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# Provider Perspectives on Factors Influencing Breast and Cervical Cancer Treatment among Georgia's Women's Health Medicaid Enrollees

By

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An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
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in the Hubert Department of Global Health
2016

# ABSTRACT

Provider Perspectives on Factors Influencing Breast and Cervical Cancer Treatment among Georgia's Women's Health Medicaid Enrollees

By Leslie Riddle

**Background:** Breast and cervical cancer are the second and fourteenth leading causes of cancer death among women in the United States, respectively. Despite nationwide implementation of a Medicaid expansion program for breast and cervical cancer treatment, differences in treatment among low-income and ethnic minority women persist that cannot be explained by clinical differences alone.

**Objective:** The objective of this study was to understand, from the perspective of providers serving low-income, uninsured and underinsured women, what factors influence treatment patterns among these populations. Comparisons across clinical and allied health care providers were also of interest.

**Methods:** The data consisted of 18 interviews with providers actively serving patients with breast and/or cervical cancer who were enrolled in the Georgia Women's Health Medicaid Program. The transcripts were coded using MAXqda 11 software, and descriptive and comparative analyses were performed for the factors that providers noted influenced patients' treatment decisions and behaviors.

**Results:** Three primary factors emerged as influencing patients' cancer treatment behaviors: 1) Patients' socioeconomic conditions, 2) Patients' knowledge, attitudes and beliefs, and 3) The availability of institutional-level support and resources. There were greater variations among clinical and allied health providers' perspectives relative to the first factor, with both groups conveying similar responses relative to the second and third factor.

**Discussion:** The study's findings point to the need to address economic barriers to treatment faced by low-income patients. The findings also call for a more holistic approach to cancer care that offers mental health and psychosocial support and linkages to resources across the cancer care continuum.

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# I. INTRODUCTION

## A. Background and Problem Statement

Breast cancer is the second leading cause of cancer death among women in the United States; cervical cancer is fourteenth.[1] The introduction and advancement of medical technologies for breast and cervical cancer screening and early detection have largely contributed to reductions in mortality for both cancers;[2; 3] however, disparities in breast and cervical cancer outcomes by race/ethnicity, income and insurance status persist. While differences in cancer survival have largely been attributed to barriers to screening that result in the lack of cancer detection or detection at a later stage, disparities in treatment may also play a role.[4]

To address the issue of access to screening of breast and cervical cancer for underserved populations, the United States Congress directed the Centers for Disease Control and Prevention (CDC) to establish the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) in 1991. The program provides federal funding for states to implement free cancer screening, diagnostic testing and referrals for treatment services for eligible low-income, uninsured and underinsured women. The Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) was subsequently signed into law in 2000, permitting states to extend Medicaid coverage to women screened and diagnosed with breast or cervical cancer through the NBCCEDP (and later through non-NBCCEDP-funded providers), in order to cover the cost of cancer treatment for these populations.[5]

Breast and cervical cancer screening has increased exponentially thanks to the NBCCEDP, with 4.8 million women served to date and more than 67,959 breast cancers, 3,715 invasive cervical cancers, and 171,174 precancerous cervical conditions diagnosed between 1991 and 2015.[6] However, despite these improvements, disparities by race/ethnicity and income persist in receipt of diagnostic follow-up and initiation and completion of treatment. Both quantitative and qualitative research methods have been utilized to shed light on these persisting disparities, with mixed results. Existing data suggest that BCCPTA facilitates access to equitable treatment for all patients but that treatment modalities differ somewhat by race.[7] However, to date the research on the overall effect of BCCPTA on access to timely and appropriate treatment for low-income and minority women has been relatively limited, suggesting the need for further investigation.

## B. Study Objective

The objective of this study is to explore how this unique pathway to treatment facilitates women's receipt of cancer care from the perspective of providers who participate in Georgia's BCCPTA program, known as the Women's Health Medicaid Program (WHMP). Further, it examines the remaining barriers to timely and complete treatment that have not been resolved by Medicaid enrollment alone. The purpose is not to evaluate whether women's cancer treatment in the WHMP is clinically appropriate, but rather to explore providers' perceptions of barriers to care, including the full continuum of cancer-related services. The comparison of perspectives among clinical and allied health care providers, including social workers and patient navigators, is of particular interest. Many studies to date have focused on patient perspectives regarding health care access; the goal of this study is to understand the views of providers as an additional set of key stakeholders. The use of qualitative methods facilitates an assessment of health beliefs and other "unobservable" factors that may influence receipt of cancer treatment. Findings from this study can inform the continued development and improvement of programs like BCCPTA in closing the treatment gap among underserved women with breast and cervical cancer nationwide.

## C. Study Aims

1) To understand providers' perspectives on factors influencing cancer treatment decisions and behaviors among enrollees of the Georgia Women's Health Medicaid Program.

2) To compare perceptions of these influencing factors among clinical and allied health providers.

## D. Study Significance

Research on BCCPTA has shown that the program has expanded access to life-saving cancer care for thousands of low-income, uninsured and underinsured women.[8] However, disparities in cancer treatment and outcomes persist that necessitate further inquiry. This analysis is part of a larger mixed-methods study that included a qualitative component focused on understanding the factors that underlie these disparities by shaping treatment perceptions, decision-making and reasons for patient delays in treatment. Here, the focus is on providers' perceptions of the barriers that their WHMP patients experience and the challenges to serving these patients. Several studies have gathered qualitative data on the cancer treatment experiences of low-income patients, including women enrolled in the Georgia WHMP.[7] This analysis aims to contribute to our understanding of persistent barriers to care in order to improve current practices and develop new strategies for treatment initiation and retention.

## II. LITERATURE REVIEW

### A. Breast and Cervical Cancer Facts and Statistics

Breast cancer is a leading cause of cancer death among women in the United States, second only to lung cancer, with a projected 246,660 new cases diagnosed and 40,450 related deaths in 2016.[1] It is estimated that 12.3% of all women have a lifetime risk of developing the disease.[9] Several immutable etiological factors have been attributed to breast cancer development, namely genetics and family history.[10] Thus, behavioral prevention strategies may be less relevant than those targeting early detection. In fact, when detected early, breast cancer has a much better prognosis than later stage cancers. The gold standard for breast cancer screening is the use of routine mammography, which has been shown to reduce breast cancer mortality by as much as 42% in some trials.[2] While survival rates have improved with these advances in medical technology and the implementation of free screening programs, the literature has identified multiple barriers to receipt of screening services, particularly for low-income, uninsured and underinsured women. Indeed, nearly half of all breast cancers (39%) are diagnosed at later stages, when the cancer is no longer localized and is more challenging to treat.[4]

Despite a 50% decline in the last 30 years, cervical cancer also remains a significant threat to women's health.[3] It is estimated that 12,990 new cases of invasive cervical cancer will be diagnosed and approximately 4,120 women will die from cervical cancer in the U.S. in 2016.[1] While the development of cervical cancer may also be attributed to certain immutable risk factors, it is most commonly associated with human papillomavirus (HPV) infection, which is passed via skin-to-skin contact, primarily during sexual activity. Indeed, several high-risk strains of the virus are accountable for 70% of all cervical cancers.[1] HPV can cause abnormal cell growth on the cervix, which when undetected and untreated may progress to cancer. The primary screening tool for cervical cancer is the Papanicolaou (pap) smear, which collects cells from the cervix and vagina to evaluate for malignancy.[3] Pap screening has been shown to vastly reduce mortalities from cervical cancer, with declines in recent decades largely attributable to the test.[3] Additionally, the introduction of an HPV vaccine in 2006 has been credited with a 56% reduction in vaccine-type strains among females ages 14-19.[11] As with breast cancer, however, barriers persist to the timely and routine receipt of cervical cancer screening and prevention services.

Accurate staging is an important part of determining treatment options and prognosis for both breast and cervical cancer. The TNM staging system (American Joint Committee on Cancer) and/or FIGO staging system (International Federation of Gynecology and Obstetrics) may be used to assess the size of the tumor, lymph node involvement, and the presence of distant metastases. When these factors are combined, a cancer stage of 0, I, II, III or IV is assigned, with stage 0 indicating a non-invasive cancer and stage IV being the most advanced stage. The location of cancer cells (local, regional, or distant) is also assessed, and generally corresponds to the TNM system.[4] Treatment is most effective at earlier stages when the cancer is localized, and options for treatment vary depending on the stage, location, and size of the tumor.

