

DEVELOPMENT AND VALIDATION OF THE CANCER LITERACY MEASURE FOR  
AFRICAN AMERICANS

BY

JENNIFER BIANCA MAYFIELD

DISSERTATION

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Doctoral Committee:

Associate Professor Lydia P. Buki, Chair  
Professor Helen A. Neville  
Professor Reginald Alston  
Assistant Professor Diana Grigsby-Toussaint

## **Abstract**

Research has shown that higher levels of cancer health literacy are related to improved health outcomes. However, there is a dearth of research regarding the influence of health literacy on breast and cervical cancer health disparities within the African American community. To further explore this area, researchers need a psychometrically validated measurement tool. The current study represents an exploration of the Cancer Literacy Measure for African Americans (CLM-AA), designed to measure African American women's cultural and conceptual knowledge of breast and cervical cancer. Survey data were collected from 301 African American women using online survey methodology. Exploratory factor analyses revealed factors that measured women's beliefs, attitudes, knowledge, and emotions regarding breast and cervical cancer. In addition, the CLM-AA assessed participants' breast and cervical cancer screening behaviors, gender preferences for healthcare providers, and referral sources for cancer screening. Coefficient alphas for the factors ranged from .67 to .97, with one factor requiring revision to improve reliability. Despite this limitation, the CLM-AA has the potential to be a useful tool for researchers and practitioners to assess the breast and cervical cancer health literacy of African American women.

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## Table of Contents

Chapter 1: Introduction.....	1
Chapter 2: Review of the Literature.....	10
Chapter 3: Methodology.....	35
Chapter 4: Results.....	51
Chapter 5: Discussion.....	63
References.....	74
Tables and Figures.....	96
Appendix A: Sociodemographic Questionnaire.....	115
Appendix B: Focus Group Interview Guide.....	125
Appendix C: Focus Group Informed Consent.....	126
Appendix D: Survey Recruitment Email.....	127
Appendix E: Survey Informed Consent Form.....	128
Appendix F: Cancer Literacy Measure for African Americans Preliminary Draft.....	129
Appendix G: Cancer Literacy Measure for African Americans Preliminary Final Draft.....	137

## **Chapter 1**

### **Introduction**

Despite recent advancements in breast and cervical cancer prevention, early detection, and treatment modalities, cancer health disparities still exist within the African American community. Breast cancer is the second leading cause of cancer death among this group, due in part to their disproportionate detection at advanced stages (Ghafoor et al., 2002; Jemal et al., 2009; Siegal, Naishadham, & Jemal, 2012). Likewise, compared to non-Latina White women, African American women have a higher incidence rate of cervical cancer and a mortality rate that is twice as high (Ghafoor et al., 2002; Jemal et al., 2009; Siegal, Naishadham, & Jemal, 2012). Factors that contribute to these cancer disparities include biological and environmental determinants, cancer screening behaviors, and levels of cancer health literacy (Ackerson & Greteback, 2007; Bazargan, Bazargan, Farooq, & Baker, 2004). Among these, cancer health literacy is an area of particular interest because health literacy influences an individual's ability to access health information and to navigate the healthcare system [Institute of Medicine (IOM), 2004].

Research has provided evidence of the role of health literacy as a mediator between the skills of an individual and the demands of health systems (Bennett, Chen, Soroui, & White, 2009; IOM, 2004). Researchers have found that individuals with higher levels of health literacy have better health outcomes. However, studies have not specifically addressed the role that cancer health literacy plays in the breast and cervical cancer health disparities that affect African American women. In order to delve into research on cancer health literacy among African American women, researchers require an empirically-based health literacy assessment tool focused on breast and cervical cancer that can capture the cultural nuances that influence health

literacy among African Americans. Yet, to date, no such health literacy assessment exists.

Using a cancer health literacy measure tailored for African Americans, researchers would be able to advance the theoretical conceptualization of the ways in which African American women gain knowledge about, and understand the risks and benefits of, breast and cervical cancer prevention, screening, and treatment. Researchers would have the tools to gain further insight into the factors that influence the disproportionate burden of breast and cervical cancer outcomes among African American women, and would have information to tailor educational interventions to this population.

An important consideration in investigations into the breast cancer health disparities in the African American community research is the stage of diagnosis. Existing research has identified stage of diagnosis (ranging from stage I, least advanced, to stage IV, most advanced) as a significant factor in poor breast cancer outcomes, with survivorship rates decreasing significantly at higher stages (American Cancer Society, 2011). Between 1999 and 2006, the 5-year survival rate for African American women with breast cancer was 78% compared to 90% for non-Latina White women (American Cancer Society, 2011; Horner et al., 2009). Early detection is the best strategy to decrease breast cancer mortality rates, and can be achieved through breast self-examinations, clinical breast examinations, and mammography (American Cancer Society, 2011; National Cancer Institute, 2012). Currently, mammography is the most highly recommended early detection method within the medical community (American Cancer Society, 2011).

Unlike breast cancer, cervical cancer is a preventable disease. Nonetheless, African American women have higher incidence rates of cervical cancer per 100,000 women compared to non-Latina White women (10 vs. 8, respectively) (American Cancer Society, 2011; Horner et

al., 2009). From 1999 to 2007, the five-year cervical cancer survival rate for African American women was lower (61%) than for non-Latina White women (72%) (American Cancer Society, 2011; Horner et al., 2009). The vast majority of cervical cancer cases are caused by certain strains of the Human Papillomavirus (HPV) (American Cancer Society, 2011). A Papanicolaou test, commonly known as a Pap smear, is recommended by physicians for detection of precancerous cells and small tumors caused by HPV that can later develop into cervical cancer if the condition is left untreated (American Cancer Society, 2011). Early detection can allow women to obtain treatment for abnormal cells before they become cancerous, effectively preventing the development of cancer (American Cancer Society, 2011; Watson et al., 2008).

Given the importance of early detection, the majority of studies examining breast and cervical cancer health disparities are focused upon nonadherence to screening guidelines (Bazargan, Bazargan, Farooq, & Baker, 2004; Harris, Miller, & Davis, 2003; Sairaya et al., 2009). Socioeconomic factors such as lack of adequate health insurance coverage and limited access to care can hinder African American women's ability to obtain regular cancer screenings (Mickey, Vezina, Worden, & Warner, 1997; O'Malley, Forrest, & Mandelblatt, 2002; Robinson & Shavers, 2008; Schueler, Chu, & Smith-Bindman, 2008). Additionally, there is growing evidence that culturally-based knowledge, beliefs, attitudes, and emotions regarding breast and cervical cancer influence women's screening behaviors (Ackerson & Greteback, 2007; Buki, Jamison, Anderson, & Cuadra, 2007). In particular, fatalistic beliefs about cancer, lack of knowledge regarding the etiology of breast and cervical cancer, lack of awareness of cancer screening guidelines, and negative perceptions of cancer screening methods have been associated with nonadherence to cancer screening guidelines in African American women (Paskett et al., 2004; Peek, Sayad, & Markwardt, 2008). Despite evidence of this link, research regarding

African American women's culturally-based breast and cervical cancer knowledge, beliefs, attitudes, and emotions is limited. Information about these factors is critical to gain a conceptual understanding of the cultural antecedents of breast and cervical cancer screening, and for the development and implementation of psychosocial interventions designed to increase screening behaviors.

Health literacy research has the potential to address the role of knowledge, beliefs, attitudes, and emotions on women's cancer screening behaviors. Generally, health literacy refers to a patient's ability to obtain, process, understand, and use health-related information (IOM, 2004). Within a conceptual framework of health literacy, literacy serves as the foundation for health literacy and health literacy acts as a mediator between individuals and the health context, later affecting individuals' health outcomes (IOM, 2004; White, 2008). The health context includes all institutions and individuals responsible for providing accurate health-related information and services to the public (IOM, 2004). Health literacy encompasses three skills: oral literacy (i.e., listening and speaking skills), print literacy (i.e., reading and writing skills), and numeracy (i.e., basic mathematical calculations). Furthermore, health literacy is determined in part by cultural and conceptual knowledge, which refers to individuals' knowledge of health conditions and understanding of health-related risks and benefits (IOM, 2004). Within this construct, culture plays a primary role in the development of attitudes, beliefs, and emotions about health, thereby influencing individuals' health literacy (IOM, 2004). The conceptual component of cultural and conceptual knowledge takes into account an individual's ability to cognitively process health information based on prior knowledge; it relates to an individual's ability to understand and integrate health information, as well as the likelihood that the individual will seek additional health information (IOM, 2004). Within the context of the current

study, cultural and conceptual knowledge is conceptualized as African American women's knowledge, beliefs, attitudes and emotions about breast and cervical cancer.

Based on this conceptual framework, health literacy is a significant determinant of a person's ability to gain knowledge about various health conditions, as well as a determinant of a person's engagement in appropriate behaviors for disease prevention, detection, and treatment (White, 2008). There is empirical evidence to support the health literacy conceptual framework with findings indicating that lower levels of health literacy are associated with a limited ability to obtain or understand health-related information and adverse health outcomes (Berkman et al., 2011; Joyner & Williams, 2011; Rudd, 2010). Likewise, within cancer research, lower levels of health literacy are associated with lower screening adherence and adverse cancer outcomes (Amalraj et al., 2009; Davis et al., 2002). Scholars have found that women with higher levels of health literacy are more likely to report positive interactions with the healthcare system as well as higher levels of adherence to breast and cervical cancer screening guidelines (Davis et al., 1996; Lindau et al., 2002).

Therefore, health literacy should be an important consideration in breast and cervical cancer research regarding African American women. In a qualitative study of 114 African American women, the investigators found that the following knowledge, beliefs, attitudes, and emotions negatively influence women's likelihood to receive mammograms: (a) greater risk assessment for illnesses besides breast cancer, (b) age is not a risk factor for breast cancer, (c) overreliance on breast self-examination for detection of breast abnormalities, (d) fear of a breast cancer diagnosis, (e) expectation of body image issues related to side effects of breast cancer treatment, (f) lack of prioritization of mammography medical costs within personal budget, (g) lack of perceived need for preventative healthcare, and (h) reliance on social support networks as

sources of health information (Tessaro, Eng, & Smith, 1994). Additional culturally-based breast cancer beliefs and emotions include prioritization of religious/spiritual beliefs to address health concerns, a belief that surgery causes cancer to spread, fear that an intimate partner would not be supportive if cancer is diagnosed, and the erroneous assumption that cancerous breast cancer lumps are always painful (Lannin et al., 1998).

Likewise, Ackerson (2010) conducted a qualitative study with 24 African American women and found that the following factors were related to higher likelihood of Pap smear screening behaviors: (a) belief that Pap smears test for both cancer and sexually transmitted diseases, and (b) high risk assessment due to family history. The women were less likely to have a Pap smear if they had a sexual, physical, or medical trauma history. Despite the utility of similar studies focused on African American women for the development of interventions, research in this area is surprisingly limited.

Research regarding breast and cervical cancer health literacy within the African American community may be limited by the few empirically-based scales available to measure health literacy within cancer research. The two most commonly used scales, the Test of Functional Health Literacy in Adults (TOFHLA; Parker et al., 1995) and the Rapid Estimate of Adult Literacy in Medicine (REALM; Davis et al., 1993), primarily focus on print literacy by assessing a person's ability to read and understand health-related written materials (IOM, 2004). These assessments are not focused on a specific medical condition such as cancer, instead focusing on an individual's basic ability to obtain, process, and understand general health information (IOM, 2004). The TOFHLA and the REALM also do not measure the cultural and conceptual knowledge component of health literacy.

To date, there are few health literacy assessments that focus specifically on measuring cultural and conceptual knowledge of cancer, and only two breast cancer health literacy measures specific to African American women. For instance, The Stieglitz Informal Reading Assessment of Cancer Text (SIRACT; Agre, Stieglitz, & Milstein, 2006) measures print literacy as well as conceptual knowledge regarding a broad range of cancers. The Latina Breast Cancer Scale was created by Borrayo and colleagues (2009) to measure Latina women's culturally relevant beliefs about breast cancer and breast cancer screening. Furthermore, The Culture Cancer Screening Scale (Betancourt, Flynn, Riggs, & Garberoglio, 2010) measures cultural factors related to breast and cervical cancer screening among Latina and non-Latina White women. Buki and Yee (2010) have developed two versions of a health literacy scale to measure women's knowledge, beliefs, attitudes, and emotions about breast and cervical cancer, which will be called the Cancer Literacy Measure. One version of the measure is designed for use with Latina women of Mexican descent, and the other version for Filipina women (Buki & Yee, 2010). In addition, the measure has been adapted for use with Uruguayan women (Buki & Reich, 2012) and is being adapted for use with Navajo women (Buki personal communication, May 1, 2011).

Although the aforementioned scales measure aspects of breast or cervical cancer cultural and conceptual knowledge, the scales do not take into account cultural factors specific for African American women. Champion and colleagues (2008) developed a scale that measures several aspects of African American women's beliefs about breast cancer including perceived susceptibility, fatalism, health behavior self-efficacy, fear, and barriers to mammography screening. This scale is a revised version of the Breast Cancer Beliefs in African American Women scale (Champion & Scott, 1997). The scale created by Champion and colleagues (2008)

does not measure African American women's perceptions of their healthcare providers, experiences of racial discrimination within the healthcare system, and knowledge of breast cancer symptoms and breast self-examinations. Furthermore, the scale does not measure attitudes about breast cancer, only beliefs and emotions. To date, there are no health literacy scales focused on African American women's cultural and conceptual knowledge of cervical cancer. Additionally, research related to the cultural nuances (e.g., Blake, Weber, & Fletcher, 2004; Bigby, Ko, Johnson, David, & Ferrer, 2003) has largely relied on qualitative data or the use of non-empirically validated questionnaires to measure African American women's knowledge, beliefs, attitudes, and emotions about breast and cervical cancer. Therefore, a gap remains for a breast and cervical cancer literacy measure that is tailored for use within the African American community.

