast or cervical cancer, from the time you were screened for the cancer, through the diagnosis, and through treatment as well. We will ask you to talk with us about when you were screened for the cancer, why you chose to be screened, how you learned of your diagnosis, and what courses of treatment you chose and were offered as well. In particular, we are interesting in hearing your experience with the WHMP. We will ask you to tell us how you learned about this program, how you enrolled in the program, and how you found cancer treatment providers through this program. We are also interested in learning what if any barriers you've experienced accessing your cancer treatment through this program

A colleague and I will be taking written notes of your answers, and the interview will be digitally recorded with your permission. If you do not agree to have the interview recorded, please let me know.

Risks and Discomforts
There are no foreseeable risk or discomforts associated with this study.

Benefits
This study is not designed to benefit you directly. This study is designed to learn more about the Women's Health Medicaid Program (WHMP). The information you provide, however, will add to our knowledge about the WHMP.

Compensation
You will be given $50 for your participation in the interview. We will give you emergency care if you are injured by this research. However, Grady Health System has not set aside funds

to pay for this care or to compensate you if a mishap occurs. If you believe you have been injured by this research, you should contact Dr. Kathleen Adams at 404-727-9370.

Confidentiality

Certain offices and people other than the researchers may look at the study records. Government agencies, Emory employees overseeing proper study conduct may look at your study records. Study sponsors may also look at your study records. These offices include the Office for Human Research Protections, the sponsor(s), the Emory Institutional Review Board, the Emory Office of Research Compliance and the Office for Clinical Research. In addition, study records can be opened by court order or produced in response to a subpoena or a request for production of documents. Emory will keep any research records we produce private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

Contact Persons

If you have questions, I invite you to ask them now. If you have any questions about the study later, you may contact me at scblake@emory.edu or 404-712-9713. You may also contact the study's Principal Investigator, Dr. Kathleen Adams at 404-727-9370 or at eadam01@emory.edu.

If you have questions about your rights as a participant in this study, you may contact the Emory University Institutional Review Board at 404-712-0720 or toll free at 1-877-503-9797, which oversees the protection of human research participants.

If you are a patient receiving care from the Grady Health System, and you have a question about your rights, you may contact Dr. Curtis Lewis, Senior Vice President for Medical Affairs at (404) 616-4261.

Voluntary Participation and Withdrawal

Participation in this research is voluntary. You may refuse to participate, or refuse to answer any questions that you do not want to answer. If you decide to be in the study and change your mind, you may withdraw at any time. Your participation or nonparticipation will have no negative repercussions.

Consent

I have read this consent form (or it has been read to me). All my questions about the study and my part in it have been answered. I freely consent to be in this research study.

By signing this consent form, I have not given up any of my legal rights.

_____

Name of Subject

_____ _____

Signature of Subject Date

_____ _____

Signature of Person Conducting Informed Consent Discussion Date

7.0 APPENDIX B: CERVICAL CANCER INTERVIEW GUIDE

Life History Interview Guide - Cervical Cancer or Pre-cancer

Suspicion

When did you first suspect that something was wrong? Why?

- ***Disclosure***: Did you talk to anyone? Who? Provider?
- ***Thoughts/Feelings***: What were you thinking/feeling at the time?
- ***Health Care***: Did you have a regular provider then? [Where were you receiving care?]
- ***Delays***: Did you act on your suspicions right away, or did it take some time?
- ***Other events***: What else was happening in your life at the time?

Screening

When did you get tested/screened? What was that like?

- ***Process***: Where did you go? What did you have done?
- ***Communication***: How did you find out it was abnormal? When?
- ***Delays?***
- ***Thoughts/Feelings***: What were you thinking/feeling when you found out?
- ***Knowledge:*** How did you learn about your condition and the procedures?
- ***Support:*** What kind of support did you have?
- ***Other events***: *follow up on home, work, family, support, challenges/facilitators, faith*

Diagnosis

What was it like hearing that you had cancer?

- ***Communication***: What were you told about your cancer?
  - Type and stage of cancer
- ***Diagnostic process***: Did you have to have additional tests/procedures?
  - What were you told about these?
  - Referrals for treatment?
- ***Delays?***
- ***Thoughts/Feelings***: How did you react to all of this?
- ***Other events***: *follow up on home, work, family, support, challenges/facilitators, faith*

Treatment

How was your treatment – or treatment options – discussed with you?
How did you decide what to do?

- ***Discussion***: Who did you talk to about it? [provider, second opinion, support]
- ***Information***: Did you seek out more information about your cancer/treatment options?
- ***Access***: WHMP, Distance, referrals, enrollment in CMO [care management organization]

What was your treatment experience like? When did it begin? What was involved? Where are you now?

- ***Modalities***: Surgery (lymph nodes), radiation, chemotherapy, etc.
- ***Experience***: Duration, Side-effects, Mental Health
- ***Other events***: What else was happening in your life and how did that affect your treatment?

Closing

- Is there anything else you'd like to share with me about your story?
- Is there anything you wish that other women could know about your story?
- What about providers? What would you like them to take away from your experience?

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