Surgical treatment for breast cancer typically involves either breast-conserving surgery, such as lumpectomy or partial mastectomy, or mastectomy. Breast cancer may also be treated with radiation therapy, chemotherapy, hormone therapy, or targeted therapy.[4] These adjuvant therapies are often recommended in conjunction with surgery to reduce the likelihood of cancer recurrence. The standard regimen for hormone therapy after surgery is 5 years, which underscores the importance of long-term access to cancer care services after primary surgery. Surgical treatment for cervical cancer may include conization, in which tissue is removed from the cervix; hysterectomy, in which part or all of the reproductive organs are removed; or other surgeries that remove affected tissues, organs and/or lymph nodes. Radiation, chemotherapy, and targeted therapy may also be used to treat cervical cancer, depending on the type and stage of the cancer.[12] Routine follow up care is also essential after primary treatment of cervical cancer.

### B. Available Free Screening and Treatment Services

A substantial body of literature has illustrated disparities by race/ethnicity, income and insurance status in breast and cervical cancer screening, treatment and, subsequently, outcomes. Acknowledging these disparities, the United States Congress passed the Breast and Cervical Cancer Mortality Prevention Act in 1990.[13] Under this law, the CDC's Division of Cancer Prevention and Control administered the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which provides screening and diagnostic services for breast and cervical cancer, including clinical breast exams, mammograms, pelvic exams and pap screenings for low-income, uninsured and underinsured women.[14] Program beneficiaries are between the ages of 40-64 for breast cancer services and 21-64 for cervical cancer services, in line with the recommended ages for screening set forth by the American Cancer Society, the American College of Obstetrics and Gynecologists and the United States Preventive Services Taskforce.[14] While states have some flexibility to determine eligibility criteria in terms of age and income, most states provide access to NBCCEDP services for women who are within 250% of the federal poverty line. Currently, all 50 states as well as the District of Columbia and other qualifying territories and tribal organizations receive funding for cancer-screening initiatives through the NBCCEDP.[6]

Notably, the CDC has adopted a social ecological model to represent the NBCCEDP's multi-level approach to cancer prevention.[6; 15] While there are numerous adaptations of the model, the underlying premise is that each individual affects and is affected by their environment at multiple levels—from larger systems down to institutional and individual levels—and that no single level alone can entirely explain individual health behaviors and outcomes.[16] The CDC's social ecological model for breast and cervical cancer prevention conceptualizes influences of cancer prevention at five levels: 1) Policy, which includes implementation of guidelines, recommendations, laws, regulations and programs that support cancer screening; 2) Community, which includes provision of resources and support by research institutions, health disparities collaboratives, community based organizations and survivorship support groups; 3) Organizational, which includes state and local health departments, health plans, academic medical institutions, and professional associations; 4) Interpersonal, which includes screening recommendations and reminders and support from family, providers, friends, and community health workers; and 5) Individual, which includes one's knowledge, attitudes and beliefs regarding the need for and risks/benefits of screening and the availability of screening services.[17]

While the NBCCEDP mandates that local treatment resources be secured prior to initiating screening, it does not provide coverage for treatment of cancer or precancerous conditions. Sharing anecdotes from women in the program, policymakers argued that the lack of coverage for treatment caused women to delay and/or receive incomplete treatment or experience catastrophic debt from treatment expenses.[5] In order to close this treatment gap, the Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) was passed in 2000.[13] BCCPTA allowed states to expand their Medicaid coverage to women under age 65 diagnosed through NBCCEDP with breast or cervical cancer or cervical pre-cancer, while maintaining some flexibility regarding eligibility requirements. The program was later expanded to allow states to extend coverage to women diagnosed through non-NBCCEDP providers, although only 12 states have adopted this provision, known as Option 3. By 2003, all states had approved the Medicaid waver, signaling prioritization of breast and cervical cancer treatment for the previously uninsured on a national scale.[5]

In 2001, Georgia adopted its own BCCPTA program, known as the Women's Health Medicaid Program (WHMP). Data on the state's program has shown that BCCPTA increases enrollment in Medicaid and decreases time to enrollment for women with breast and cervical cancer.[18] It has been suggested that broader eligibility requirements and the lack of income/assets tests or waiting periods under BCCPTA has provided a simpler pathway to Medicaid enrollment for uninsured cancer patients than traditional Medicaid.[19] As part of the larger study on which the present study is based, Johnston et al. (2014) examined the breast cancer treatment patterns of women enrolled in the Georgia WHMP and found that they received equitable treatment regardless of race or urban/rural location.[7] However, qualitative findings from the study illustrated differences in specific treatment modalities by race, such as breast reconstruction, and the authors suggested that these treatment differences were largely due to individual factors such as cancer knowledge and beliefs.[7] Further exploration of these non-quantifiable factors through the use of qualitative methods will help elucidate reasons for persistent differences in cancer care not resolved by Medicaid enrollment alone.

## C. Treatment Disparities and Barriers

Differences in overall cancer survival by race have been well established, with African Americans at a 33% higher risk of dying from cancer than Caucasians.[20] While breast cancer incidence is lower among African American women than Caucasian women, their mortality rates are higher. African American women have both higher cervical cancer incidence and mortality than Caucasian women.[21] Disparities in cancer survival by race have been largely attributed to late-stage diagnoses resulting from barriers to cancer screening; however, differences in treatment may also play a role. A comprehensive review of the literature by Shavers et al. (2002) examined trends in access to and use of specific cancer treatment regimens in 87 studies conducted between 1990 and 2001. They identified racial disparities in treatment that could not be explained by clinical differences alone, such as stage at diagnosis.[20] African American women were less likely than Caucasian women to receive adjuvant radiation therapy following breast-conserving surgery, and were more likely to receive fertility-sparing treatment for Stage 1A cervical cancer, which is not a recommended treatment option for such patients per the National Cancer Institute's Physician Data Query.[20] Similar findings have also been illustrated in more recent literature, including a study by Powers et al. (2015) using 2004-2010 hospital registry data for female stage I and II breast conserving treatment patients, which found that African American women were significantly less likely to achieve timely radiation therapy completion (TRTC) than Caucasian women.[22] The persistence of these findings suggest that there may be nonclinical factors contributing to racial/ethnic disparities in treatment receipt, such as structural barriers to access, inadequate physician recommendations, or individual treatment preferences, among others.

There are discrepancies in the literature as to whether income and insurance status play a larger role in cancer treatment disparities than race/ethnicity, and it can be difficult to extricate the independent effects of these often interacting variables.[20] Medicaid has been shown to reduce differences in breast cancer care by race by providing access to appropriate treatment for low-income patients of all races; however, cancer outcomes have been shown to be worse among low-income, uninsured and Medicaid-insured patients overall when compared with the privately insured.[23; 24] Barriers to Medicaid participation may account for disparities among low-income and uninsured populations, with research identifying challenges to enrollment such as complicated and excessive requirements for documentation.[21] According to a study by Bradley et al. (2002), having health insurance, specifically Medicaid, may not be enough to close the survival gap between upper- and lower-income cancer patients.[25] The authors' hypothesis is based on findings that Medicaid recipients present with later stage breast cancer and have poorer survival rates than privately insured women, with mortality rates among Medicaid-insured and uninsured breast cancer patients found to be approximately equal.[25] A study by Churilla et al. (2016) analyzed data from the National Cancer Institute's Surveillance, Epidemiology and End Results Program (SEER) database for invasive cervical cancer patients from 2007 to 2011 to evaluate overall and cause-specific survival by insurance status. Similarly, their findings suggested that even with Medicaid, women had prognostic outcomes on par with those who lacked health insurance. These prognostic differences could be explained in part by advanced clinical presentation, associated socioeconomic factors and variations in treatment.[26]

Despite such findings, research investigating disparities in cancer treatment and, subsequently, survival has largely presumed that lack of health insurance, rather than inequities in treatment or other underlying factors, is the cause of poor health outcomes among underserved populations. Under this premise, policies that provide coverage for cancer screening and treatment should effectively reduce differences in cancer survival among low-income and previously uninsured persons.[25] However, racial/ethnic and income disparities have persisted for BCCPTA patients in receipt of diagnostic follow up and initiation of treatment, reflecting disparities in the U.S. population at large.[13] A large body of literature suggests that low-income patients may forego needed treatments due to the burden of out-of-pocket costs for associated travel, insurance copayments and prescriptions, among others.[27] However, barriers to care may exist beyond the economic, and at multiple levels. Shavers et al.'s conceptual framework on potential barriers to the receipt of optimal cancer treatment borrows largely from the socio-ecological model by proposing factors at the individual level, such as patients' level of family/other support and preferences regarding treatment; the clinical level, such as clinical stage/other prognostic indicators and physician recommendations, perceptions and biases; and the structural level, such as health insurance status/type and geographic area of treatment facility.[20] Conceptualizations of what constitutes each level of influence vary from one analysis to the next. In their study on barriers to cervical cancer screening and treatment in 13 high-risk counties in Florida, Daley et al. (2010) used a socio-ecological approach to frame their examination of influences at the policy, community, institution and individual levels.[16] Data were collected through semi-structured interviews with regional program coordinators, including those from the Florida BCCEDP and the Florida Association of Planned Parenthood Affiliates, as well as health care providers and administrators from several county health departments. Findings identified multiple barriers at each level, including scarcity of community resources; patients' cultural values and beliefs; and population characteristics, namely poverty.