In order to understand African American women's cultural and conceptual knowledge related to breast and cervical cancer, it is important to develop a scale that taps into the unique aspects of the African American health experience. This scale would expand upon previous scales by incorporating items related to African American women's knowledge, beliefs, attitudes, and emotions related to breast and cervical cancer, which are critical cultural factors in our conceptualization of African American women's cancer health behaviors. By understanding these cultural factors, researchers would have the ability to further identify and conceptualize psychosocial determinants of health disparities. These factors influence screening behaviors regardless of levels of access to the healthcare system. Therefore, this research provides the opportunity to address determinants of breast and cervical cancer health disparities on an individual level, allowing for the development of psychosocial interventions that are focused on changing knowledge, beliefs, attitudes, and emotions. The latter factors are more amenable to

change than institutional- (e.g., hospital policies) or community-level factors (e.g., neighborhood characteristics).

Therefore, the purpose of the current study is to develop an empirically-based assessment of health literacy that measures African American women's cultural and conceptual knowledge of breast and cervical cancer. The assessment will be designed to increase understanding of African American women's knowledge, beliefs, attitudes, emotions, and behaviors regarding breast and cervical cancer. This measure will be adapted from a Cancer Literacy Measure recently developed by Buki and Yee (2010) that is focused on measuring the cultural and conceptual knowledge of breast and cervical cancer among Latinas. The new assessment will be called the Cancer Literacy Measure for African Americans.

## Chapter 2

### Review of the Literature

The health disparities that exist between African American women and non-Latina White women diagnosed with breast or cervical cancer are striking. African American breast and cervical cancer survivors experience higher mortality rates and lower 5-year survival rates than their non-Latina White counterparts (American Cancer Society, 2011). As researchers have striven to identify the determinants of these cancer health disparities, they have primarily focused on the association between late detection and institutional, biological, and environmental factors. In fact, there is extensive empirical evidence that institutional factors such as health insurance, access to healthcare, and formal education influence screening behaviors (e.g., Ackerson & Greteback, 2007; Laing, O'Campo, & Harris, 2010; von Wagner et al., 2011). However, few studies have explored the role that health literacy plays in African American women's cancer screening behaviors.

Health literacy is an emerging line of research. An examination of all of the components of health literacy has the potential to further enrich our understanding of cancer screening behaviors (IOM, 2004). Research in this area has primarily involved the exploration of the influence of print (e.g., ability to read handouts about medical conditions), oral (e.g., ability to ask relevant questions), and numeracy (e.g., ability to calculate medication dosage) skills on general health behaviors (IOM, 2004). Cultural and conceptual knowledge is an understudied component of health literacy (IOM, 2004). This health literacy research gap includes a very limited literature on cultural and conceptual knowledge regarding breast and cervical cancer in African American women, despite the potential for scholarship in this area to provide insights

about culturally-based factors (e.g., cancer beliefs) that interface with distal factors (e.g., access to health insurance) to contribute to late detection of cancers.

Although researchers have theorized about them, there currently is no way to examine these associations empirically because appropriate measures do not exist. It is critical to have a cancer health literacy scale that focuses on breast and cervical cancer so that researchers can assess the contribution of cancer health literacy to late detection. Therefore, this is the first study to specifically focus on creating a measure of African American women's cultural and conceptual knowledge of breast and cervical cancer. In the remainder of this chapter, I will first focus on the outcome variables, namely breast and cervical cancer screening. I will then present a review of existing research related to the role of biological and environmental factors in breast and cervical cancer screening behaviors. Next, I will highlight research related to institutional factors as determinants of screening behavior. Finally, I introduce the concept of "health literacy" and contextualize the association between health literacy and health behaviors within the health literacy conceptual model presented.

### **Breast Cancer: Statistics and Screening Methods**

Breast cancer is the most common cancer among African American women, although they are less likely to be diagnosed with the disease than non-Latina White women, who have a breast cancer incidence rate of 122 per 100,000 individuals (American Cancer Society, 2011). In turn, African American women have a higher incidence rate of breast cancer than other racial/ethnic minorities with an incidence rate of 116 per 100,000 individuals compared to rates of 85 per 100,000 among Asian American/ Pacific Islanders, 89 per 100,000 among American Indian/Alaska Natives, and 92 per 100,000 among Latinas (Siegal, Naishadham, & Jemal, 2012). African American women are more likely to be diagnosed at an advanced stage of the disease,

with only 51% being diagnosed at an early stage, compared with 61% of non-Latina White women (American Cancer Society, 2011; Smigal et al., 2006). Detection at a late stage contributes to a disproportionately lower 5-year survival rate among African American breast cancer survivors, namely 77% compared to 91% among non-Latina White women (American Cancer Society, 2011). Accordingly, the mortality rate of African American women with breast cancer is 39% higher than the corresponding rate for non-Latina White women (American Cancer Society, 2011; Smigal et al., 2006), despite the lower incidence rate.

Given that factors causing breast cancer cannot be easily changed through public health intervention, the best practice recommended by physicians to increase survival rates among breast cancer survivors across racial and ethnic groups is early detection of the disease (American Cancer Society, 2011). Specifically, with early detection, 5-year survival rates for women across racial/ethnic groups are 88% for Stage I breast cancer compared to 15% for Stage IV breast cancer (American Cancer Society, 2012). The American Cancer Society (2011) and National Cancer Institute (2012) recommend three breast cancer early detection tools: mammography, breast self exam, and clinical breast exam.

### **Mammography**

Mammograms are x-rays that are utilized to examine breast tissue for normal and abnormal lumps (National Cancer Institute, 2012). Currently, mammograms tend to have the highest level of specificity and sensitivity for breast cancer detection (National Cancer Institute, 2012). Sensitivity refers to the amount of cancerous cells detected within the breast tissue and specificity refers to the accuracy of determining the absence of cancerous cells within the breast tissue (National Cancer Institute, 2012). Mammograms can (a) detect breast cancer lumps that are too small to detect during breast self-examinations or clinical breast examinations, and (b)

detect ductal carcinoma in situ, which are abnormal cells found within the breast duct that can metastasize to other regions of the breast tissue (National Cancer Institute, 2012). Despite the benefits of mammograms, there are also risks associated with the procedure. Patients risk exposure to radiation, false positives, false negatives, and overdiagnosis, which involves positive results that will not lead to medical problems (National Cancer Institute, 2012). The risks of false positives, false negatives, and overdiagnosis can be attributed to human error, quality assurance failure, pressure to give a definite answer for unclear mammography results, limited understanding about the biology of certain tumors, and the inability of mammograms to detect certain lumps (Smith et al., 2003).

Although mammograms have emerged as a highly effective method of detecting carcinoma at an early stage, the exam is less sensitive for women under the age of 50. Researchers have posited that higher breast density in younger women may result in decreased sensitivity in mammography screenings (Buist et al., 2004). Therefore, in 2009, the USPSTF changed the mammography screening age recommendations to age 50 and older and encouraged younger women to discuss with their health provider whether earlier screenings are warranted due to biological risk factors such as family history of breast cancer (USPSTF, 2009). However, the American Cancer Society (2011) continues to recommend that women over the age of 40 receive a mammogram every year, although women at high risk may want to start screening at an earlier age. The National Cancer Institute (2009) recommends that women age 40 and older have mammograms every 1 to 2 years. The guidelines also suggest that women who have a high risk of breast cancer should consult with their physician regarding whether they should begin mammography screening at an earlier age (National Cancer Institute, 2012).

### **Breast Self-examinations**

A breast self-examination involves a personal examination of the breast for abnormal lumps within the breast tissue (National Cancer Institute, 2012). Breast self-examinations are primarily recommended for women in their 20s to become familiarized with their breast tissue and check for any abnormalities such as lumps (American Cancer Society, 2011). However, since Kösters and Gøtzsche (2003) found that breast self-examinations were not predictors of early breast cancer detection among women from Russia and Shanghai, there has been a controversy regarding the utility of breast self-examination as a screening method. Despite the controversy, the American Cancer Society (2011) notes that women age 20 and older can conduct breast self-examinations to become familiarized with how their breasts normally look and feel so they can detect any subsequent changes in their breasts and consult a doctor.

### **Clinical Breast Examinations**

A clinical breast examination involves the physical examination of the breast by a healthcare provider to detect abnormal lumps within the breast tissue. Clinical breast examinations should be performed by healthcare providers for women in their 20s and 30s at least every three years to discuss any changes in the breasts and assess risk for breast cancer (American Cancer Society, 2011). Clinical breast examinations may be helpful in identifying lumps that can later be confirmed using a mammogram, but whether clinical breast examinations are useful in detecting lumps in the breast tissue of asymptomatic women still warrants further investigation (Smith et al., 2003). Despite its limitations, Smith and colleagues (2003) promote the continued use of clinical breast examinations because the exam could provide an opportunity for physicians to discuss with their patients issues concerning breast cancer in terms of its etiology and the usefulness of mammograms.

### **Cervical Cancer: Statistics and Screening Methods**

Although incidence rates of cervical cancer have decreased for women over the past few decades (Barnholtz-Sloan et al., 2009), African Americans are diagnosed with cervical cancer 32% more often than non-Latina White women, who have a cervical cancer incidence rate of 8 per 100,000 individuals (Siegal, Naishadham, & Jemal, 2012). In turn, African American women have a higher incidence rate of cervical cancer than other racial/ethnic minorities, with rates of 11 per 100,000 individuals compared to 7 among Asian American/Pacific Islanders, 10 among American Indian/Alaska Native, and 12 among Latinas (Siegal, Naishadham, & Jemal, 2012). Cervical cancer is diagnosed across four stages ranging from Stage I, indicating the presence of a malignant tumor in the cervix, to Stage IV, indicating the spread of cancer from the cervix to nearby organs and other parts of the body (American Cancer Society, 2011). African American women are more likely to be diagnosed with regional or distant stage cancer (i.e., Stages III or IV), both of which have less treatment options and worse prognosis than Stage I. Consequently, the 5-year survivorship rate of African American women is 61% in contrast with 70% among non-Latina White women (Siegal, Naishadham, & Jemal, 2012).

Research has shown that cervical cancer incidence in women is closely linked to certain types of the human Papillomavirus (HPV) (American Cancer Society, 2011). HPV refers to a group of over 100 virus strains that can cause warts (or Papillomas), and can only survive in cells in the body that are located on the surfaces of the skin, mouth, throat, vagina, cervix, vulva, anus, and head of the penis. These viruses are transmitted via skin-to-skin contact as a result of oral, vaginal, or anal sexual intercourse (American Cancer Society, 2011). HPV is present in 99% of cervical cancer cases (Walboomers et al., 1999). The prevalence of HPV for African American women is 39% compared to 24% among non-Latina White women (Dunne et al., 2007). In

terms of symptomatology, some HPV strains will cause the appearance of warts within weeks, months, or years of exposure whereas many other strains produce no symptoms because the body's immune system causes the viruses to become inactive (American Cancer Society, 2011). There are no treatments for HPV, though the body's immune system will usually eradicate 70% of HPV infections within a year and 90% of infections within two years (American Cancer Society, 2011; Markowitz et al., 2007).

### **HPV Vaccination**

Although there are several high-risk HPV types that are related to cervical cancer, 70% of cases are caused by HPV 16 or 18. In 2006, the Food and Drug Administration (FDA) approved the use of a vaccine for the prevention of HPV 16 and 18 as well as two types of HPV that cause 90% of genital warts (American Cancer Society, 2011). The vaccine is called Gardasil and manufactured by Merck (it is also recommended for men). In 2009, the FDA approved Cervarix, manufactured by GlaxoSmithKline Biologicals, which also protects against HPV 16 and 18 and is approved for girls and women age 10 to 25 years. Due to the continuing risk of acquiring an HPV infection among sexually active women, it is important for researchers to investigate women's knowledge, beliefs, attitudes, and emotions about HPV vaccination across racial/ethnic groups (Castellsagué, Schneider, Kaufmann, & Bosch, 2009).

A study of 206 African American women suggested that there may be differential access to the HPV vaccine due to lack of awareness (Hughes et al., 2009). Specifically, only 69% of African Americans were aware of the vaccine compared to 87% of non-Latina White women in one study (Hughes et al., 2009). Another study found that among medically underserved minority women, HPV vaccine acceptability was related to the women's perceived risk of HPV infection, perceived safety and effectiveness of the vaccine, physician recommendation, and

prior preventative health behaviors (Gerend, Lee, & Shepherd, 2007). Because the HPV vaccine is available for girls as young as 9 years old, researchers have also explored caregivers' beliefs about the vaccine as well their intentions to vaccinate the girls.

The results of these studies on caregivers' beliefs are inconclusive. Whereas research has shown that the majority African American women are accepting of the vaccine, many women are unsure in regards to whether they would be willing to vaccinate their daughters (Constantine & Jerman, 2007; Fazekas, Brewer, & Smith, 2008; Scarinci, Garces-Palacio, & Partridge, 2007). For example, Scarinci and colleagues (2007) found that African American women's concerns about the HPV vaccine included uncertainty about the effectiveness of the vaccine, possible side effects, and whether a perception of safety from HPV may lead women to engage in increased risky sexual behavior. Conversely, researchers have reported that women across racial/ethnic backgrounds report feeling less skeptical about the vaccine when they perceive the vaccine as effective, affordable, and covered by health insurance plans (Fazekas, Brewer, & Smith, 2008; Reiter, Brewer, Gottlieb, McRee, & Smith, 2009; Zimet, Mays, Winston, Kee, Dickes, & Sue, 2000). Women across racial/ethnic groups also reported that they would be more likely to get vaccinated when the vaccine was recommended by a health care provider and when they had information regarding the association between cervical cancer and HPV (Hughes et al., 2009; Zimet et al., 2000).