The inclusion of provider perspectives, as in the aforementioned study, in evaluating barriers to treatment is not common, but can be a useful tool. In a qualitative study examining providers' perceptions of their cancer patients' barriers to treatment, Bickell et al. (2007) interviewed surgical oncologists about reasons underlying adjuvant treatment omission, which were categorized as 1) not recommended, 2) recommended but declined, or 3) system failure—in which treatment was recommended and not refused, but not initiated.[28] The findings indicate that a third of patients who were recommended treatment declined and another third experienced system failure. Physicians' perceptions of the reasons for treatment omission were elicited, such as difficulty with financial, emotional, or social support; resistance to treatment; misunderstanding risks and benefits of treatment; or intolerance of treatment. Interestingly, a large proportion of providers did not know why their patients had not completed the recommended treatment.[28] These findings present a unique opportunity to evaluate how providers' own perceptions of their patients' treatment behaviors (and the factors underlying them) may influence their provision of care. Additionally, when combined with the literature on patient experiences with accessing health care, providers' perspectives may help provide a more complete picture, particularly regarding institutional and policy level barriers.

# III. METHODOLOGY

## A. Introduction

The present study utilized qualitative methods to explore provider experiences with caring for breast and cervical cancer patients enrolled in the Georgia WHMP. Individual interviews with a variety of providers involved in direct patient care were conducted by Emory University Rollins School of Public Health researchers as part of a larger mixed methods study that examined the effects of WHMP on enrollment in Medicaid and treatment for breast and cervical cancer for low-income, uninsured and underinsured women in Georgia. Quantitative methods included an analysis of linked Medicaid claims data with Georgia Comprehensive Cancer Registry (GCCR) data to examine the effects of the WHMP on the timing and cancer stage at time of enrollment in Medicaid, before and after WHMP, by race. Results from these analyses have been reported elsewhere.[8; 29] Research for this larger study was supported by an American Cancer Society grant awarded to Emory University, Rollins School of Public Health (Principal Investigator, Dr. E. Kathleen Adams). The Emory University Institutional Review Board and the Grady Hospital Institutional Review Board granted human subjects approval prior to initiating the study. The present study, and the views expressed herein, is not necessarily representative of the views of the funding agency.

The qualitative arm of this study had two components. The first focused on women enrolled in the WHMP and key moments of their cancer experience; the second focused on the perspectives of providers who care for WHMP patients. The present study presents findings gathered from the interviews with these providers.

## B. Population and Sample

Eligible participants for the in-depth interviews were clinical and allied health providers actively serving patients diagnosed with breast or cervical cancer or cervical pre-cancer enrolled in the WHMP. The original sampling frame included 32-36 providers serving breast and cervical cancer patients in urban and rural practice settings (8-10 in each combination of strata). The sampling frame included any provider who provides direct patient care for WHMP enrollees, including clinical care, health education, counseling and patient navigation. The desired focus for clinical providers was on the specialties of radiology, oncology and surgery, as these were the providers most likely to be involved in the actual treatment. Allied health providers included social workers, patient navigators and psychologists. There were some obstacles to provider recruitment despite efforts to engage provider organizations and personal contacts and offering a monetary incentive. This was addressed by expanding the types of providers to be interviewed. The final sample consisted of 18 clinical and allied health workers with a range of <1-31 years' professional experience in their field, working in or outside of Atlanta and in both urban and rural settings (See Table 1). Participants included one obstetrician-gynecologist, four OB-GYN oncologists, two medical oncologists, one oncology physician assistant, one oncology nurse practitioner, one radiation oncologist, three oncology social workers, four patient navigators, and one psychologist.

**Table 1: WHMP Provider Participant Characteristics**

| | Characteristic | | |
|---|---|---|---|
| | Total | Clinical Providers | Allied Health Providers |
| Sex | | | |
| Male | 8 | 7 | 1 |
| Female | 10 | 3 | 7 |
| Race | | | |
| African American | 6 | 2 | 4 |
| White | 6 | 4 | 2 |
| Asian | 2 | 2 | 0 |
| Hispanic | 2 | 1 | 1 |
| Unknown | 2 | 1 | 1 |
| Years in Field | | | |
| <5 | 7 | 2 | 5 |
| 5-15 | 6 | 3 | 3 |
| >15 | 5 | 5 | 0 |
| Location | | | |
| Metro Atlanta | 11 | 6 | 5 |
| Outside Atlanta | 7 | 4 | 3 |

## C. Research Design

The qualitative arm of the study served to shed light on the processes underlying the "observable" quantitative data on differences in treatment patterns by race. In-depth interviews were conducted with providers about their experiences serving breast and cervical cancer patients enrolled in the WHMP. In particular, providers were asked about how they discuss treatment options with these patients, what factors made it challenging to treat or help them and what services and support were available to help patients navigate their care.

## D. Procedures & Instruments

Beginning in 2006, patients in the WHMP were required to enroll in one of three Care Management Organizations (CMOs): Amerigroup Community Care, WellCare, or Peach State

Health Plan. Emory study staff coordinated with the Department of Community Health and administrators at each CMO to recruit WHMP-participating providers, and also coordinated with Georgia CORE to recruit member providers. Letters were sent to providers seeking their participation in a one-hour interview either in-person or by telephone, depending on the providers' workload and preference. Informed consent forms (Appendix A and B) were designed by the study team and given to participants to sign prior to initiating the interview. In-person interviews were held at the health care facilities where providers worked and audio recorded. Participants received a gift card incentive of $100 for their participation. Separate semi-structured interview guides were developed for clinical providers (Appendix C) and allied providers (Appendix D). Both provider guides were developed from the literature as well as the guiding principles of the study's conceptual framework of Andersen and Aday (1974). The framework outlines five interconnected variables for the study of health care access, starting with health policy objectives and moving through the characteristics of the health care system to the populations at risk and actual utilization of health care services.[30] The guides were thus designed to capture the experiences of providers serving women enrolled in the WHMP, such as the treatment options they presented and the treatment options women chose with respect to their cancer. Particular interest was given to learning about what, if any, differences providers noted across racial groups in terms of patient understanding, barriers and compliance with recommended treatment. Sample questions from the guides included: What support is available to help women navigate their care? How do you discuss cancer treatment with women? What issues do women face that make it challenging for you to treat/help them?

## E. Data Preparation and Analysis

The present study utilized the 18 interview transcripts of providers serving breast and cervical cancer or cervical pre-cancer patients enrolled in the WHMP. All personally identifiable information was removed from the transcripts and each interviewee was assigned a pseudonym. Transcripts were entered into MAXQDA version 11 textual data analysis software (Verbi Software, Berlin). A set of largely deductive codes was applied to the data that reflected the larger study aims of understanding providers' perspectives on treating WHMP beneficiaries, including patients' cancer perceptions and beliefs, socioeconomic conditions, and disparities and differences among the patients they treat based on race and urban/rural location. After a focused review of text segments, memos were written on segments representing additional themes from providers' perspectives, such as their scope of care and the type of information and education they provided to their patients. The present analysis focuses on three codes in particular: Barriers/Facilitators, Cancer Perceptions/Beliefs, and Resources/Support. The definitions of these codes are outlined below (See Table 2).

**Table 2: Code Names and Definitions**

| Code | Definition |
|---|---|
| Barriers/Facilitators | Any reference to patient barriers to obtaining cancer care and to that which helps overcome such challenges. Use for: Issues such as finances, insurance, childcare, transportation, time constraints, employment, health literacy, etc. Includes references to patient compliance with their care. |
| Cancer Perceptions/Beliefs | Any discussion of patient knowledge, attitudes and beliefs about cancer and cancer treatment and how they influence behaviors regarding decision-making and care-seeking. Includes patients' understanding of cancer and feelings of fear, blame, guilt, etc. |
| Resources/Support | Any reference to support and resources, either practical or symbolic, available to patients. Includes support groups, social workers, psychiatrists, patient navigators, family members, religious/faith communities, etc. |

Data captured by the codes of interest were systematically retrieved and organized into a table by code, transcript and provider type. The data were summarized and compared by theme in order to identify patterns and variations in providers' perspectives on influential factors in their patients' receipt of cancer care.