### **Papanicolaou Test**

The Papanicolaou test, commonly referred to as a Pap smear, is the screening method utilized to detect precancerous conditions (e.g., abnormal cell changes) and tumors within a woman's cervix before and after the development of cervical cancer. The USPSTF (2003) recommends that women begin receiving Pap smears approximately 3 years after they begin to

have vaginal intercourse for women under 21, and annually for women over the age of 21, regardless of their sexual history given other risk factors for cervical cancer such as a family history. Furthermore, the American Cancer Society (2011) recommends that women over the age of 30 who have had normal Pap smear results 3 years in a row and are in a monogamous relationship may begin having the exam every 2 – 3 years. Women aged 70 and older who have not had abnormal Pap test results 3 or more times in a row and no abnormal results in the past 10 years, may discontinue the Pap test (American Cancer Society, 2011; USPSTF, 2003). The National Cancer Institute (2012) recommends beginning having a Pap test approximately 3 years after the first time a woman engages in sexual intercourse, or when a woman reaches the age of 21, whichever comes first. Furthermore, women are advised to continue having the Pap test every 1 to 3 years and women over the age of 30 should have an HPV test conducted with their Pap test (National Cancer Institute, 2012). Women age 65 and older are recommended to consult with health professionals regarding the frequency of their Pap tests (National Cancer Institute, 2012). For women who have obtained an HPV vaccine, a Pap smear is still recommended as an early detection method given that HPV vaccines do not protect against all types of HPV that cause cervical cancer, and cervical cancers can develop even in the absence of HPV (National Cancer Institute, 2012).

Although it is widely reported in the research literature that African American and non-Latina White women receive Pap smears at similar rates, there remains a subset of African American women who do not screen for cervical cancer on a regular basis despite the benefits of the exam (Paskett et al., 2004). The lack of regular Pap smear screenings may be due to a lack of knowledge and awareness about the risk of cervical cancer, the usefulness of Pap smears as a cervical cancer early detection method, or cultural differences in perceptions of Pap smears

(Bigby, Ko, Johnson, David, & Ferrer, 2003; Blake, Weber, & Fletcher, 2004; Mosavel & El-Shaarawi, 2007; Saraiya et al., 2009). Specifically, research has shown that African American women's knowledge, attitudes, beliefs, and emotions play an important role in their cervical cancer screening behavior (Paskett et al., 2004).

### **Influence of Institutional Factors on Cancer Screening Behavior and Access to Care**

Research on breast and cervical cancer (e.g., von Wagner et al., 2011) has also addressed the institutional factors that affect women's access to healthcare services and influence their health behaviors. Institutional factors such as education levels, socioeconomic status, quality of care and access to health insurance can have a significant impact on women's ability to access the healthcare services required for prevention, early detection, and treatment of cervical and breast cancer. This section provides an overview of empirical research on the relation between institutional factors and cancer screening behaviors.

### **Socioeconomic Factors and Screening Behaviors**

Lower education levels limit women's economic opportunities and their ability to work in industries that provide employer-based health insurance coverage (Kaiser Family Foundation, 2004). Relatedly, there is a wide income gap between African Americans and non-Latina Whites, not only due to educational levels, but also to discriminatory practices in the workplace such as unequal pay and unfair hiring practices (Kaiser Commission, 2000). The median household income for African Americans in 2010 was \$32,068 compared to a median income of \$51,846 among non-Latino Whites (DeNavas-Walt, Proctor, & Smith, 2011). African Americans have a poverty rate of 27% compared to a rate of 10% among non-Latina Whites (DeNavas-Walt, Proctor, & Smith, 2011). These institutional factors (i.e., low levels of formal

education, limited access to healthcare, and lack of adequate health insurance) serve as barriers to breast and cervical screening among African American women (Otero-Sabogal et al., 2004).

Approximately 21% of African Americans are uninsured, 28% are covered by Medicaid, and 44% have employer-based coverage (DeNavas-Walt, Proctor, & Smith, 2011). Uninsured African American women or women covered by Medicaid are more likely to seek healthcare at a health center or clinic rather than a private physician due to the increased cost of private physician visits (Kaiser Family Foundation, 2004). This is concerning because research has shown that the personalized attention women receive from private physicians is associated with increased cancer screening behaviors such as obtaining mammography and Pap smears (Barr, Franks, Lee, Herther, & Schachter, 2001; O'Malley, Forrest, & Mandelblatt, 2002; Robinson & Shavers, 2008). The relation between health insurance and cancer screening behavior is evidenced by African American women's greater likelihood of receiving mammograms if they have increased access to healthcare within their communities, and their greater likelihood of receiving regular Pap tests if they have a primary care physician (Coughlin, Leadbetter, Richards, & Sabatino, 2008). Furthermore, African American women who are uninsured and do not receive personalized healthcare attention are more likely to be diagnosed at an advanced stage of breast cancer and to have a higher incidence of invasive cervical cancer than African American women with health insurance (Benard et al., 2008; Roetzheim et al., 1999).

### **Physician-Patient Communication**

It is well documented that cultural mistrust among African Americans of the healthcare system may play a role in the health disparities that exist within the African American community (Halbert, Armstrong, Gandy, & Shaker, 2006). This tendency towards mistrust is not unfounded, given the history of social and economic inequality and systemic discrimination

perpetrated against African Americans and other racial/ethnic minorities within the United States. For instance, many African Americans are aware that the Tuskegee Study involved scientific misconduct that compromised the health of the participants and this legacy supports their fears and concerns not only about medical research, but also medical care (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Freimuth, Quinn, Thomas, Cole, Zook, & Duncan, 2001). The African American history of racism, segregation, discrimination, and stereotyping has created a culture of nihilism within the African American community (Powe & Johnson, 1995). In the context of cancer research, Powe and Johnson (1995) described nihilism as a pervasive sense of hopelessness in the face of perceived insurmountable barriers that often leads to cancer fatalism, defined as the belief that cancer will lead to death regardless of early detection attempts and treatment efforts (Powe & Johnson, 1995). This pessimism fueled by the interplay of institutional racism and socioeconomic barriers create an environment where access to adequate healthcare appears out of reach for many African Americans (Powe & Johnson, 1995).

Indeed, within general health studies (e.g., Cooper, Beach, Johnson, & Inui, 2006), researchers have shown that African Americans across socioeconomic statuses have received less attentive care from race discordant physicians than non-Latina Whites. Moreover, a study of patient and physician communication found that physicians across racial/ethnic backgrounds tended to be more verbally dominant and engage in less patient-centered communication with African-American patients than with non-Latina White patients (Johnson, Roter, Powe, & Cooper, 2004). African Americans have reported receiving a better quality of care from physicians who are race concordant or who have an extensive history of working within the African American community (Cooper, Beach, Johnson, & Inui, 2006). African Americans are

also more likely than non-Latina Whites to have greater trust in informal sources of health information (i.e., family, friends, church or religious leaders) than in their primary care physicians (Musa et al., 2009; Yang, Matthews, & Hillemeier, 2011).

It is important to consider the quality of patient-physician communication because physicians play an important role in the screening behavior of patients. A seminal study by Bartlett and colleagues (1984) found that demonstration of interpersonal skills such as concern, respect, and empathy lead to higher patient satisfaction, recall, and adherence to treatment regimens than merely providing the patients with informative teaching statements about their health. In subsequent years, additional research has been published that supports the important role that physicians play in promoting patient health behaviors. For instance, research regarding cancer early detection behaviors has shown that having a long term primary care physician is associated with higher mammography screening among women across racial/ethnic groups (Mickey, Vezina, Worden, & Warner, 1997; O'Malley, Forrest, & Mandelblatt, 2002; Schueler, Chu, & Smith-Bindman, 2008).

Through effective communication with their patients, physicians can play an important role in raising women's awareness about breast and cervical cancer screening. Furthermore, physicians can emphasize to their patients the importance of adherence to screening guidelines and timely follow-up appointments (Mickey, Vezina, Worden, & Warner, 1997; O'Malley, Forrest, & Mandelblatt, 2002; Gierisch et al., 2009; Pearlman et al., 1997). For instance, women whose physicians display a high level of enthusiasm when communicating information about mammograms have over twice the odds of being adherent to mammography screening guidelines than women whose physicians communicate health information with lower levels of enthusiasm (Fox, Heritage, Stockdale, Asch, Duan, & Reise, 2009). Moreover, women whose physicians are

highly enthusiastic communicators are five times more likely to have a mammogram than women whose physicians do not convey any health information (Fox, Heritage, Stockdale, Asch, Duan, & Reise, 2009). The importance of effective patient-physician communication is also evidenced by Liang and colleagues' (2006) study on 7 faculty general internists and their women patients across racial/ethnic groups. Patients who perceived their communication with their internist as "deep," "trusting," and "bonding" were more likely to report an intention to have a mammogram than those who perceived their physician communication as less trusting (Liang, Kasman, Wang, Yuan, & Mandelblatt, 2006).

Mistrust of physicians also plays a role in health experiences. The research literature has linked physician mistrust with decreased patient satisfaction and lower adherence to treatment regimens as well as poorer health outcomes (Benkert, Peters, Clark, & Keves-Foster, 2006; Bogart et al., 2004; Halbert, Armstrong, Gandy, & Shaker, 2006). African American women who trust their physicians and view them as an important source of cancer health information are more likely to obtain mammograms and be up-to-date in their screening than women who are less trusting of their physicians (Metsch, McCoy, McCoy, Pereyra, Trapido, & Miles, 1998; Musa, Schulz, Harris, Silverman, & Thomas, 2009).

### **Health Literacy**

Health literacy is an important consideration in research on breast and cervical cancer among African American women because health literacy has been found to mediate disparities in health outcomes and preventive behaviors (Bennett et al., 2009). Specifically, health literacy is defined as follows:

The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Ratzan & Parker, 2000).

This definition's emphasis on the utilization of health literacy skills makes an important distinction between health literacy and school-based literacy. School-based literacy requires "learning to read" whereas health literacy requires "reading to learn" (White, 2008, p. 8). Furthermore, health literacy requires knowledge of health-related terms, medical and scientific abbreviations, insurance and medical forms, and medication labels as well knowledge of the procedures of the U.S. healthcare system (White, 2008).

Health literacy plays an important role in cancer research regarding patients' adherence to screening and treatment recommendations. In regards to cancer screening, low literacy skills among women are associated with decreased knowledge about mammography (Davis et al., 1996) as well as decreased knowledge about Pap tests as a screening tool for cervical cancer (Lindau et al., 2002). Furthermore, low health literacy is related to nonadherence with treatment recommendations, lack of participation in cancer-related clinical research trials, and less effective communication with healthcare providers (Davis, Williams, Marin, Parker, & Glass, 2002; Williams, Davis, Parker, & Weiss, 2002). Researchers have also found that physicians often overestimate their patients' health literacy level, especially with African American patients, which increases the physicians' risk of miscommunicating important health information such as test results and treatment recommendations (Kelly & Haidet, 2007).

There are four performance categories related to health literacy: below basic, basic, intermediate, and proficient (White, 2008). Within a nationwide health literacy study, researchers found that Latinos (41%), American Indian/Alaska Natives (25%), and African Americans (24%) reported low health literacy levels compared to only 9% of non-Latina White women and 13% of Asian/Pacific Islanders (White, 2008). Moreover, African Americans and Latinos were more likely to have below basic or basic health literacy than other racial/ethnic

groups (Kutner et al., 2007). Only 41% of African Americans reported intermediate health literacy compared to 58% of Non-Latina White women, 52% of Asian/Pacific Islanders, and 59% of multiracial respondents (Kutner et al., 2007).

### **Health Literacy Conceptual Framework**

The Institute of Medicine (2004) provided a detailed conceptualization of health literacy that will be summarized within this section. The researchers hypothesized that health literacy is a “shared function of cultural, social, and individual factors.” Specifically, a conceptual framework of health literacy situates literacy as the basis of health literacy and health literacy serves as the mediator between the skills and abilities of individuals and the health context. Subsequently, it is expected within the model that health literacy will have an influence on health outcomes and costs. There are three factors that may serve as intervention points for improving health literacy: culture and society, the health system, and the health context (IOM, 2004).

Culture refers to “the shared ideas, meanings, and values acquired by individuals as members of society (IOM, 2004, p. 33).” Conditions in culture and society such as language, socioeconomic status, education, gender, and the mass media comprise social determinants of health and are useful to consider for interventions related to health literacy. The education system from grades K-12 forms the foundation of English literacy and numeracy skills. Access to education is an important consideration because research has consistently shown that as individuals achieve higher levels of formal education, their health literacy levels increase as well. The health context consists of individuals providing health-related services within clinics, hospitals, public health agencies, home health care, accreditation groups, regulatory agencies and physicians’ offices. Patients’ health literacy levels will affect the quality of their interactions within the health context. For instance, Paasche-Orlow and Wolf (2007) presented a causal

model of health literacy which suggests that access to and use of healthcare, the patient-physician relationship, and patients' levels of self-care are influenced by health literacy.

There are four components of health literacy: print, oral, numeracy, and cultural and conceptual knowledge. Print literacy refers to “the ability to review and utilize information from noncontinuous texts including forms, applications for services, maps, and nutrition labels” (Cutilli & Bennett, 2009). Patients are often required to fill out forms in order to request services or report their medical history and insurance information. Additionally, maps may be utilized to navigate through hospitals and large clinics. Oral literacy includes the ability to formulate health-related questions and understand oral instructions from a healthcare provider (IOM, 2004; White, 2008). Finally, numeracy literacy refers to a person's ability to read and understand dosages on prescription medications (Cutilli & Bennett, 2009). For instance, patients require numeracy skills to take the proper dosage of their medication according to prescription labels, or to follow written nutritional guidelines.