## F. Ethical Considerations

The present study is a secondary data analysis that draws upon data collected in a larger mixed-methods study on the Georgia WHMP. Accordingly, all participant data was previously de-identified and the author had no access to identifiable data while conducting this analysis.

# IV. RESULTS

## A. Introduction

From the perspectives of providers serving patients in the Georgia WHMP, three factors influencing treatment emerged: 1) Patients' socioeconomic conditions, 2) Patients' knowledge, attitudes and beliefs and 3) The availability of institutional resources and support. There were greater variations among clinical and allied health providers relative to the first factor, with both groups conveying similar perspectives relative to the second and third factors. In particular, socioeconomic issues were perceived to affect patients' ability to receive comprehensive cancer care at multiple levels.

## B. Findings

### Influence of patients' socioeconomic conditions

Providers almost unanimously noted the influence of patients' socioeconomic conditions, both prior to and throughout the cancer treatment process. They described socioeconomic conditions as including access to resources such as transportation and childcare as well as the ability to maintain employment and housing during treatment. Patients lacking these resources faced substantial barriers to receiving and completing their cancer treatment, according to the providers serving them. Allied health providers were somewhat more likely to make note of these barriers to care than clinical providers.

Nearly half of the providers cited transportation as an issue in terms of availability and cost, depending in part on patients' residential distance from the clinic. Patients might not have their own vehicles or have only one person in their household with a drivers' license. Several providers mentioned Medicaid-funded transportation services, though travel times could be up to several hours for women living in rural areas in particular.

> You know, some of these patients don't make their appointments or don't make them anywhere near time and the transportation systems bring them to the office two hours late. And sometimes it brings them other places two hours late where they aren't as understanding as I am and so their therapy doesn't get done properly…And so that, that does complicate our ability to take care of them. (Oncologist, urban, 235)

An oncologist working at a large urban safety net hospital described how patient complaints about transportation for appointments resulted in the implementation of the *Breast Friends* service, a breast cancer support network providing practical assistance for patients. However, the service was no longer receiving as much funding, demonstrating how economics were influential at the institutional level as well. Several providers expressed that women living alone faced greater challenges to completing treatment, noting that a transportation service was nothing like being taken to appointments by a family member. In one provider's experience, African-American patients tended to be more dependent on the transportation service than Hispanic patients, who usually seemed to have a family member available to accompany them. Thus, patients' level of social support might also influence how socioeconomic conditions shaped their access to treatment. Providers also noted that gas expenses and parking fees could be prohibitive for patients, particularly for those requiring multiple appointments each week or month for treatment.

> People find it difficult. Finances, they don't have money to pay for their co-pays and out of pocket expenses. Sometimes they don't have the family support even though the patient has to come five days a week. --- have someone to bring them back and forth and when gas is $4 a gallon, people truly could not come because they didn't have gas money. (Oncologist, urban, 173)

Residential distance from the clinic not only made treatment compliance challenging but also influenced women's treatment options in some cases. One provider described how patients living too far from the site of clinical trials did not qualify for participation. In these cases, clinical trials would not even be mentioned as an option.

About a third of the providers cited patients' caregiving responsibilities as a barrier to accessing treatment. Patients were often the sole caretakers in their household, and the debilitating effects of cancer treatment were thought to put a strain on their families. Those women caring for children and other family members had difficulty leaving home because of they couldn't obtain and/or afford childcare; one provider described how their staff would bend the rules by taking turns watching a woman's children in the waiting room while she underwent chemotherapy treatments. Another provider described how a patient chose to defer her cancer treatment while her daughter, who also had cancer, went through her own treatment. As she explained it to her provider, she did not want her treatment to debilitate her and compromise her ability to care for her daughter. In this case, her daughter's needs took precedence over her own cancer care.

Over half of the providers noted that cancer treatment often affected women's ability to maintain jobs and income, leading some to avoid or discontinue care.

> Other issues are the fact that, you know, people have jobs. You know, whether they pay not so good, they can't, they don't have sick time. Or if they do, they don't have a lot of it. Well, you can't keep missing, you know, to go to the doctor. You lost your job. So, you know, that's somebody's livelihood. They're trying to feed a family and they can't because they got to go for cancer treatment. So you have that hurdle to overcome. (Patient navigator, metro Atlanta, 110)

Providers described that loss of jobs from taking time off for treatment or not having paid leave time from work could result in the inability to pay utility bills or make house payments. One social worker described how a private donation was used to assist a patient struggling with utilities that had backed up during treatment, though private donor support was not generally cited as an available financial resource for patients. Several providers noted that loss of jobs and income could even result in homelessness.

> So, we've had right off the top of my head, like, five patients, both GYN and breast that were basically homeless and needed to get chemotherapy. And so we had to place them in what they call a medical shelter…most of the time they're for women only or they're women and children or men only…As far as housing, we've also had some other women that didn't live anywhere but that was living with family but the dynamics in the family wasn't right…that's what the American Cancer Society person that's on site, she usually helps with that. (Oncologist, metro Atlanta, 467)

One provider expressed that for victims of domestic violence, the focus on her cancer care could worsen her situation at home, in which case the provider team would try to intervene to help the woman into temporary housing. These were challenging situations in terms of maintaining not only the patients' safety, but her continuity of care. The challenges of accessing cancer treatment while living away from home, regardless of the circumstance, were noted by several of the providers. In addition, they suggested that substance abuse might also contribute to cycles of homelessness and poverty, with the stress of cancer and cancer treatment often exacerbating existing substance use and resulting in noncompliance in care.

> It really depends on what the other extenuating circumstances are. So is it financial? It is, are they on the street? Are they homeless? Or do they have a substance abuse problem, which is really what prompts their homelessness? You know, do they have housing? Are they still using drugs? Are they clean? So there's other sort of extenuating circumstances…a lot of people don't show up for appointments. You know, especially for using. (Psychologist, metro Atlanta, 84)

A number of providers said that addressing patients' myriad socioeconomic issues affected their ability to perform their primary role of providing cancer care.

> I mean, I love my job but like every patient who comes in tends to be a total social nightmare. And I don't mean, like, mentally, but just like I can't get a ride to the clinic, I don't have enough money to take MARTA, I don't, you know, and it's just, it's exhausting because I don't end up doing medicine, I end up playing, I mean the social worker is totally overrun too so it's like, everyone's just trying to cobble together some way to even get them here. (Oncologist, metro Atlanta, 93)

Most providers understood that for many women, cancer care might take a back seat to other survival needs. However, conceptualizations of patient compliance with treatment varied by provider type, with some recognizing the difficulties of adherence under strained socioeconomic and personal situations and others believing that patients were simply being passive in their own care. Generally, clinical providers were less cognizant of the barriers facing patients than allied staff.

> Yeah, I mean I think the hardest thing for the providers is the understanding that diagnosis is not top priority for our patients. And whereas their belief is that there would be nothing that should keep you from the treatment plan, period. There is a different value system that the patients here have…It's hard to understand that if you've never had to look for your basic needs. If you've never had to look for housing, rent, water, and food, you don't know a lot of those things are important to make certain that you care of those for each month. So there's not an understanding of why patients would put something like that over an appointment or a variety of things that go with treatment. And I think that's the biggest difficulty. (Social worker, metro Atlanta, 230)

The majority of providers (both clinical and allied) noted that across the board, their patients faced the same barriers regardless of race, geographic location or other factors; most providers agreed that economics and insurance were primary barriers to accessing care.

> You know sometimes at the end of the day it's just, what I see is just that fight to complete treatment that everybody kind of balances, they tend to be, you know the work like I said, and the financial pressures and stuff like that. So I think the obstacles are pretty, you know they are the same in both populations. (Oncologist, metro Atlanta, 195)

One patient navigator did note diagnosis and treatment disparities by race, also believing that they resulted from economics.

> Between whites and blacks, African American women, the treatment is, you know, it's not as aggressive as that of white Americans and I'm going to tell you why. That's one of the reasons why black women are diagnosed the least so we die the most. Because the aggressiveness in terms of treatment is not there. And a lot of it is based on economics. They don't have the means to get the aggressive treatment. There's a lot of technology but…unless you have the money to tap into that advanced stage, well then you'll never

> get that treatment…we're just going to give you something to get by and then that's it. You know, whatever happens, happens. (Patient navigator, rural/urban, 195)

Although the WHMP provides coverage that includes the full range of cancer services, the above sentiment illustrates the persisting belief that certain patients will receive inferior care based on their socioeconomic status—discussed more in the following section. Overall, these findings illustrate the prominent role of economics in shaping women's cancer treatment experiences. Providers' perceptions of how their patients' socioeconomic conditions shaped their treatment behaviors were also notable, and varied among clinical and allied providers. These differential perceptions are linked to patient-provider relationships more generally, also discussed in the following section.

### ***Influences of patients' knowledge, attitudes and beliefs***

The second factor that providers noted influenced patients' treatment behaviors was their knowledge, attitudes and beliefs about cancer and cancer treatment. These factors were affected by 1) their level of health literacy and engagement, 2) their relationship with their provider and the medical institution as a whole, and 3) the role of religion and faith in their lives.

Low health literacy was cited by the majority of providers as a barrier to care because it made patients' ability to process information related to treatment more difficult. For instance, providers noted that confusion about the stage of their cancer or designated treatment plan might lead patients to believe that treatment was completed after chemotherapy, when they still needed radiation or surgery.

> Treatment choices are not always driven by educational level or socioeconomics but I must admit, it is easier to discuss a complex treatment related issue with someone who's, who can intellectually process the information. Sometimes they process it and become confused just by the plethora of choices but if you have someone that doesn't understand even the basics of what you're talking about, it's very, very difficult to communicate, you know, complex information in that setting. (Oncologist, urban, 110)

Providers also perceived more educated patients to be better engaged in their health care and, consequently, more adherent to treatment.

> You don't have the education or the wherewithal to get higher income jobs and that's always going to hold you back to a certain degree…That translates into, a lot of times, I don't really care to know. That's way over my, I can't understand that. I don't want to know that. Don't even talk to me like that. For what? I don't know what you're saying, so don't tell me…However, what you tend to find is people who have better insurance who are more educated tend to comply because they understand the implications and ramifications if they don't do it. And for them, it's a matter of life or death. (Patient navigator, metro Atlanta, 123)

With few exceptions, providers expressed the importance of communicating information about cancer and cancer treatment in lay terms, rather than highly clinical language. Only one oncologist did not feel that there was a challenge to treating patients due to health literacy, expressing that treatment for cervical cancer was fairly straightforward and therefore patients complied without question. For other providers, a lack of active patient engagement and questioning was seen as a red flag, indicating poor understanding of the severity of their situation that could result in delaying care. In addition, they suggested that patients might understand the seriousness of their situation, but feel too defeated to actively seek treatment. This sentiment was often linked to patients' age: several providers expressed that older patients were more resigned to their cancer because they felt they had less to live for. At the same time, others expressed that young patients appeared to take their disease less seriously.

> I mean, a lot of people are young, like, especially cervical cancer, young, in denial. Well, this isn't going to kill me. And that's really sad, ones that come in with a pretty curable disease and just don't show back up or, you know, they got other things going on and they come back in two years later and you've got metastatic disease. Like, well, this is something that we could've cured, but, it's just invincible attitude. Which you don't see in older patients because they're, with age you become wiser. (Oncologist, metro Atlanta, 135)

In contrast to feelings of invincibility, providers noted that fear was a primary driver of women delaying care. According to some providers, patients avoided treatment because they believed it was a death sentence. Women who knew someone personally or had heard of someone who had died after undergoing cancer treatment associated treatment with negative outcomes.

> …you get these really, really old-fashioned thought processes, or I don't even know if you call them old fashioned. I just call them basically, a lot of them have to do with the environment that you were raised in and grew up in, and people will say things to them like yeah, when so and so got cut, you know [referring] to surgery, but when so and so got cut, the cancer spread and they died. So you got to help dispel this kind of stuff that they hear. And that chemo, they hit that chemo and they never come back right. I mean, they really believe this in their heart and soul. So they associate treatment with death. (Patient navigator, metro Atlanta, 110)

Nearly half of the providers expressed that patients' mistrust of providers or of the medical system at large influenced their treatment choices and level of compliance. In some cases, mistrust of one's provider stemmed from poor patient-provider communication; several clinical providers noted that being transparent and compassionate with their patients was the best solution to mitigating this mistrust.

> If they don't understand you, that breeds mistrust, if they don't kind of click with you personally, it breeds mistrust. If they for some reason don't like something you say, it breeds mistrust. You know, if you don't explain something enough and they get surprised by something, it breeds mistrust. So, being open, candid, thorough and caring I guess would be the only way to get around that. (Oncologist, urban, 133)

Another provider thought that their own level of clinical experience and expertise contributed to their trustworthiness. Being knowledgeable and, again, spending adequate time talking with patients facilitated treatment compliance.

> I'm not bragging but I've been doing this a long time and I have a good rapport with patients and I also am experienced enough that I can say things with a certain degree of authority. And so I spend a lot of time with new patients. So they learn to trust what I'm doing and so---don't really challenge the therapy. And I also, this is a significant part of

> my practice, I always offer patients that are in any way reluctant or don't seem to understand a chance to get a second opinion…Of course the second opinion always agrees with me. Because we don't have any secrets in this specialty. (Oncologist, urban, 148)

Providers noted that African American patients in particular held negative views of the health care system, believing that they would receive sub-standard care compared with white patients. One provider felt that African American patients had a distrust of the medical community because they felt they would not be given the correct medical information and would be treated just enough to be sent home. Discussions of mistrust were particularly salient in terms of clinical trials, with several providers noting that African American patients were reluctant to participate. They suggested this might be due to historical abuses of black patients in medicine; two providers specially cited the infamous Tuskegee syphilis study as a potential reason for mistrust.

> A lot of them still, still, a lot of African-Americans still think clinical trials are just experimentation meaning they have no idea whether this medicine is going to work or they don't even know whether the FDA has even, you know, given, approved it or even approved just the clinical trial aspect of it. (Patient navigator, rural/urban, 236)

While providers acknowledged that patients participating in clinical trials would at minimum receive the standard of care, one oncologist alluded to their benefits, which illustrates the importance of dispelling misconceptions about trials to ensure equitable access to this form of treatment.

> So we do put a whole lot of patients in trial because it allows them to perhaps get something a little better than they would ordinarily…there's an advantage that we have trial nurses so they almost have their own nurse concierge and I'm not saying that they get a little better care than people who are not on trial but the reality is because they have a 24/7 number to call a specific nurse. (Oncologist, urban, 140)

Providers also perceived that some patients feared receiving sub-standard care at large public health care facilities, regardless of race. One provider working in a public safety net hospital described having to reassure patients that they would receive quality care, given negative associations with the facility as being a “last stop.”

Other beliefs that were influential in patients’ treatment behaviors included their religiosity and faith in God, which served to both impede and facilitate their treatment. Nearly half of the providers cited women’s faith as playing a significant role in treatment decision-making; some women elected to pray about what choice they should make about their treatment, and others felt that God would simply take care of their cancer somehow. According to one provider, this was a major source of delay for women who needed treatment more urgently due to having a late-stage or aggressive cancer.

> So we do have some people that say they’re really religious, right, and that they’ve spoken to God and God has said to them that they mustn’t have whatever it is. So it’s either radiation or chemotherapy or surgery. And sometimes they’ll go through some certain part of it but they’ll say, uh uh, God said I shouldn’t do this so therefore I’m not doing it. Or even hormone therapy. Some, sometimes they say, uh uh, I spoke to God and the Holy Spirit spoke to me and I don’t need it, I don’t need that. So that has been one of the challenges that I feel that we’ve had. (Oncologist, metro Atlanta, 445)

Alternatively, communicating the importance of cancer treatment through the lens of faith was helpful for some providers in relating to these patients and improving treatment compliance. For example, one provider explained to his patients that God put doctors here for a reason, and that was to help treat cancer. Another told a joke about the signs God was trying to give them about undergoing treatment.

> A person is in his house and the water’s coming up over the---and so he has to go to the second floor and there’s this boat that comes by and says, John, get out, jump in the boat, we’ll save you. And he says, the Lord will save me. And so a few hours go by and now John’s on top of his roof and now a Coast Guard cutter come by and says, hop in, this is your last chance. And he says, I do not need it, God will save me. Now he is on the antenna of his house and a helicopter comes back and drops down a rope and they say,

> climb on, this is your last chance. And he says, I do not need it, God will save me. The next thing he knows, he's in heaven. And God comes by and he says, God, why didn't you save me? What do you mean, I sent you a boat, a cutter and a helicopter…And so I tell them, I am your helicopter. (Oncologist, urban, 258)

Faith influenced more than treatment decisions; according to some of the providers, choices regarding what types of mental or emotional support to seek out, if any, were also influenced. For example, one provider expressed that African American patients were more prone to consulting a religious leader for support than a psychiatrist or support group, illustrating the importance of community leaders as key players in the cancer care continuum.