Cultural and conceptual knowledge are components of health literacy that can exert a great influence at an individual level (IOM, 2004). In the current study, cultural and conceptual knowledge of breast and cervical cancer will be operationalized through knowledge, beliefs, attitudes, and emotions. Within the cultural and conceptual knowledge construct, culture plays an integral role in the development of an individual's health-related attitudes and beliefs, and in the likelihood of an individual seeking additional health information. In turn, conceptual knowledge refers to the cognitive processes that influence health literacy such as an individual's understanding of health conditions, awareness of preventative health behaviors and treatment options, and ability to understand and integrate health information (IOM, 2004). Within the context of breast and cervical cancer research, understanding African American women's

cultural and conceptual knowledge can provide a theoretical basis for understanding their cancer health behaviors and can inform the design and implementation of interventions created to increase African American women's adherence to cancer screening guidelines. In the next section, I introduce, define, and review the literature related to the four components of cultural and conceptual knowledge, namely, knowledge, beliefs, attitudes, and emotions.

**Knowledge.** Knowledge is defined as a "justified true belief" in regards to an object (Hilpinen, 1970). In this case, the object could include breast or cervical cancer risk factors, symptomatology, screening methods, treatment options, and prognosis. An example of knowledge about cervical cancer screening is awareness that a Pap smear is utilized to detect cervical cancer. Evidence exists that knowledge about breast cancer risks, symptoms, and early detection methods is associated with higher rates of adherence to mammography screening guidelines among racial and ethnic minority women (Buki, Jamison, Anderson, & Cuadra, 2007; Schueler, Chu, & Smith-Bindman, 2008), including African American women (Laing & Makambi, 2008; Phillips & Wilbur, 1995). Moreover, researchers have found that among symptomatic African American women, those with low levels of knowledge regarding breast cancer symptoms are likely to delay screening, increasing their risk of diagnosis at an advanced stage (Facione et al., 2002). African American women have disclosed that they could not or were unsure about how to screen for breast cancer (Barroso, McMillan, Casey, Gibson, Kaminski, & Meyer, 2000). Furthermore, a quantitative study of 198 African American women aged 50 and older revealed that women who were not aware of the guidelines for age-related frequency of screening were less likely to have up-to-date screening mammographies (Farmer, Reddick, D'Agostino, & Jackson, 2007).

Unfortunately, research on African American women's knowledge of cervical cancer is limited. In fact, to date, the only study that provides insight into African American women's misconceptions involved a focus group of 48 African American women. Within the study, the women who never received a Pap smear reported being unfamiliar with the term "cervical cancer" and "cervix," and having a lower level of awareness of either Pap smears or the purpose of a Pap smear as a screening tool, and having low knowledge levels regarding the distinction between a Pap smear and a pelvic examination (Bigby, Ko, Johnson, David, & Ferrer, 2003).

**Beliefs.** Beliefs refer to the characteristics that an individual associates with an object (Eagly & Chaiken, 1993; Fishbein & Ajzen, 1975), which in this case could include screening, disease symptomatology, risk factors, or cancer treatment options. The thought that luck is associated with the risk of being diagnosed with breast cancer is an example of a cancer belief. The majority of research on African American women's beliefs about breast cancer has focused on fatalism, which in this line of research refers to the belief that a breast cancer diagnosis will lead to certain death (Moy et al., 2006; Russell, Perkins, Zollinger, & Champion, 2006). Researchers have associated fatalism with nonadherence to breast cancer screening guidelines (Moy et al., 2006; Russell, Perkins, Zollinger, & Champion, 2006). For example, a quantitative study of older African American women found that women who reported fewer fatalistic beliefs and higher levels of optimism were less likely to perceive any barriers to cancer screening in one study (Farmer et al., 2007).

There is also a growing body of research on the possible influence of spiritual beliefs on African American women's health behaviors. In a study of 280 African American women, women over the age of 40 and women with lower levels of formal education were more likely than both younger women and women with higher levels of formal education to (a) believe that

God works through physicians to provide healing or (b) prioritize religious/spiritual beliefs over seeking medical attention (Mitchell, Lannin, Mathews, & Swanson, 2002). Furthermore, within a nationally-based sample, Dessio and colleagues (2004) found that 43% of the African American women in the sample reported using religion/spirituality to address their health concerns compared to 37% of non-Latino Whites, 19% Mexican Americans, and 7% Chinese Americans. There is a concern noted within the research literature that overreliance on religious/spiritual beliefs may lead to a delay in seeking medical treatment, which can cause a poorer disease prognosis (Mitchell, Lannin, Mathews, & Swanson, 2002). This concern is evidenced in research by Gullatte and colleagues (2009) who reported that African American women who relied on their religious/spiritual beliefs to seek guidance about a potential health problem (e.g., talking to God about their health concern) were more likely to delay seeking medical treatment than women who disclosed their health concerns to peers.

The influence of religious/spiritual beliefs on African American women's cancer screening behavior, knowledge, beliefs, attitudes, and emotions is an emerging area of research; existing research on the topic is limited and has produced inconclusive results. Specifically, some researchers have found an association between spirituality and mammography utilization (Benjamins, 2006) and others have not (Fox et al., 1998; Katz, Kauffman, Tatum, & Paskett, 2008; Russell, Monahan, Wagle, & Champion, 2007). For instance, Holt and colleagues (2003) found that among a sample of 1,227 African American women, those who believed that God encouraged people to take care of themselves were more likely to report perceived benefits of receiving a mammogram than women who reported that health outcomes are entirely controlled by God. On the other hand, quantitative data from Russell and colleagues' (2007) study did not find any differences in mammography adherence as a function of religious/spiritual beliefs.

Nevertheless, researchers have noted that churches are an effective intervention site to increase mammography screening among African American women, suggesting that at least for some women, religious beliefs, knowledge acquisition, and/or the support they gain at church facilitate breast cancer screening (Duan, Fox, Derose, & Carson, 2000; Erwin, Spatz, Stotts, & Hollenberg, 1999). Is there any information you can include about cervical cancer screening here? If not, note that fact.

**Attitudes.** Attitudes are defined as a learned predisposition to respond in a consistently favorable or unfavorable manner with respect to an object (Fishbein & Ajzen, 1975). An example of an attitude regarding breast cancer screening is having a dislike for mammograms. Currently, there is a dearth of research on African American women's attitudes about breast cancer. However, existing research on women of other ethnicities and races has found that maladaptive attitudes can act as a barrier to mammography screening (Crump, Mayberry, Taylor, Barefield, & Thomas, 2000; Husaini et al., 2005; Peek, Sayad, & Markwardt, 2008). For instance, women with maladaptive breast cancer attitudes have reported avoidance of screening, body image concerns related to mastectomies, and a perceived lack of need for mammography (Crump, Mayberry, Taylor, Barefield, & Thomas, 2000; Husaini et al., 2005; Peek, Sayad, & Markwardt, 2008). African American women's attitudes regarding cervical cancer have also been understudied. However, a quantitative study by Jennings-Dozier (1999) of 108 African American women found that those who held favorable attitudes about Pap smears and believed that receiving a Pap smear is easy were more likely to express an intent to receive a Pap smear annually.

**Emotion.** Emotion refers to the synchronized change in an individual's state in response to the evaluation of an internal or external stimulus event as relevant to the major concerns of the

individual (Scherer, 2005). Common emotions include anger, fear, and sadness (Scherer, 2005). In the context of emotions regarding cancer screening, an individual may report feeling embarrassed to receive a mammogram. Several large-scale quantitative studies including African American women have reported that maladaptive emotions can act as a barrier to breast cancer screening among African American women (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004; Crump, Mayberry, Taylor, Barefield, & Thomas, 2000; Husaini et al., 2005). These emotions include fear of the healthcare system, fear of a potential cancer diagnosis, and embarrassment concerning mammography (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004; Crump, Mayberry, Taylor, Barefield, & Thomas, 2000; Husaini et al., 2005). Maladaptive emotions among African American women are concerning because research has shown that individuals with high levels of cancer fear or who hold negative views about cancer, in comparison to those who do not, are more likely to avoid obtaining cancer information (Miles, Voorwinden, Chapman, & Wardle, 2008) and are more likely to be nonadherent with cancer screening guidelines such as mammography (Hall et al., 2008).

There is limited research on the influence of emotions on cervical cancer screening. However, the few studies that exist have identified fear of death associated with cervical cancer and fear of pain during a Pap smear as emotions that act as barriers to regular screening behavior (Hoyo et al., 2005; Johnson, Mues, Mayne, & Kiblawi, 2008).

### **Review of the Measurement of Health Literacy**

Most assessments that have been created to measure health literacy have focused on individuals' level of print and numeracy literacy, two key components of health literacy (IOM, 2004). However, to address health disparities resulting from individuals' lack of health knowledge or cultural differences in attitudes, beliefs, and emotions, measures of literacy are

needed that assess cultural and conceptual knowledge, another important component of health literacy.

The two most commonly used health literacy assessments within the research literature are the Test of Functional Health Literacy in Adults (TOFHLA; Parker, Baker, Williams, & Nurss, 1995) and the Rapid Estimate of Adult Literacy in Medicine (REALM; Davis et al., 1993). Both of these assessments measure basic print literacy in the context of clinical settings, excluding the influences of outside contexts such as social and cultural factors (IOM, 2004). Specifically, these assessments cannot distinguish health literacy levels among participants based upon knowledge of a specific illness or culturally-based differences in health behaviors (IOM, 2004). The Breast Cancer Screening Belief Scales in African American Women does take into account beliefs about a specific illness, breast cancer, but only measures a limited aspect of African American women's cancer cultural and conceptual knowledge (Champion & Scott, 1997). Within this study, I plan to develop a reliable and valid measure of cultural and conceptual knowledge that is specific to both breast and cervical cancer and takes into account the sociocultural nuances relevant to African American women. My aim is to provide researchers with a tool to further explore the influence of cancer health literacy on the disparities that exist in breast and cervical cancer outcomes for African American women.

This measure will be adapted from the Cancer Literacy Measure – Breast and Cervical Cancer (CLM-BCC) recently developed by Buki and Yee (2010) that is focused on the cultural and conceptual knowledge of breast and cervical cancer among Latina and Filipina women. The purpose of the scale is to measure the cultural and conceptual knowledge component of cancer health literacy by assessing women's knowledge, beliefs, attitudes, and emotions about breast and cervical cancer. The development of the CLM-BCC occurred in three phases. The first

phase involved a review of the research literature and in-depth individual interviews with a small group of Mexican and Filipina women. Then the researchers created items for the scale based upon the literature review and information gained during the interviews. Scale construction experts then reviewed the items for face and content validity. After incorporating the experts' feedback into the scale, the researchers administered the revised version of the CLM-BCC to a sample of either Mexican or Filipina woman through a series of focus groups. Within the focus groups, participants with differing levels of English proficiency, socioeconomic status, formal education, and health literacy provided feedback on the face and content validity of the CLM-BCC. A final version of the CLM-BCC scale items incorporated feedback on the items from the focus group. The researchers developed the CLM-BCC as a tool to (a) advance theoretical conceptualizations about health literacy, (b) understand the influence of cultural and conceptual knowledge on cancer disparities, (c) identify areas of focus for psychosocial interventions, and (d) measure the effectiveness of psychosocial interventions aimed to improve breast and cervical cancer health literacy levels among immigrant women. The researchers are in the process of examining the psychometric properties of the CLM-BCC.

### **Rationale and Purpose of the Study**

To date, few studies have investigated African American women's cultural and conceptual knowledge of breast and cervical cancer. Furthermore, there does not exist an empirically-based health literacy assessment that researchers can utilize as a tool to enhance our conceptualization of African American women's cancer screening behaviors as well as explore the role of cultural and conceptual knowledge in the breast and cervical cancer health disparities within the African American community. To address these gaps in the literature, the aim of this investigation is to develop, pilot test, and conduct large-scale psychometric testing of a new

measure of African American women's cultural and conceptual knowledge regarding breast and cervical cancer. This new assessment will be called the Cancer Literacy Measure for African Americans (CLM-AA). Specifically, the CLM-AA will assess women's knowledge, beliefs, attitudes, and emotions about breast and cervical cancer. Details about the methodology are presented next in Chapter 3.

## Chapter 3

### Methodology

In this chapter, I will review the research design for the development of the CLM-AA. First, I will provide an overview of the targeted sample population, study measures, and data analysis procedures. Then, I will provide a detailed description of the four phases of data collection. Phase One consisted of CLM-AA item development. Phase Two involved a panel of experts reviewing the items. Within Phase Three, I pilot tested the CLM-AA with community participants. Finally, in Phase Four, I administered the CLM-AA over the Internet to a broad population of African American women and conducted psychometric testing to examine the underlying structure of the CLM-AA.

### Participants

**Phases One and Two.** In these phases, no participants were needed for the study. In Phase One, I derived items for the measure from the literature review, and in Phase Two, experts reviewed the items.

**Phase Three.** To pilot test the measure, I conducted two focus groups to provide feedback on the draft measure, one in Champaign, IL and the second in Chicago, IL. Inclusion criteria included that women must self-identify as African American, be at least 18 years of age or older, and report no personal history of breast or cervical cancer. The age restriction of 18 years or older allowed for inclusion of adult women who may have a history of Pap smears. The initial rationale for excluding women with a history of breast and cervical cancer was based on the premise that these women's cultural and conceptual knowledge of breast and cervical cancer may be higher from that of women who have never been diagnosed. However, emerging research (e.g., Nissen et al., 2012) has suggested that individuals may continue to have lower

cancer health literacy after a diagnosis and during treatment, supporting their inclusion in the study. I recruited African American women from varying socioeconomic backgrounds and formal education experiences in order to utilize the focus group as an opportunity to counteract the possibility of a restricted sample during the online survey phase of the study, which may be characterized by a sample limited to participants who are computer literate and have access to the Internet.

Four women attended the Champaign focus group although I recruited 10 women to join. Three of the women were in the 40 to 50 age group and one of the women was in the 50 to 60 age group. All of the women were single and had children. Their education levels varied with half the women earning high school diplomas and another two working towards a graduate degree. The women reported personal incomes under \$40,000. All except one of the women reported having health insurance. Regarding cancer psychoeducational experiences, two of the women reported having attended a cervical cancer workshop.

The second focus group was located in Chicago, IL. Eight women attended this group. Among these participants, three women were in the 25 to 30 age group and the remainder of the women represented one of the following age categories: 18 to 25, 30 to 35, 35 to 40, 40 to 50, or 50 to 60. Five of the participants reported that their highest degree was a high school diploma. Three of the women reported pursuing either undergraduate or graduate degrees. Six of the women were single and only two women reported having children. The women reported personal incomes under \$30,000, with the exception of a woman with an advanced degree who earned under \$50,000. The majority of women had health insurance and three women reported having no health insurance. Regarding cancer psychoeducational experiences, two of the women reported having attended a cervical cancer workshop.

**Phase Four.** I recruited women who self-identify as African American to complete the CLM-AA for psychometric testing of the measure. The initial inclusion criteria for participants included being 18 years or older and having no personal history of breast or cervical cancer. However, given that research has shown that cancer survivors often retain beliefs incongruent with scientific knowledge during and after treatment, women who identified as breast or cervical cancer survivors were retained in the study (Constanzo et al., 2006; Constanzo et al., 2010; Nissen et al., 2012). Within the online survey, 18 women reported a previous diagnosis of breast cancer and 4 women reported a previous diagnosis of cervical cancer. The online survey in Phase Four was distributed to participants online across several U.S. states. Of 351 women who accessed the survey, 301 women were retained for data analysis. Participants were excluded from the analysis if their survey was incomplete ( $n = 32$ ), if they identified a racial group other than African American ( $n = 13$ ), or did not identify a racial group ( $n = 5$ ), leaving a final sample of 301 women. Incomplete surveys included surveys in which respondents discontinued the survey prior to the last page of the survey. Data was collected from women in several states, with the largest proportion of women from Illinois, Missouri, Texas, California, and Florida (see Figure 1).

### **Measures**

**Sociodemographic Questionnaire.** A 24-item sociodemographic questionnaire was given to participants in the focus group and online survey to collect information regarding the participants' age, race, ethnicity, educational background, personal and household income, employment status, and personal and family history of breast and cervical cancer (see Appendix A).

**Focus Group Interview Guide.** I administered an 11-item focus group interview to participants during the two Phase Three focus groups (see Appendix B). The questions were open-ended to allow for flexibility during the focus groups such as exploring issues that are important to the participants or to follow-up on participant responses (Seidman, 2006). I verbally administered the questions to the participants in a group setting. Specifically, six questions inquired about participants' perceptions of individual items on the Cancer Literacy Measure for African Americans. Sample questions in this area included: "Do you feel that this question could have been worded in a clearer or different way that would have made it easier to answer?" and "Do you believe that this question is an accurate description of some women's beliefs about breast cancer (or cervical cancer)?" Another five questions inquired about the participants' perceptions of the overall survey. Sample questions include: "How was the experience of completing the questionnaire for you?" and "Do these questions describe important aspects of your experience obtaining and using cancer health information?"

**Cancer Literacy Measure for African Americans.** The revised Cancer Literacy Measure for African Americans (CLM-AA) measured African American women's knowledge, beliefs, attitudes, and emotions about breast and cervical cancer. This measure was an adaptation of the existing Cancer Literacy Measure Breast and Cervical Cancer (CLM-BCC; Buki & Yee, 2010). The CLM-BCC includes 127 items that measure knowledge, beliefs, attitudes, and emotions related to breast and cervical cancer screening. Questions related to cancer knowledge include "A woman's chance of surviving breast cancer is low if it is detected late" and "It is possible to have cervical cancer without symptoms." Among the anchored scale items included in factor analysis, I expected factors to emerge that were related to participants' beliefs, attitudes, and emotions about breast and cervical cancer. For instance, questions related

to beliefs cover beliefs about cancer in general, cancer treatment in general, as well as beliefs specific to breast or cervical cancer. Sample items include “If I find out that I have cancer, I should keep it to myself and take it to the Lord in prayer” and “Cancer treatment is worse than the disease.” Items that measure attitudes include attitudes toward the healthcare providers as well as toward the two types of cancer. Sample items include “How much do you trust doctors?” and “How much do you like getting a Pap smear?” Items designed to tap into emotions (e.g., fear, worry, embarrassment) measure emotions related to cancer, to screening, and to treatment. Sample items include “If you found out you have breast cancer, how embarrassed would you feel?” and “How afraid are you of cancer treatment?”

The survey contains three response choice scales: two likert-type and one forced choice. The anchored scale ranging from 1 (*not at all*) to 5 (*very much*) was utilized to measure the intensity of respondents’ endorsement of the items assessing attitudes and beliefs. This response choice type is often used in scales measuring attitudes due to researchers’ assertions that attitudes tend to vary in strength (Schwarz & Bohner, 2001). Belief items were also measured using this scale in order to measure the intensity of participants’ risk perceptions and interest in cancer education. The anchored scale ranging from 1 (*strongly agree*) to 5 (*strongly disagree*) was utilized to measure respondents’ level of agreement with items related to beliefs and emotions. Specifically, I designed items using this scale to determine whether the items were characteristic of the participants’ schemas about cancer and emotional reactions to cancer diagnosis and treatment. The categorical scale that included the choices “yes,” “no,” and “I don’t know” was utilized to measure the respondents’ knowledge about breast and cervical cancer. A forced choice option for the knowledge scale items was appropriate for measuring facts. However, the choice “I don’t know” was included to capture the responses of participants who were unsure of

whether a knowledge item was true or false. This response format is consistent with existing cancer knowledge measures within the research literature (Bovbjerg et al., 2005; Su, Chen, & Kuo, 2009). The forced choice items will be referred to as the Breast Cancer Knowledge subscale and Cervical Cancer Knowledge subscale. Similar to Su and colleagues' (2009) knowledge measure, within the CLM-AA's knowledge subscales, correct answers are assigned a score of 1 point and incorrect answers and "I don't know" responses are scored as 0 points. The knowledge subscales create an index score with higher scores representing better knowledge about breast (highest possible score = 12) and cervical (highest possible score = 13) cancer.

### **Procedure**

#### **Phase One: Item Development**

Scale adaptation for the study was informed by scale development guidelines set by DeVellis (1991) and Clark and Watson (2003) as well guidelines for health measurement scales posited by Streiner and Norman (2003) and Aday (1996). Specifically, items were adapted from the CLM-BCC (Buki & Yee, 2010) to capture African American women's knowledge, beliefs, attitudes, and emotions regarding breast and cervical cancer based upon a review of the extant literature. I also included items with limited cultural embeddedness from the CLM-BCC (e.g., "How painful are mammograms") as well as modified items to measure more culturally congruent constructs in the African American community (e.g., "How much do you feel that doctors treat you differently because you are African American?").

As recommended by DeVellis (1991), I avoided including items that were redundant, exceptionally lengthy or double barreled (i.e., contain two or more ideas) or contain multiple negatives, ambiguous pronoun references, misplaced modifiers, and singular adjective forms instead of noun forms. Items adapted from the CLM-BCC for cultural congruence within the

CLM-AA were written for a fifth grade reading level or lower so that the scale can be accessible for use in the general population (Clark & Watson, 2003; DeVellis, 1991). For instance, the terms “doctor” and “nurse” were incorporated in items instead of less accessible terms such as “physician” and “healthcare providers.”

### **Phase Two: Item Review by Panel of Experts**

In Phase Two, to enhance construct validity, I consulted a panel of three experts to review the item pool and determine whether the items are a suitable measurement of breast and cervical cancer cultural and conceptual knowledge (DeVellis, 1991). All experts were selected because of their expertise in cancer issues and health promotion specific to the African American community. Two were faculty members, and one a doctoral student, at a large Midwestern university. I provided the experts with a document containing definitions of four constructs for the scale: knowledge, beliefs, attitudes, and emotions. Beneath each construct definition was a list of corresponding items. The experts were asked to evaluate whether they believed that the items were appropriately matched with each construct based upon the provided construct definition. I also asked the experts to evaluate the redundancy, clarity, and conciseness of the items, including the suitability of the scale's reading level for use with populations with low literacy. Information provided by the experts was utilized to make revisions to the item pool, and the revised scale draft was then pilot tested with community-dwelling African American women. Sample feedback included using the term "African American" consistently throughout the survey instead of switching between the terms "Black" and "African American" which participants may interpret variously as either race or ethnicity.

### **Phase Three: Pilot Testing with Community Participants**

Prior to data collection, I obtained approval from the Institutional Review Board (IRB). Next, I facilitated two focus group discussions with African American women to pilot test the measure and obtain detailed feedback on face validity, clarity of items, breath of content, and ease of administration (DeVellis, 1991). Specifically, I recruited a total of 12 women within the

Champaign/Urbana and Chicago area who self-identified as African American to provide feedback on the draft measure within two focus groups.

To recruit participants, I contacted community gatekeepers in Champaign and Chicago to ask them to identify African American women over the age of 18 who may be potential participants for the focus groups. Within Champaign/Urbana, I contacted an organization known as SisterNet. SisterNet is a local network of African American women within the Champaign/Urbana area whose mission is to promote information and support regarding the physical, emotional, spiritual, and intellectual health of African American women. Within Chicago, I contacted community gatekeepers in local churches and small businesses that catered to African American women. In each location, I asked the community gatekeepers to identify prospective participants and provide them with general information about the study. Furthermore, I requested that they provide potential participants with an interest form and envelope. Interested participants were asked to fill out the form, place it in the envelope, seal it, and give the envelope back to the community gatekeepers. After receiving the envelope, I contacted the women to provide them with a brief description of the purpose of the study and inform them that their participation in the focus group would be voluntary. If the women agreed to participate in the study, I asked them to meet me at specified time and location that was easily accessible for them and suitable for conducting each focus group. Both focus groups were held in the conference room of a local business during the day at a date and time coordinated with the focus group participants.

When the participants arrived for the two focus groups, I obtained informed consent and reminded them that their participation in the focus group is voluntary and they can discontinue participation at any time during the study. I also told them that their refusal to complete the

survey would not result in any loss of rights or privileges to which they would be otherwise entitled. The informed consent form (see Appendix C) included information related to their rights as participants, related risks and benefits, and contact information for the researchers. The consent form also informed the participants that the focus group would be audiotaped.

After going over the informed consent information, I provided the participants with pencils, a colored highlighter, and a survey packet including a demographic questionnaire as well as the CLM-AA for completion. This version of the CLM-AA contained 88 items that measured participants' screening behaviors, knowledge, attitudes, beliefs and emotions regarding breast and cervical cancer. I asked participants to review the questions directly on the printed survey. However, in order to ensure that the items were understood by women with low levels of literacy, I also displayed the items on a projection screen and read each item aloud. I asked the participants to note questions that they deemed confusing with the colored highlighter. At the end of each section of the CLM-AA, I asked the participants to discuss their perceptions of the phrasing and clarity of the items included in that section using a focus group interview guide. For instance, the participants offered feedback to change the term "healthcare provider" to "doctor/nurse" to make the items more accessible at a 5<sup>th</sup> grade reading level. Additionally, women shared whether items appeared congruent with their personal experiences regarding African Americans beliefs, attitudes and emotions about cancer. For instance, participants shared whether they believed that African American women with low health literacy would endorse "having sex during menstruation" as a cervical cancer risk. The women stated that they had never heard anyone endorse that statement, although a couple of women shared that they believed some of their elderly relatives may believe the statement is true due to lack of awareness of cervical cancer risk factors. The women drew their perceptions from comments

they had heard from either friends or older generations within their family. After the focus group was conducted, I debriefed the participants by asking them questions about their experiences in the focus group. I then incorporated feedback from the participants into the CLM-AA, rendering it ready for psychometric testing. For example, the item measuring women's understanding that having sex during menstruation might be a risk factor for cervical cancer was kept in the measure, as it was deemed a potential misunderstanding women may have (that should be measured and subsequently addressed in educational programs). Although the number of items and focus of the survey remained the same, some items were reworded to improve clarity (e.g., term "healthcare provider" was changed to "doctor/nurse"). Overall, the women provided support for the face validity of the survey. The most commonly given feedback, in fact, was that reviewing the questions enhanced their awareness of gaps in their knowledge of breast and cervical cancer.

#### **Phase Four: Psychometric Testing of the CLM-AA**

To examine the psychometric properties of the scale, the CLM-AA was administered to a national sample. The targeted participant pool was women aged 18 and older who self-identified as African American. I recruited African American women to complete the scale through purposeful sampling, consistent with expert recommendations (Worthington & Whittaker, 2006). The targeted participant pool was women aged 18 and older who self-identified as African American. The goal was to recruit at least 300 women to complete the survey. Sample size is an important consideration in psychometric research because too few participants can lead to unstable patterns of covariation among the items, producing a false impression internal consistency (Clark & Watson, 2003; DeVellis, 1991; Worthington & Whittaker, 2006). A small sample also may not be representative of the larger population,

leading to a more restricted range of the measured constructs within the sample than would be expected within the larger population (Clark & Watson, 2003; DeVellis, 1991; Worthington & Whittaker, 2006). Furthermore, the groupings of interrelated items during factor analysis may be atypical because the small sample may be qualitatively different from the larger population (Clark & Watson, 2003; DeVellis, 1991).