### ***Influence of institutional resources and support***

The third factor providers noted that influenced women's cancer treatment experience was the availability of institutional-level support and resources beyond curative care. The perceived utility of these resources varied from provider to provider, in part depending on their place of employment. Some providers believed that services addressing other facets of cancer care, such as physical changes resulting from treatment, were robust in their facilities; others felt that these "ancillary" services were lacking. Three providers, all oncologists, noted that patients had a plethora of resources at their disposal and expressed no need for additional services.

> Yeah, there's various things for the cancer society. Also there's the wellness center that the medical center runs that has special programs for cancer patients…Exercise programs, swimming programs, various things…we work very closely with the American Cancer Society here and they provide those…We have genetic counselors, we have all kinds of things here. (Oncologist, urban, 69)

Case management and patient navigation services were touted by many of the providers as highly beneficial components of cancer care. However, in some settings where there were no patient navigators, nurses provided the bulk of care coordination and navigation, potentially influencing their ability to focus on clinical care. One oncologist explained that he would refer patients to support groups that he found on the web, but that he did not have a list of resources to provide to patients. Some providers seemed to have conceptualized patient navigation to be an exclusively logistical process that linked patients to various members of the provider team, as opposed to someone who helped connect them to additional resources and support.

> We don't have---for GYN oncology because there's really not much to navigate in a sense. There are patient navigators for other services. And the reason is, for gynecology oncology you usually do the chemo, we do the surgery, we do most of the stuff and the only thing they have to go to a different provider is radiation. And often for that we help them out too. So a patient navigator is important for something like breast cancer where somebody does the surgery, somebody else is doing radiology, a third person is doing chemo, the fourth person is taking care of their diabetes. (Oncologist, urban, 88)

For other providers, patient navigation was about much more than coordinating services among the provider team. Some of the clinical providers were unable to describe the roles of these staff members in detail, or were unsure whether there were even designated patient navigation programs in place. A nurse practitioner, on the other hand, described an American Cancer Society social worker as someone who helped patients secure essential items such as transportation, childcare, food, housing and clothing. Some providers expressed the importance of allied staff in assisting patients throughout the continuum of care, from treatment through survivorship.

> So we have patient navigators for those that just found out that they have cancer and to help them through that multimodal treatment journey. And then we have another set of navigators that take them after they've completed their treatment to navigate through survivorship going back into regular society again without being that oncology patient per se that needs treatment every week. So we have, you know, both sides of the spectrum here. (Oncologist, metro Atlanta, 182)

While the majority of providers expressed that their social workers and patient navigators greatly assisted patients in accessing resources and support during their cancer treatment, one clinical provider and several of the allied providers noted that these staff were largely consumed by addressing patients' financial burdens, taking attention away from other types of assistance.

These sentiments highlight the influence of economics beyond the individual level to include the systems level.

> You know, I pause because I don't know who, we obviously don't know who social workers are anymore. Social workers are people that have basically become financial counselors in our community…I mean, I don't know too many people at the moment who identify themselves as social workers. Fifteen years ago it was extraordinarily common. It's financial resourcing that most of these folks are involved in…there are very few true social workers anymore. (Oncologist, urban, 68)

Funding cuts also left some cancer centers without adequate staffing of these and other "ancillary" services. Notably, of all of the services providers expressed wishing were available for their patients, over half specifically cited the need for more mental health services. One oncologist noted that depression and anxiety was common among his cervical cancer patients; according to several providers, patients might have had underlying mental health issues that were exacerbated by their cancer experience and others may have developed these conditions after being diagnosed.

> Psychiatric issues, I don't know if psychiatric issues are more likely to make you poor, that's what they say and that puts you on the Medicaid program. But we have a significant number of people that are psychotic and manic-depressive and that can be a challenge to have them adequately treated so they can get through this stressful time. (Oncologist, urban, 241)

The lack of trained mental health staff often forced clinical providers into an informal counselor role, again shifting them away from their primary role of providing cancer care.

> We used to have a psychiatrist on staff here and her funding got cut so she's gone…there's a psychologist here we can refer patients to but psychologists can't prescribe medications and so we really don't have anyone. I mean, these patients are dealing with a lot of depression. You know, cervical cancer is such a big issue anyway but, why are they [here] to begin with, because they're indigent, they don't have any money. And so it's like one more problem. And we really don't, it's totally overwhelming for them. And we try to lend an ear, that type of thing but I think, you know, they would benefit in large part from like a true mental health professional as opposed to, we're trying to see 85 patients at once and I don't have time for a psych visit also, not that I wouldn't want to, but it's kind of hard. (Oncologist, metro Atlanta, 85)

Several providers echoed the challenge of patients not being able to access psychiatric medications. Access to mental health care was also prevented when these providers did not accept Medicaid. Thus, patients in need of mental health care could sometimes face as cumbersome a process to obtaining it as their cancer treatments. A psychologist illustrated this issue by explaining that without a psychiatrist on staff, the process of getting a patient into psychiatric care required a chain of referrals through several providers and long wait times to be seen, often at a separate facility from the cancer center.

Lastly, while providers generally noted good availability of resources for breast cancer patients—from organizations providing wigs, bras and prostheses to breast cancer patient navigator support through the American Cancer Society and other sources—this was less so the case for cervical cancer patients. The amount of external funding for cervical cancer support relative to breast cancer was one contributing factor.

> So breast cancer, they're going to love it when I say this. Breast cancer is a ton of money and you'll find this across the board like when people hear about it because they just have so much money and they have a lot more access. Not access but since they have the money they're able to provide a lot more services, I think, to their patients. And cervical cancer is not that glamorous of a disease and so, you know, there's not a lot of money there. And I think I can safely say this, you know, for all practices, we just, we don't have anything like navigators…only breast cancer has navigators. (Oncologist, metro Atlanta, 67)

Several OB-GYN oncologists noted that cervical cancer is associated with greater stigma, shame and embarrassment than breast cancer. Sentiments like these may be unintentionally linked to the relative lack of resources for cervical cancer patients. In particular, several providers expressed the need for support around the effects of cervical cancer treatment on sexual function. One social worker believed that having an individual therapist to specifically address problems with intercourse and intimacy following treatment would be of benefit to cervical cancer patients, but that current funding would not permit it.

# V. DISCUSSION

## A. Recommendations

BCCPTA has successfully expanded access to breast and cervical cancer treatment for low-income and uninsured/underinsured women over the last 15 years, yet the literature has identified persistent barriers to and differences in treatment receipt among these populations. The goal of this study was to understand Georgia providers' perspectives on what factors influence breast and cervical cancer treatment among their WHMP patients. Qualitative interviews produced rich narrative data on several factors underlying disparities in cancer treatment that would not have emerged through quantitative methods alone.

Many of the study's findings are consistent with the literature on barriers to care at multiple levels of influence and illuminate differences among clinical and allied health providers' perceptions of these barriers and approaches to addressing them. Economics has been largely identified in the literature as a key impediment to health care for low-income populations regardless of insurance status. The findings in the present study largely support this by illustrating that while the Georgia WHMP was invaluable in facilitating access to health coverage for treatment that might otherwise be unattainable for its recipient population, financial barriers prevented this access from being fully realized. According to the majority of providers interviewed, being in or near poverty prior to a cancer diagnosis could make the timely and complete receipt of cancer care challenging, since Medicaid enrollment alone does not eliminate the secondary costs associated with treatment, such as transportation costs and copayments. Furthermore, getting cancer treatment—a huge undertaking for any patient—may exacerbate low-income patients' already strained economic resources by affecting their ability to retain employment and income. The precarious nature of being low-income, including a lack of stable employment, health benefits and income, may mean that for many of these women, a cancer diagnosis could be the tipping point.

Programs that reimburse out-of-pocket costs for treatment-related expenses such as transportation and childcare would be of great benefit. While there are many programs that offer financial assistance for patients with cancer, it is essential that allied health professionals are aware of these resources in order to refer patients in a quick and seamless manner. Furthermore, existing services like bus transportation must be adequately financed and operated so that they do not place an additional burden on patients, particularly those traveling large distances for care. While Medicaid funds the *Breast Friends* service, the patient complaints that were noted with the service suggest that novel partnerships may be needed to improve transportation efficiency. In April 2016, Hackensack University Medical Center in New Jersey announced a new partnership with Uber ridesharing services to provide transportation for staff, patients and visitors.[31] While the Hackensack UMC will be assisting with the costs of Uber trips from the medical center to patients' homes, little information is available on the exact plan for budgeting and implementation. Nonetheless, it is the first program of its kind to adopt such a strategy to improve health care access for patients, and could provide a model for other health systems nationwide.

This study's findings also illustrate how patients' financial needs put a strain on those overseeing their care. By spending a great deal of time addressing patients' financial concerns, time was taken away from providers' primary role of providing curative care or more comprehensive support. The complexity of poverty and its ripple effect over patients' lives meant that, according to the allied health providers in this study in particular, the bulk of their energy could be spent trying to resolve these seemingly insurmountable issues. Without adequate staffing of allied providers, including case managers, social workers and patient navigators, systems meant to support patients will become overburdened and unable to fully address their needs. Multiple allied health providers in this study expressed their desire for more staff to help them take on patient caseloads; it is critical that any cancer program ensure the sufficient availability of personnel serving both the financial and psychosocial needs of patients.

It has been widely acknowledged that programs offering patient support activities are central to helping women navigate the complex and challenging path from cancer treatment through survivorship.[32] One of the present study's participants felt strongly that the introduction of a patient navigation program in their cancer center was responsible for a significant improvement in cancer treatment completion among their patients. In Rizzo et al.'s study on racial disparities in cancer outcomes among African American women, the authors describe how one public hospital's use of a medical oncology nurse practitioner and patient navigators to track patients and emphasize the importance of multimodal therapy resulted in an increase from 75.8% to 95.8% treatment compliance.[33] The fact that these navigators were themselves cancer survivors may have contributed to the success of the program, as women could possibly identify with them on a more personal level.[33] Additionally, since patient navigators are often members of the same communities as their patients, a level of trust and rapport may be possible that is less present in the patient-physician relationship. Patient navigators can play a crucial role in instilling trust and dispelling misconceptions about treatment and/or the health care system, the implications of which should not be underestimated.

Overall, the study's findings suggest that there were differences in the extent to which providers understood and addressed the difficulties of their patients' lives beyond the clinic environment. When asked to provide an example of a case that illustrated the challenges of treating their patients, clinical providers—oncologists in particular—were more likely to describe a situation that was complex from a medical standpoint, such as a patient with an especially aggressive cancer. By and large, clinicians struggled to provide a rich narrative example, deferring to their nurses' role in managing non-clinical issues or, in some cases, concluding that patients who miss treatments were simply noncompliant. Alternatively, allied health providers provided more detailed narratives of challenging patient cases, offering insights into the complexities of their patients' lives and navigation of cancer as a low-income person. These findings illustrate the need for clinicians to view their patients not only as people with cancer, but as mothers, daughters, workers and women with many other complex roles and identities. The providers in this study who understood that patients' finances and other factors played a role in their treatment compliance were better equipped to prevent them from slipping through the cracks, making stronger efforts to coordinate patients' care by getting them into navigation programs or making special accommodations to ensure the receipt of critical services.

Providers acknowledged that good communication and adequate provision of information were important elements in ensuring patient participation and quality care, something that has been well established in the literature.[34] Ascertaining patients' level of health literacy is one way that providers can help ensure they are communicating health information and addressing their patients' questions and concerns in the manner most conducive to their understanding and, subsequently, compliance with their treatment plan. There are a number of available health literacy assessment tools that could easily be incorporated into an oncology care setting. Clinicians could perform these assessments on a sample of patients to gather information about their patients' average reading level, oral understanding, health knowledge, navigation skills and other indicators of health literacy in order to guide the development of patient education materials and improve patient-provider communication. It is promising that health literacy initiatives, particularly those grounded in research on health disparities, have been prioritized in recent years to meet the goals of Healthy People 2010, and continue to be for Healthy People 2020.[35]

The study's findings on available institutional-level resources and support suggest that mental health services for cancer patients were needed, yet limited. The primary issue from providers' perspectives was a shortage of trained mental health professionals within their respective cancer centers or communities, including those who accept Medicaid—a problem reflective of the overall state of public mental health in the U.S. This issue cannot be ignored, as evidence continues to mount implicating psychological functioning in cancer outcomes.[36] It has been suggested that other health care professionals such as nurses and oncology social workers be trained to manage, for instance, depression care for cancer patients.[37] At minimum, providers in the present study noted the need to perform preliminary psychiatric evaluations in the absence of mental health staff, despite being overburdened and ill prepared to do so. Incorporation of tools for basic mental health assessment into oncology care practice would help ensure that providers are well equipped to screen, refer and, as needed, set treatment plans for their patients with mental health care needs. The Mental Health Assessment and Dynamic Referral for Oncology (MHADRO) program is one such example. The MHADRO is a computerized program that evaluates psychosocial variables in patients with cancer so that they can review and discuss findings with their provider. It also offers a "dynamic referral" option that matches patients' behavioral health profile, insurance status and residential location with an appropriate mental health professional.[38]

Lastly, the study's findings suggest that services specifically for cervical cancer patients may not be as robust as those for breast cancer patients. A need for cervical cancer support groups was noted both for women in active treatment and survivors, as well as for women of all backgrounds, ages and identities. In particular, providers cited the need for support around changes in sexual function and intimacy that often resulted from cervical cancer treatment. Prioritizing public funding for these support services will require an acknowledgment of the underlying causes of cervical cancer, namely the human papillomavirus and its link to women's sexuality. Notably, when BCCPTA was first introduced it included a clause on establishing surveillance and reporting of HPV as well as HPV warning labels on condoms. Only once this language was removed—which had been the source of some debate—was the bill passed by both houses and signed into law, possibly due to the stigmatized nature of cervical cancer and its association with a sexually transmitted infection.[5] Although strong bipartisan support led to the groundbreaking Medicaid expansion program under BCCPTA, politics surrounding these "taboo" issues and funding priorities for certain diseases over others limit its full potential.

In conclusion, the present study's findings exemplify the assertion by the authors of *Cancer Care for the Whole Patient* that psychological and social problems can be created or exacerbated by cancer, weakening treatment adherence and causing further suffering overall.[39] They also illustrate how influences on cancer patients' treatment behaviors are localized and represented at multiple levels in their lives, from the individual outward to the social and environmental. Programs assisting underserved cancer patients in accessing treatment are well situated to adopt frameworks that help enumerate which influences are most salient for their recipient populations. Armed with a better understanding of these barriers, such programs can develop new ways to facilitate access to high quality, holistic health care. An area of further research will be assessing how the Patient Protection and Affordable Care Act (ACA) will expand access to women's health care and the implications for women whose health needs were the focus of BCCPTA. While the ACA mandates affordable and accessible coverage regardless of health status or preexisting condition, evidence suggests that some women will continue to face barriers to care due to unaffordable premiums and lapses in coverage, among other reasons.[32] Furthermore, states like Georgia that have opted out of Medicaid expansion see large health disparities by race/ethnicity and income, indicating that BCCPTA and other safety net programs will continue to be an invaluable resource for cancer services among underserved populations.

## B. Study Limitations

The larger study collected data from providers actively serving women in the Georgia Women's Health Medicaid Program with breast and/or cervical cancer or cervical pre-cancer. As with any qualitative study, the use of purposive sampling and the small sample size make it impossible to generalize the results to the larger population. Additionally, while providers were specifically asked to refer to their patients who were enrolled in WHMP, it is possible that they may have collapsed these patients with those enrolled in traditional Medicaid, or their low-income patients in general. Furthermore, it is somewhat difficult to learn about patients actual circumstances through the perspectives of providers alone. Ideally, these data will complement previously collected data on this topic from the perspectives of patients enrolled in the WHMP.

Lastly, while the larger study aimed to assess racial and ethnic disparities in cancer treatment access, regimens and completion, evaluating these disparities was not highly feasible for the present analysis. While providers were asked to describe the perceived differences among their patients by race, the data obtained on racial and ethnic disparities were not rich. Some providers conceptualized their patients as a somewhat monolith group that experienced similar barriers due to being low-income, and did not feel that race was a factor. Others noted differences in patients' personal beliefs and behaviors by race, but largely expressed that education and income were the primary drivers.

Nevertheless, health care providers offer a unique perspective on the cancer treatment behaviors of their patients. By using qualitative methods, rich data were obtained that helped "give voice" to the quantitative findings in the larger study, and the literature at large, regarding disparities in cancer treatment among low-income, uninsured and underinsured women.

# VI. APPENDICES

## A. Appendix A: Informed Consent Form (Standard)

### Emory University Rollins School of Public Health
### Consent to be a Research Subject

### Women's Health Medicaid Program (WHMP) Provider 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 you are a provider who cares for women 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 30 to 45 minutes. The interview may be conducted on the phone or in person, depending on your availability and preference. 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 what types of treatment options Medicaid providers offer and women choose with respect to their cancer, as well as what information providers give to WHMP clients about their cancer treatment options. Also, we are interested to know what, if any, barriers exist for WHMP providers in treating Medicaid clients.

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 $100 for your participation in the interview.