Thus, to minimize these limitations and to ensure a large, national sample, the scale was administered to participants via an online website. The benefits of online surveys include increased access to a broader population, quicker turnaround of surveys, and decreased cost of distribution to a large sample size (Shih & Fan, 2008). Additionally, the online survey format minimized missing data by ensuring that participants complete all scale items on the page before advancing to the next page of the survey. However, participants were allowed to skip sociodemographic questions because it was possible that some questions (e.g., type of health insurance) would not be applicable to all participants. Disadvantages of online data collection have included lower response rates and limited access to individuals who are not computer literate or do not have access to the Internet (Shih & Fan, 2008). As mentioned previously, I utilized the Phase Three focus groups to temper this limitation by obtaining the perspectives of women who may be less likely to participate in an online survey. To ensure wide dissemination of the survey and maximize response rates, I utilized U.S. census data (i.e., Rastogi, Johnson, Hoeffel, & Drewery, 2011) to prioritize recruitment in cities with a large population of African Americans. I then searched for organizations that serve African Americans in densely populated areas within these cities (e.g., Chicago, St. Louis), and asked community gatekeepers within the organization to act as community liaisons for distribution of the online survey link to possible participants.

Specifically, I contacted community liaisons within states with a high density of African American communities (based on census data) and asked them to identify African American women over the age of 18 who may be willing to complete the survey. I then provided the community liaisons with an online link to my survey and asked them to distribute the links via email listservs or a posting on their website. I provided a brief email to accompany the survey link describing the purpose of the study, including a statement that the study has IRB approval and will be supervised by a university faculty member (see Appendix D).

The online survey contained a sociodemographic questionnaire as well as the CLM-AA. Consistent with recommendations in the literature, additional measures were not included within the survey in order not to influence the participants' responses to the CLM-AA scale items during this initial development phase (Worthington & Whittaker, 2006). Therefore, including additional measurements to obtain information regarding convergent and discriminant validity is beyond the scope of the current study.

I posted the demographic questionnaire as well as the CLM-AA online using Survey Monkey. Survey Monkey allows for development of an informed consent page, which I added at the beginning of the online survey (see Appendix E). The online informed consent form, using lay language, included an explanation of the purpose of the study, the voluntary nature of participation in the study, the risk/benefit assessment of the study, the estimated amount of time to complete the survey (20-30 minutes), contact information for the researchers and the University of Illinois IRB, as well as information about voluntary entry into a raffle for compensation. On the bottom of the consent page, participants could endorse "yes" and "submit" icons if they agreed to complete the survey. Participants who did not wish to complete the survey endorsed the "no" icon and then were directed to a webpage thanking them for their

consideration and providing links to informational websites about breast and cervical cancer. Participants who completed the survey were also guided to breast and cervical cancer websites that they can use to access information regarding early detection and prevention screening guidelines. Additionally, the last webpage of the survey provided participants the option to click a link to a separate survey on Survey Monkey to enter a raffle for ten \$25 gift certificates from Walmart to compensate them for their time and participation in the study. The separate raffle survey ensured that the participants' contact information could not be connected with their survey responses.

### **Data Analyses**

Descriptive statistics were obtained for demographic variables and the Breast and Cervical Cancer Knowledge subscale. Factor analysis was used to examine the construct validity of the CLM-AA (Garson, 2009; Worthington & Whittaker, 2006). Specifically, I utilized exploratory factor analysis to determine the underlying structure of the scale variables (Bryant & Yarnold, 1995; Garson, 2009; Worthington & Whittaker, 2006). Although guidelines for adequate survey sample size within the research literature are inconsistent, DeVellis (1991) suggests that samples of at least 300 participants are adequate. The Breast and Cervical Cancer Knowledge subscale was not included because categorical data is not appropriate for factor analysis (Reise, Waller, & Comrey, 2000).

The goal of the initial exploratory factor analysis was to determine which items to retain or remove from the dataset by examining item communalities greater than .5 or item loadings greater than .32 (e.g., items were deleted if they cross-loaded at .32 or higher on two or more factors) (Costello & Osborne, 2005; Worthington & Whittaker, 2006). Then, I utilized Bartlett's test of sphericity to determine whether the correlation matrix of the data was appropriate for

factor analysis.

Once I determined the data set was appropriate for analysis, I chose an extraction method based upon the distribution of the data (Costello & Osborne, 2005). The purpose of factor extraction is to reveal the underlying factor structure of the data by removing the shared variance from the variables' unique variance and error variance. Given that the data were not normally distributed, I utilized principal axis factoring as an extraction method (Costello & Osborne, 2005).

Next, I decided the number of factors to retain for rotation by using the Guttman-Kaiser criterion, which stipulates the removal of factors with eigenvalues lower than 1 (Garson, 2009). I also obtained a scree plot, which involves plotting the eigenvalues to search for a natural break point within the data where the plotted curve flattens out, to determine factor retention (Costello & Osborne, 2005). The number of datapoints above the break determine the number of factors to retain. If any discrepancies existed between the number of factors retained using the Guttman-Kaiser criterion and the scree plot, then I used the results to determine an appropriate range of factor solutions to explore using factor analysis (Costello & Osborne, 2005; Garson, 2009).

The determination of rotation method can be either data or theory driven (Fabrigar, Wegener, MacCallum, & Strahan, 1999; Worthington & Whitaker, 2006). Given the theoretical associations among beliefs, attitudes, and emotions within the research literature, I expected the factors within the "Not at all" to "Very Much" anchored scale and "Strongly Agree" to "Strongly Disagree" anchored scale to be correlated. However, a preliminary factor analysis extracting initial unrotated factors within the data from both anchored scales indicated that the factors were uncorrelated. Therefore, the final analysis included an orthogonal rotation, which allows the factors to be uncorrelated, to obtain the simplest factor structure for the data (Fabrigar, Wegener,

MacCallum, & Strahan, 1999). The best factor solution was chosen because it contained item loadings above .32 and exhibited limited crossloading of items (Costello & Osborne, 2005; Worthington & Whittaker, 2006). Problematic items were dropped after careful consideration of the best decision to maintain the integrity of the data (Costello & Osborne, 2005). The final analysis step included conducting the factor analysis again to ensure that the deletion of previous items did not result in changes to factor structure, factor intercorrelations, item communalities, factor loadings, or cross-loadings (Worthington & Whittaker, 2006).

## Chapter 4

### Results

Within this section, I describe and summarize the results of the statistical analyses. First, I describe the demographic characteristics of the online survey participants. Next, I report the results of the participants' healthcare experiences including breast and cervical cancer screening behaviors, sources of health-related information, and knowledge, beliefs, attitudes, and emotions about breast and cervical cancer. Finally, I present the results of the exploratory factor analyses, including the factor solutions for each of the CLM-AA anchored scales.

#### Characteristics of Online Survey Participants

**Online Survey Sample.** The final sample consists of 301 self-identified Black women. The majority of women (94%) identified as African American, 4% had Biracial ancestry (i.e., African American and another racial group), and 2% of women identified as Latina. On average, women took 30-45 minutes to complete the survey. Approximately half of the women (45%) endorsed age group 35 to 40 or younger, and the remainder was in age group 40 to 50 or older. In regards to marital status, nearly two-thirds of women were not married and not cohabitating with a partner. Almost two-thirds of the women in the sample were mothers (62%), with 72% of them reporting 1-2 children. In regards to formal education, approximately 1 in 5 women reported having attended some college or attained an advanced degree. The majority of women (87%) had a job for which they received income. Approximately 14% of women lived below 200% of the U.S. poverty level based upon total household income. The majority of the women had health insurance that covered mammograms (95%) and/or Pap smears (87%). Furthermore, 88% reported that they have access to a regular clinic and physician to receive health services such as checkups. Approximately half of the participants reported that they had attended a

workshop on the importance of breast cancer screening. However, only 38% of women had attended a workshop on the importance of cervical cancer screening. Table 1 provides a more detailed overview of participants' age, marital status, level of formal education, personal income, and type of health insurance.

**Breast Cancer Screening Behavior and Knowledge.** In regards to clinical breast examinations, 61% of women in the age group 40 to 50 and older reported having a clinical breast exam within the last year. Yet, across age groups, 74% of participants understood that women should receive clinical breast examinations once a year. Women aged 25 to 30 constituted the largest age cohort (19% of women within that age group) who did not know when a woman should receive a clinical breast examination. Among women of all ages who had obtained a clinical breast exam, the majority (87%) reported that they received their last clinical breast examination because it was a part of their regular medical check-up. Regarding breast self-examinations, the majority of women across age groups also reported that they had been shown how to conduct a breast self-examination and examined their own breasts for abnormalities.

Of the 165 women in age groups 40 and older within the sample, only 2 women reported having never received a mammogram. Of the women aged 40 and older who reported having a mammogram, 85% had a mammogram within the last year and 67% had at least 5 mammograms in the past 5 years. Regarding their knowledge of mammography screening recommendations, the majority of women age 40 and older (i.e., 81.3% of women aged 40-50, 84.9% of women aged 50-60, 83.3% of women aged 60-70, and 85.7% of women aged 70 and over) believed that they should be screened once a year. The women in age groups 40 and over who received mammograms in the past provided the following reasons for their first

mammogram: 36% stated their doctor/nurse recommended it, 22% stated that screening was a part of their routine healthcare, 10% asked their doctor for a referral, 6% had a problem in their breast, and only 2% received a reminder card in the mail. The women in age groups 40 and over who received mammograms in the past also endorsed the following reasons for having their last mammogram: 30% endorsed it was part of their routine healthcare, 18% received a reminder card in the mail, 16% endorsed their doctor/nurse recommended it, 8% asked their doctor for a referral, and 7% stated they had a problem in their breast. The women aged 40 and over reported the following reasons for having a mammogram: 39% reported that no one recommended it and 25% stated they prefer to receive regular checkups, 29% a doctor/nurse recommended it, 15% their mother recommended it, and 14% endorsed friends recommended it. A small percentage of women (less than 10%) endorsed other sources of recommendation such as family members or church congregation.

Table 2 provides an overview of the participants' correct responses to the Breast Cancer Knowledge subscale. The results demonstrate that a large percentage women within the sample correctly responded to the breast cancer knowledge items. However, the three items that had the highest percentage of incorrect responses were related to potential breast cancer symptoms (e.g., change in skin texture, nipple discharge) and the level of sensitivity of mammograms.

**Cervical Cancer Screening Behavior and Knowledge.** In regards to cervical cancer screening, 94% of the women across age groups reported having ever had a Pap smear, with 54% having their last Pap smear within the last year. Thirty-five percent of women 30 and older reported having 5 Pap smears in the last 5 years. Although women were not screening regularly, the majority of participants reported that women in general should have a Pap smear annually. Only four women between the ages of 18 to 25 believed that women should have a Pap smear

every few months. Despite these participants' understanding, the majority of women who reported never having had a Pap smear were in the age group 18 to 25.

The women specified the following reasons for obtaining their first Pap smear: 68% endorsed it was a part of their regular medical check-up, 24% were screened while obtaining contraceptive prescription, 10% screened because a doctor/nurse recommended it, 6% reported that they had a gynecological problem, and 4% stated that the screening was a part of their prenatal care. The women reported the following referral sources as their reasons for having a Pap smear: 43% by their doctor/nurse, 40% reported they self-referred because they prefer regular check-ups, 26% were referred by their mother, 11% by friends, 9% by their sister, and approximately 6% by their aunt, husband or partner. Nineteen percent indicated that they had obtained the screening even though no one had recommended it. Among women who had never had a Pap smear, 5% reported that either they forgot or a doctor never recommended it, and 2-3% reported that they did not need a Pap smear because they are not sexually active, were concerned about the cost of the screening, or feared that they would have to wait too long for an appointment.

The following risk factors of cervical cancer were most frequently endorsed by participants: having a family history of cervical cancer (74%), having a sexually transmitted infection (59%), and having many sexual partners (45%). A lesser number of women correctly identified using birth control pills (26%) and having many children (8%) as cervical cancer risk factors. Additionally, a small subset of the sample (i.e., less than 10%) mistakenly identified not having children, having an abortion, and having sex during menstruation as cervical cancer risk factors.

Table 3 provides an overview of the participants' correct responses to the Cervical Cancer Knowledge subscale. The results demonstrate that a large percentage of women within the sample correctly responded to the cervical cancer knowledge items. However, the highest percentage of incorrect responses involved items related to the purpose of Pap smears or screening guidelines for Pap smears.

**Healthcare Provider Preference.** Approximately 60% of participants stated that they did not have a preference regarding whether the gender of the health care providers who performed their breast and cervical cancer screenings. Thirty-seven percent ( $n = 74$ ) of participants across age groups stated that they preferred a female healthcare provider to conduct their mammograms. Forty percent ( $n = 121$ ) of participants across age groups stated that they preferred a female healthcare provider to perform their Pap smears. No significant differences in healthcare provider preferences emerged based upon age group of participants.

### CLM-AA Scale Refinement

The final version of the Cancer Literacy Measure for African Americans (CLM-AA) contains 60 items, a reduction from the preliminary 85 items. Furthermore, the CLM-AA contains 30 items that measure breast and cervical cancer screening knowledge and behaviors, healthcare provider gender preferences, and sources of cancer of information.

Prior to conducting factor analysis to determine the final structure of the scale, I determined the factorability of the items measuring attitudes, beliefs, knowledge, and emotions using both Bartlett's test of sphericity and the Kaiser-Meyer-Olkin measure of sampling adequacy (Worthington & Whitaker, 2006). Both tests indicated that the sample size was sufficient to perform a factor analysis for each of the anchored scales containing these items. The results of both tests can be viewed on Table 4.

**“Not at all” to “Very Much” Anchored Scale.** This anchored scale contains 31 items measured on a response scale from 1 (*not at all*) to 5 (*very much*). I performed a preliminary exploratory factor analysis (principal axis factoring) to determine the factor structure of the subscale. A scree plot of the data suggested that 5 factors should be retained. I then re-analyzed the data, specifying a five-factor solution using an orthogonal (varimax) rotation. This five-factor solution explained 43.71% of the variance in the data. Next, I considered items for retention or deletion based on their contribution to the subscale. As recommended by Worthington and Whittaker (2006), I considered items for deletion if they contained factor loadings less than .32 or cross-loadings less than .15 difference from the item's highest factor loading. Additionally, I considered items for deletion if they loaded higher than .32 on multiple factors. This process led me to the remove the following 10 items: 1, 2, 4, 5, 9, 37, 38, 39, 41, 71, and 73.