## 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.

## 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

## B. Appendix B: Informed Consent Form (Grady Health System)

### Emory University Rollins School of Public Health
### Consent to be a Research Subject

### Women's Health Medicaid Program (WHMP) Provider 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 you are a provider who cares for women 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 30 to 45 minutes. The interview may be conducted on the phone or in person, depending on your availability and preference. 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 what types of treatment options Medicaid providers offer and women choose with respect to their cancer, as well as what information providers give to WHMP clients about their cancer treatment options. Also, we are interested to know what, if any, barriers exist for WHMP providers in treating Medicaid clients.

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 $100 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

## C. Appendix C: Physician Interview Guide

### Women's Health Medicaid Program (WHMP)
### Physician Interview Guide

Date: ______________________
Name of Interviewer: ___________________________________________
Time Started: ________________ Time Ended: ____________________

***Thank you for agreeing to talk with me today. I know how busy you are and really appreciate your time! As we go along, please do let me know if you have any questions or concerns. The following questions will address how you interact with breast and cervical cancer patients as well as the challenges you face treating them.***

### A. Background

1. Are you?
   ☐ Female ☐ Male
2. Which one best describes your race?
   ☐ Black or African American
   ☐ Native Hawaiian or other Pacific Islander
   ☐ American Indian or Alaska Native
   ☐ Caucasian or White
   ☐ Hispanic
   ☐ Asian or Asian American
   ☐ Other: ______________

3. What is your clinical specialty? (check all that apply)
   ☐ General surgery
   ☐ Internal medicine
   ☐ Medical oncology
   ☐ Radiation oncology
   ☐ Surgical oncology
   ☐ Other: _________

4. How long have you been in practice?__________ years ________months

5. Are you Board Certified? ☐ Yes ☐ No

   If yes, in what specialty? _______________________________________

6. How long have you been a Medicaid-participating provider? _________ years ____months

### B. Practice Setting

1. Could you tell me a bit about your practice? If you practice in more than one setting, please describe each briefly.
   - Location (place, type)
   - Frequency/intensity

- Patient population (insurance status, race, rural/urban)

*[If provider practices in more than one setting:]*

- Of your different practices, where do you see the most Medicaid patients?
    i. *[If same, ask where they spend the most time, or ask to select one practice to focus on.]*
- Please focus on this practice setting for the questions that follow.

2. When patients first consult you, where are they in their cancer diagnosis/ treatment process?
    - Screening
    - Diagnosis
    - Treatment planning
    - Active treatment
    - Follow-up

3. When does your involvement in their care usually end?

4. What support is available [in your practice] to help women navigate their care?
    - Staff [Patient navigators, social workers]
    - Support Groups
    - Appropriate referrals
    - Mental Health
    - What do you wish you could add or expand in these efforts?

## B. Interactions with Cancer Patients

5. When women with breast or cervical cancer come into your care, what are your first steps to develop a treatment plan?
    - diagnosis/staging
    - Multidisciplinary [types of providers]
    - Team-based approach [include allied health]
    - Patient involvement in decision-making

6. How do you discuss cancer treatment options with women?
    - Kind of information shared
    - Level of information discussed
    - Discussion of options (what and how)
        - Treatment options
        - Optional treatments [alternate modalities, clinical trials]
    - Kinds of questions patients ask [side effects]
    - Ease of understanding [different aspects]
    - Support by other staff [nurses, social workers, patient navigators]
    - Standards of care
    - Challenges to discussion

*Part of our focus in this project is to understand differences among women who have enrolled in Medicaid (through WHMP) because of their breast of cervical cancer diagnosis. The cancer literature highlights differences by race and urban/rural residence.*

- Do you find differences in the treatment choices women make?

7. What other kinds of issues do women face that make it challenging for you to treat them?
    - Literacy/education
    - Comorbidities
    - Socio-economic context [housing, employment, etc.]
    - Health and cultural beliefs
    - Mistrust/fears of medical system
    - Overcome challenges
    - Do you think these challenges differ by race and urban/rural residence?

8. Could you describe a recent case that illustrates these kinds of challenges
    - socio-demographics
    - diagnosis/treatment
    - particular challenges

## C. Challenges with Cancer Treatment: Systems Related

9. As I mentioned earlier, our study focuses specifically on women who are in the Women's Health Medicaid Program. What is your experience treating women with breast and cervical cancer who are Medicaid beneficiaries?
    - Availability of providers
    - Reimbursement issues
    - Paperwork
    - Coverage of services
    - Overcoming barriers

10. As of 2006, all Medicaid recipients in Georgia were required to enroll in a managed care organization. Has this change affected the way you provide services to your clients?
    - Peach State, Amerigroup, WellCare
    - Limiting numbers
    - Continuity of care
    - Patient understanding
    - Overcoming challenges

11. Is there anything else you would like to add about your experience treating WHMP clients?
    - Recertification
    - Disenrollment

## D. Appendix D: Allied Health Interview Guide

### Women's Health Medicaid Program (WHMP)
### Allied Health Interview Guide

Date: ______________________
Name of Interviewer: ___________________________________________
Time Started: ________________ Time Ended: ____________________

***Thank you for agreeing to talk with me today. I know how busy you are and really appreciate your time! As we go along, please do let me know if you have any questions or concerns. The following questions will address how you interact with breast and cervical cancer patients as well as the challenges you face treating them.***

## A. Background

7. Are you?
   □ Female □ Male

8. Which one best describes your race?
   □ Black or African American
   □ Native Hawaiian or other Pacific Islander
   □ American Indian or Alaska Native
   □ Caucasian or White
   □ Hispanic
   □ Asian or Asian American
   □ Other: _____________What is your professional specialty? (check all that apply □Nurse or nursing assistant
   - □ Social worker
   - □ Psychologist
   - □ Physical therapist
   - □ Therapist
   - □ Case manager
   - □ Physician assistant
   - □ Other: ______________________________
9. How long have you been in practice?__________ years ________months

**10.** How long have you been a Medicaid-participating provider? _________ years ____months**A. Practice Setting**

12. First, could you tell me a bit about [name of clinic]?
    - Location (place, type)
    - Patient Population (Medicaid/insurance status, race, rural/urban)

13. And what is your role here?
    - Occupation
    - Hours/schedule
    - Length of time in position
    - Multiple roles/balance

14. How do you typically come into contact with breast and cervical cancer patients?
    - Referral
    - Patient initiative
    - Reasons
    - Treatment Plan team

15. When patients first come to you, where are they in their cancer diagnosis/ treatment process?
    - Screening
    - Diagnosis
    - Treatment planning
    - Active treatment
    - Follow-up

16. When does your involvement in their care usually end?

17. What support is available to help women navigate their care?

    - Staff [Patient navigators, social workers]
    - Support Groups
    - Appropriate referrals
    - Mental Health
    - What do you wish you could add or expand in these efforts?

## B. Interactions with Cancer Patients

18. [How] do you discuss cancer treatment with women?
    - Kind of information shared
    - Level of information discussed
    - Discussion of options (what and how)
        - Treatment options
        - Optional treatments [alternate modalities, clinical trials]
    - Kinds of questions patients ask [side effects]
    - Ease of understanding [different aspects]
    - Patient involvement in decision-making
    - Support by other staff [nurses, social workers, patient navigators]
    - Challenges to discussion

*Part of our focus in this project is to understand differences among women who have enrolled in Medicaid (through WHMP) because of their breast of cervical cancer diagnosis. The cancer literature highlights differences by race and urban/rural residence.*

- Do you find differences in the treatment choices women make?

19. What kinds of issues do women face that make it challenging for you to help them?
    - Literacy/education

- Comorbidities
- Socio-economic context [housing, employment, etc.]
- Health and cultural beliefs
- Mistrust/fears of medical system
- Overcome challenges
- Do you think these challenges differ by race and urban/rural residence?

20. Could you describe a recent case that illustrates these kinds of challenges
    - socio-demographics
    - diagnosis/treatment
    - particular challenges

## D. Challenges with Cancer Treatment: Systems Related

21. As I mentioned earlier, our study focuses specifically on women who are in the Women's Health Medicaid Program. What is your experience working with women with breast and cervical cancer who are Medicaid beneficiaries?
    - Availability of providers
    - Reimbursement issues
    - Paperwork
    - Coverage of services
    - Overcoming barriers

22. As of 2006, all Medicaid recipients in Georgia were required to enroll in a managed care organization. Has this change affected the way you work with these clients?
    - Peach State, Amerigroup, WellCare
    - Continuity of care
    - Patient understanding
    - Overcoming challenges

23. Is there anything else you would like to add about your experience treating WHMP clients?
    - Recertification
    - Disenrollment

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