I then performed another principal axis factoring analysis on the resulting 18-items using a five-factor solution and an orthogonal (varimax) rotation, the results of which are presented in Tables 5 and 6. This analysis was conducted to ensure that the deletion of previous items did not result in changes to the factor structure, factor intercorrelations, item communalities, factor loadings, or cross-loadings (Worthington & Whittaker, 2006). Based on these criteria, I retained the five-factor solution, which explained 48.51% of the variance. Table 7 provides an overview of factor inter-correlations and Table 8 provides an overview of the subscale items' descriptive statistics. Table 9 provides an overview of inter-item correlations within the "Not at all" to "Very Much" anchored scale.

The first factor accounted for 11.60% of the total variance (eigenvalue = 2.09) and contained 5 items (items 5, 6, 7, 8, and 10) (see Table 8). The internal consistency estimate for this factor is .74. This factor was named Physician Trust because the items measure perceptions of trust in physicians' ability to provide treatment. A representative item from this scale is item 8, "How much do you trust doctors who are African American?" The mean scores of individual items within this factor indicated that the women endorsed moderately high levels of trust with their healthcare providers. As shown in Table 9, being treated differently by physicians as an African American was negatively correlated with general trust in physicians, trust in race discordant physicians, trust in African American physicians, and the belief that physicians are effective in curing illness.

The second factor accounted for 11.50% of the total variance (eigenvalue = 2.07) and contained 7 items (items 36, 43, 63, 64, 65, 66, 67) (see Table 8). The internal consistency estimate for this factor is .74. This factor was named Breast and Cervical Cancer Diagnosis because the items measure emotional reactions to breast and cervical cancer diagnosis and

treatment. A representative item from this scale is item 65, “How afraid are you that a Pap smear will show that you have cervical cancer?” The mean scores on individual items within this factor indicate that the women endorsed moderately negative emotional reactions to cancer diagnosis and treatment.

The third factor accounted for 10.63% of the total variance (eigenvalue = 1.91) and contained 2 items (items 69 and 70) (see Table 8). The internal consistency estimate for this factor is .97. This factor was named Cancer Education Interest because the items measure preferences in learning more about breast and cervical cancer. The items are as follows: “How interested are you in learning more about breast cancer?” and “How interested are you in learning more about cervical cancer?” Both items are highly correlated ( $r = .93$ ), which corresponds with Worthington and Whittaker’s (2006) recommendation of only retaining 2 item factors with correlations greater than .70. The mean scores on individual items within this factor indicated a moderately low interest in learning more about breast and cervical cancer among participants within this sample.

The fourth factor accounted for 8.75% of the total variance (eigenvalue = 1.88) and contained 2 items (44 and 45) (see Table 8). The internal consistency estimate for this factor is .84. This factor was named Cancer Risk Perceptions because the items measure participants’ beliefs about their risk for developing breast and cervical cancer. The items are as follows: “How likely are you to get cervical cancer?” and “How likely are you to get breast cancer?” Both items were highly correlated ( $r = .72$ ). The mean scores of individual items within this factor indicated moderately low perceptions of cancer risk among participants.

The fifth factor accounted for 6.12% of the total variance (eigenvalue = 1.98) and contained 2 items (40 and 41) (See Table 8). The internal consistency estimate for this factor is

.67. This factor was named Feeling Healthy because the items measure beliefs about screening behaviors when an individual does not feel symptomatic of cancer. The items are as follows: “How likely are you to get a mammogram if you are feeling healthy?” and “How likely are you to get a Pap smear if you are feeling healthy?” The items were not highly correlated ( $r = .50$ ), but the items were retained in the scale because there may be differences in responses based on perceptions of breast and cervical cancer. The mean score for each individual item within this factor indicated moderately low likelihood of cancer screening if participants are feeling healthy.

**“Strongly Agree” to “Strongly Disagree” Anchored Scale.** This anchored scale contained 30 items measured on a response scale from 1 (*strongly agree*) to 5 (*strongly disagree*). I performed a preliminary exploratory factor analysis (principal axis factoring) to determine the underlying factor structure of the items. A scree plot of the data suggested that 4 factors should be retained. I then re-analyzed the data specifying a four-factor solution using an orthogonal (varimax) rotation. This four-factor solution explained 36.82% of the variance in the data. Next, I considered items for retention or deletion from the scale based on their contribution to the scale. As recommended by Worthington and Whittaker (2006), I considered items for deletion if they contained factor loadings less than .32 or cross-loadings less than .15 difference from the items’ highest factor loading. Additionally, I considered items for deletion if they loaded higher than .32 on multiple factors. This process led to the removal of the following 13 items: 11, 12, 14, 16, 20, 22, 24, 25, 27, 30, 33, 34, and 62.

I then performed another principal axis factoring analysis on the remaining 17-items using a four-factor solution and an orthogonal (varimax) rotation, the results of which are presented in Tables 10 and 11. This analysis was conducted to ensure that the deletion of previous items did not result in changes to factor structure, factor intercorrelations, item

communalities, factor loadings, or cross-loadings (Worthington & Whittaker, 2006). Based on these criteria, I retained the four-factor solution because it explained the highest amount of variance, 57.05%. Table 12 provides an overview of factor inter-correlations and Table 13 provides an overview of the scale items' descriptive statistics. Table 14 provides an overview of inter-item correlations within the scale.

The first factor accounted for 20.72% of the total variance (eigenvalue = 3.52) and contained 4 items (items 58, 59, 60, and 61) (see Table 13). The internal consistency estimate for this factor is .96. This factor was named Breast and Cervical Cancer Diagnosis because the items measure emotional reactions to breast and cervical cancer diagnosis. A representative item from this scale is item 60, "If you found out you have cervical cancer, you would feel sad." The mean scores for individual items within this factor indicated a high endorsement of negative emotional reactions to a breast or cervical cancer diagnosis.

The second factor accounted for 15.71% of the total variance (eigenvalue = 2.67) and contained 3 items (items 28, 29, and 30) (see Table 13). The internal consistency estimate for this factor is .97. This factor was named Breast Cancer Screening Embarrassment because the items measure feelings of embarrassment regarding breast self-examinations. A representative item from this scale is item 30, "I would feel embarrassed checking my breasts for hard lumps when I look at myself in the mirror." The mean scores for individual items within this factor indicated a low level of endorsement of embarrassment regarding breast self-examinations. Table 12 reveals positive inter-item correlations within the Breast Cancer Screening Embarrassment factor.

The third factor accounted for 10.56% of the total variance (eigenvalue = 1.85) and contained 3 items (items 13, 15, and 17) (see Table 13). The internal consistency estimate for

this factor is .79. This factor was named Protecting One's Health because the items measure beliefs about taking care of one's health and preferring quality healthcare provision. A representative item from this scale is item 15, "It is important for me to have a doctor or nurse who shows respect and interest in me." The mean scores for individual items within this factor indicated a high level of interest in positive healthcare experiences.

The fourth factor accounted for 10.03% of the total variance (eigenvalue = 1.71) and contained 7 items (items 18, 19, 21, 23, 26, 32, and 35) (see Table 13). The internal consistency estimate for this factor is .67. This factor was named Cancer Burden because the items measure negative beliefs about breast and cervical cancer diagnosis and treatment. A representative item from this scale is item 19, "Cancer cannot be cured, even if it is caught early." The mean scores for individual items within this factor indicated moderately low levels of negative cancer beliefs among the participants.

**Analyses of Variance.** To determine if there were statistical differences among participants on factor scores within the CLM-AA based on sociodemographic variables, I conducted a series of one-way ANOVAs. Specifically, I tested whether any of the subscale scores differed as a function of participants' age, years of formal education, marital status, total household income, and type of health insurance. Health insurance status was not included as an independent variable due to the low number of participants without health insurance ( $n = 20$ ). The results revealed that there was a statistically significant difference in the participants' scores on the Cancer Burden factor based upon total household income levels,  $F(11, 277) = 4.14, p < .001$ . Higher scores on this factor indicate positive perceptions about cancer diagnosis and treatment. Post hoc comparisons with Tukey's statistic suggest that participants whose household incomes were over \$150,000 scored higher on the Cancer Burden factor ( $M = 29.52, SD = 3.58$ )

than participants who earned less than \$10,000 ( $M = 24.46$ ,  $SD = 2.67$ ), between \$30,000 and \$39,000 ( $M = 24.96$ ,  $SD = 4.69$ ), or had earned between \$40,000 and \$49,999 ( $M = 25.42$ ,  $SD = 3.88$ ). Furthermore, participants whose total household incomes were between \$100,000 and \$149,000 scored higher on the Cancer Burden factor ( $M = 27.98$ ,  $SD = 3.42$ ) than participants who earned between \$30,000 and \$39,000 ( $M = 24.96$ ,  $SD = 4.69$ ). No statistically significant differences were found among scores of the remaining CLM-AA factors and sociodemographic variables.

## Chapter 5

### Discussion

This study provides a unique contribution to the research literature with the development of an empirically-based assessment of health literacy that measures African American women's cultural and conceptual knowledge of breast and cervical cancer. Within this section, I provide an overview of the preliminary final factor structure of the CLM-AA and the breast and cervical screening behaviors of women within the study. Finally, I present the limitations of the study and implications of the current findings for future research and clinical practice.

**CLM-AA Factors.** The emergence of the Physician Trust factor within the “Not at All” to “Very Much” anchored scale corresponds with research that underscores the importance of physician trust on African American women's healthcare experience (Yang, Matthews, & Hillemeier, 2011; Young, Schwartz, & Booza, 2011). The retention of items regarding preference for physician race also corresponds with findings related to the influence of racism on African Americans' perceptions of the healthcare industry. In the current study, women who perceived discrimination within the healthcare system reported lower levels of trust in physicians and lower levels of endorsement of the belief that physicians are effective at curing illness. These findings are further supported by a study by Malat and van Ryn (2005), who found that experiences of discrimination within the healthcare system were associated with preference for same-race healthcare providers.

The items within the Cancer Risk Perceptions factor measure women's perceptions of their risk of being diagnosed with cancer. Research (e.g., Ackerson, 2010; Fair et al., 2011) has shown that cancer risk perceptions are associated with women's perceptions of screening as a preventative or early detection practice. These items are important to include within the CLM-

AA given that women who are unaware of cancer risk factors and wait until they are symptomatic before engaging in treatment have a higher likelihood of being diagnosed at a later stage of the disease than women who are knowledgeable about these factors (American Cancer Society, 2011). Furthermore, three factors emerged across the “Not at All” to “Very Much” anchored scale and “Strongly Agree” to “Strongly Disagree” anchored scale that addressed the importance of women’s emotional reactions to cancer screening and diagnosis (i.e., two Breast and Cervical Cancer Diagnosis factors and Breast Cancer Screening Embarrassment factor). Similar to cancer risk perceptions, research has shown that negative emotions are related to cancer screening and diagnosis may hinder early detection behaviors or negatively influence treatment decisions.

Three factors emerged across the “Not at All” to “Very Much” anchored scale and “Strongly Agree” to “Strongly Disagree” anchored scale that addressed the women’s breast and cervical cancer health beliefs. The Protecting One’s Health factor and Cancer Burden factor both measure how much women prioritize their health and the beliefs they hold regarding outcomes of their interactions with physicians. These factors are consistent with research that has shown that negative cancer beliefs are associated with lower screening rates (Lannin et al., 1998; Tessaro, Eng, & Smith, 1994). Further examination of the Cancer Burden factor revealed that women with higher income levels were less likely than women who reported lower income levels to endorse negative cancer beliefs. This finding is consistent with research that has shown that affluent socioeconomic status is associated with greater access to health-related resources, thus suggesting that women of higher financial means do not expect cancer to be as high of a burden as women who cannot access such treatment.

The current study also revealed a high rate of exposure to cancer education among participants, with 50% of women reporting having attended a workshop on the importance of breast cancer screening and 38% of women reporting having attended a workshop on cervical cancer screening. Furthermore, the high percentage of correct responses within the Breast and Cervical Cancer Knowledge subscales indicates that the women within the study sample had adequate knowledge about breast and cervical cancer. This finding is not surprising given the overrepresentation of participants with advanced degrees who may be more likely to take advantage of health education opportunities than women with lower levels of formal education. Studies have shown that exposure to cancer education is associated with higher likelihood of Pap smear and mammography screenings among women (Bailey et al, 2012; Buki, Jamison, Anderson, & Cuadra, 2007). Accordingly, the current study revealed that the majority of participants age 40 and older had engaged at least once in breast cancer screening (99%), and almost all participants 18 and older had received at least one Pap smear (92%).

In addition to demonstrating the participants' level of awareness of breast and cervical cancer, The Breast and Cervical Cancer Knowledge subscales also revealed potential knowledge gaps among participants within the study. Specifically, a review of the incorrect responses reveals that there may be a need for further education on symptoms of breast cancer and screening guidelines for cervical cancer. These items will be useful for researchers and practitioners to identify the educational needs for African American women regarding breast and cervical cancer. Additionally, it provides an opportunity to address myths about breast and cervical cancer risk factors that may act as a barrier to appropriate cancer screening behavior.

Within the CLM-AA, a factor focused on spirituality items did not emerge in the data. This is consistent with findings from a recent study conducted by Holt and colleagues (2012)

who found that religious and spiritual sources of support were not predictive of general psychological/emotional functioning among a national sample of African Americans. Although studies (e.g., Dessio et al., 2004) have shown some benefit of spirituality on coping with illness, Powell and colleagues (2003) hypothesized that the coping benefit of spirituality may be stronger among people who have lower levels of educational attainment and, thereby, less access to coping resources. Given the disproportionate number of participants within the current study with a high level of educational attainment, this may explain the lack of emergence of a spirituality factor. However, further research is needed with a sample that shows greater variability with respect to income, to further explore the relevance of spirituality in cancer health literacy.

**Screening Behaviors.** The majority of women within the study reported having engaged in breast or cervical cancer screening. Not surprisingly, women under the age of 40 were less knowledgeable about mammography screening guidelines than women aged 40 and over. Given the possibility of women being diagnosed with breast cancer under the age of 40, especially among African American women when compared to non-Hispanic White Women, this finding may highlight a need to begin educating women about breast cancer screening at an earlier age (American Cancer Society, 2011; Smith et al., 2003). The need to educate women earlier is supported by the fact that women who engage in breast self-examinations at an earlier age may be more likely to identify subsequent changes in the breast, which would promote early detection (American Cancer Society, 2011).

In regards to cervical cancer screening, the younger women within the sample also represented the largest cohort who was unaware of how often women should obtain a Pap smear. This finding may also speak to the unmet need for cancer health education among women under

the age 40, which is consistent with a recent study by Sharp and colleagues (2012), who found that young age was a predictor for women who do not follow-up after an abnormal Pap smear.

The current study also highlights the important role that healthcare providers play in women's screening behavior, outnumbering mothers and friends as referral sources within this study. Specifically, 35% of women stated that they received their first mammogram because it was recommended by their doctor. Among those aged 40 and older who had not received a mammogram, over half of women reported it was because their doctor did not recommend the screening. Only 10% of women stated that they self-initiated mammography care. In regards to Pap smears, 69% of women stated that they self-initiated Pap smears as part of their routine health care and 43% reported that they were referred by their doctor/nurse.

Within the current study, the majority of participants reported no gender preference for healthcare providers for breast and cervical cancer screening. This is contradictory to findings in the research literature, although it may also be a reflection of women's overall higher levels of formal education and income. Research regarding Latina women who are medically underserved has revealed that their preference for female healthcare providers for breast cancer screening is related to perceptions of "female commonality." This involves the belief that it is more comfortable to seek treatment from women due their shared anatomy, similar experiences as a woman, and gender socialization to be caring and trustworthy (Borrayo & Jenkins, 2001; Buki, Borrayo, Feigal, & Carrillo, 2004).

Healthcare provider gender preference may also be reflective of the changing nature of the gynecology field in which there is a larger availability of female gynecologists than there were in the past. This hypothesis is suggested in a study by Schnatz and colleagues (2007), who found that younger patients were more likely to report a preference for female obstetrician-

gynecologists. Additionally, a study by Lurie and colleagues (1997) found that women who had female physicians were more likely to express a preference for a female provider for Pap smears and mammography. The research was done in response to studies (e.g., Kreuter et al., 1995) reporting that women with female physicians have higher cancer screening rates than women with male physicians. Further research is needed to determine whether health provider gender preferences differ based on physician availability, levels of formal education, income, health insurance status, or age among African American women.

### **Limitations with Current Study**

This study aimed to collect data during the survey administration phase from a socioeconomic and geographically diverse population of African American women. However, 48% of participants had some college or an advanced degree, 87% had a job for which they received income, and 93% had health insurance. Given that these populations often have higher levels of health literacy in general, future studies should include African American women with lower levels of educational degree attainment, lower annual incomes, and no health insurance for a more representative sample. Additionally, there was overlap within the age categories used in this survey, an inadvertent oversight that caused some ambiguity in the interpretation of participants' ages.

The Cancer Burden factor had an internal consistency estimate of .67, which is lower than the recommended .70 (Bryant & Yarnold, 2005). Clark and Watson (1995) indicated that the Cronbach's alpha is often sensitive to scale length. Therefore, given that the Cancer Burden factor only contained seven items, it may be advisable to develop additional items to measure the construct to improve the internal consistency. Alternatively, it is possible that a different factor

solution would have yielded an underlying structure that was stronger conceptually, even though it would have accounted for lower levels of variance within the measure.

Since the development of the CLM-AA scale items in 2011, there have been changes in the screening recommendations for Pap smears and advanced findings in HPV vaccination that are not reflected in the survey items or this study's conceptualization of "up-to-date Pap smears" (i.e., Pap smears once a year). In March 2012, the USPSTF (2012) announced revised recommendations that women aged 30 – 65 have Pap smears once every 3 years or a combination of Pap smear and HPV screening once every 5 years. Additionally, the USPSTF recommended against Pap smears for women younger than age 21. The majority of the current study's data was collected prior to the March 2012 screening change announcement and it appears reasonable to assume that participants' responses were not affected by the recommendation change. These limitations highlight the need to remain current with advances in the prevention, early detection, and diagnosis of breast and cervical cancer and to update the CLM-AA accordingly.

The anonymous online nature of the survey distributions created difficulty in tracking whether participants received the survey through community liaisons or snowball sampling. In retrospect, the researcher would have added a question regarding referral sources to inform future studies of the most prolific method of collecting data online from African American women. Furthermore, the researcher was unable to send out reminders for participants to complete unfinished surveys due to lack of contact information.

### **Implications for Future Research and Clinical Interventions**

Future studies can utilize the CLM-AA to explore the how African American women's beliefs, attitudes, and emotions affect their cancer screening behaviors. For instance, researchers

can study whether physician mistrust accounts for nonadherence to Pap smear and mammography screening guidelines. Researchers may also study the influence of knowledge about HPV on women's likelihood to be vaccinated or refer their daughters for vaccination. Additionally, it may be helpful to understand whether African American women's breast and cervical cancer health literacy levels differ as a function of socioeconomic status, family or personal history of breast and cervical cancer, geographic location, personal experiences of racism/discrimination in healthcare systems, and access to continuity of care among their healthcare providers. Studies might investigate the influence of socioeconomic factors such as health insurance status on African American women's preference for race concordant healthcare providers for breast and cervical cancer screening. Researchers may also want to further explore whether there are generational differences in African American women's gender preference for healthcare providers, especially in regards to Pap smears and mammograms.

The focus groups conducted within this study were primarily used to assess face validity for the CLM-AA. However, future research may want to explore more in-depth the women's individual and collective experiences in regards to their interactions with the healthcare system and the factors that influenced their cultural and conceptual knowledge about breast and cervical cancer. For example, researchers can explore how women's interactions with their healthcare providers have influenced their cancer screening behaviors and how information regarding breast and cervical cancer is shared within their community.

In regards to implications for clinical practice, the field of health psychology is changing with a push for integration of psychology into primary care settings. Specifically, many healthcare institutions (e.g., Department of Veteran Affairs) have acknowledged that a preventative holistic approach to healthcare is more cost effective than medical models with a

primary focus on treatment of diseases (Kenkel et al., 2005; Schulte et al., 2004). Given that potentially preventable hospitalizations in the United States cost \$28 billion in 2008, the role that psychologists could play in reducing healthcare costs related to preventable diseases has become increasingly important. For instance, breast cancer screening has the potential of saving \$35,000 to \$165,000 per quality adjusted life year gained (AHRQ, 2012). A meta-analysis of cost-effectiveness studies by Techakehakij and Feldman (2008) projected that the HPV vaccines could potentially save between \$16,600 and \$27,231 per quality-adjusted life year (QALY) gained. A biopsychosocial approach that would facilitate cost-effective healthcare involves addressing the physical, psychological, and social aspects of health that may influence an individual's health behavior (McDaniel et al., 2002). A health psychologists' role within a primary care team, in addition to psychotherapy, would include an emphasis on patient education, health promotion, and disease prevention and management (Kenkel et al., 2005; McDaniel et al., 2002).

Primary care psychologists are expected to understand not only the biological aspects of diseases, but also the cognitive aspects (e.g., knowledge, beliefs, attitudes) and affective aspects (e.g. how emotions affect behavior) (McDaniel et al., 2002). Therefore, health psychologists on a primary care team are in an advantageous position for assessing the breast and cervical cancer health literacy of patients. The CLM-AA may be useful for primary care psychologists as an assessment tool to inform treatment planning regarding the level of intervention needed to increase knowledge about breast and cervical cancer, promote adherence to cancer screening guidelines, and encourage healthy coping mechanisms. For example, psychologists can intervene with a patient with high levels of distrust towards physicians to work towards minimizing the adverse affect of physician distrust on the patients' health behaviors.

Psychologists may also utilize the CLM-AA for interventions with families who are supporting a loved one diagnosed with breast or cervical cancer. The families' own cultural and conceptual knowledge may impact the level of support that they can provide their diagnosed loved one or their own ability to cope with the diagnosis and treatment demands.

Additionally, the CLM-AA may be utilized for intervention with women newly diagnosed with breast and cervical cancer to assess for their levels of cancer literacy concurrently with cancer treatment planning. Studies have shown that many breast and cervical cancer survivors (across race/ethnicity) maintain erroneous cancer beliefs while undergoing treatment (Costanzo et al., 2006; Costanzo et al., 2010). In a recent study including 480 breast cancer survivors of varying race/ethnicities, Nissen and colleagues (2012) found that 40% of survivors were unable to identify the stage of their disease and many women could not identify the drug used for their cancer treatment. These studies highlight the need for psychologists to fill in the health literacy gap that can occur during cancer treatment, a process that could potentially be aided by use of the CLM-AA.

### **Suggestions for Further CLM-AA Refinement**

Given that the Cancer Burden factor had a low internal consistency estimate of .67, additional items should be generated for this factor, or alternate factor solutions explored. The current study was exploratory in nature to adapt scale items and perform preliminary validation analyses. A revised CLM-AA scale (i.e., with higher reliability for the Cancer Burden factor) should be administered to a large and diverse sample of African American women aged 18 and older for a confirmatory factor analysis. Once a confirmatory factor analysis is completed, then it would be appropriate to perform differential item analyses to determine whether participant responses differ based upon sociodemographic characteristics (e.g., age, income, health

insurance status, education level, geographic location). Currently, there are no other assessments that focus on the breast and cervical cancer health literacy for African-American women.

However, if similar scales are developed in the future, then it would be appropriate to assess for convergent and discriminant validity of the CLM-AA.

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### Tables and Figures

Table 1

Background Characteristics of Participants as a Percentage of the Sample ( $n = 301$ )

Characteristic	%
<b>Age</b>	
18-30	22.7
30-40	22.4
40-50	21.4
Aged 50 and older	33.4
<b>Marital Status</b>	
Single	41.9
Married	36.5
Cohabiting/Living Together	2.7
Divorced/Separated	14.5
Widowed	4.4
<b>Education</b>	
8th grade or less	5.7
12th grade	3.7
Some college	1.3
Two-year college	5.6
Bachelor's or higher	62
<b>Personal Income</b>	
Less than \$10, 000	10.9
\$10,000-\$29,999	16.6
\$30,000-\$49,999	28.2
\$50,000-\$79,999	27.5
Over \$80,000	16.9

Table 1 (cont.)

Characteristic	%
Insurance	
Medicaid	2.9
Medicare	10
Private	86.8
No Insurance	7

Table 2

Percentage of Correct Responses to Breast Cancer Knowledge Subscale

Items	% Correct
46. It is possible to have breast cancer without symptoms.	95
47. A hard lump found in the breast is a definite sign of cancer.	91
48. A symptom/sign of breast cancer is a change in the texture of the skin of the breast.	88
49. A woman can feel the breast to find out if there is a hard lump.	97
50. The earlier a cancer is detected, the better the chances for survival.	99
51. As part of a breast self-exam, a woman looks at her breasts in the mirror.	86

Table 2 (cont.)

Items	% Correct
52. As part of a breast self-exam, a woman squeezes her nipples.	74
53. A woman needs to have a mammogram only when something is wrong with her breast.	98
54. A mammogram is an x-ray of the breast.	94
55. A mammogram can find a small breast cancer lump before my doctor/nurse or I can find it.	88
56. A mammogram is done to see if there is a growing tumor in the breast.	94
57. Younger women have a higher risk of breast cancer than older women.	91

Table 3

## Percentage of Correct Responses to Cervical Cancer Knowledge Subscale

Items	% Correct
74. It is possible to have cervical cancer without symptoms.	95
75. I know what HPV (Human papillomavirus) is.	92
76. A symptom/sign of cervical cancer is bleeding when a woman is not having her period.	81
77. A woman should have a Pap smear only after she has children.	97

Table 3 (cont.)

Items	% Correct
78. Certain types of HPV (Human papillomavirus) can cause cervical cancer.	98
79. A woman needs to have a Pap smear only when she is sexually active.	86
80. A woman should get a Pap smear only when she has a gynecological (feminine or vaginal) problem.	96
81. A woman should get a Pap smear only when she is pregnant.	99
82. A woman who is past menopause needs to get a Pap smear.	81
83. A Pap smear is used to find cervical cancer.	93
84. A Pap smear is done to see if there is a growing tumor in the cervix.	80
85. Regular Pap smears help to keep from dying of cervical cancer.	80
86. There is a vaccine that protects against certain types of HPV that can cause cervical cancer.	94

Table 4

Kaiser-Meyer-Olkin (KMO) Measure of Sampling Adequacy and Bartlett's Test of Sphericity

Anchored Scale	<i>KMO</i>	Bartlett's Test		
		$\chi^2$	<i>Df</i>	<i>p</i>
Not at All to Very Much	.663	1711.94	153	.000
Strongly Agree to Strongly Disagree	.691	3462.10	136	.000

Table 5

“Not at All” to “Very Much” Anchored Scale Factor Loadings and Communalities

Variables	Factor loadings					Communalities
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	
(67)How worried are you that if you found out you have breast or cervical cancer, you would not be able to pay for treatment?	<b>.66</b>	-.13	-.11	.07	.16	.40
(66)How worried are you that if you had cervical or breast cancer, you would not be able to take care of your family or yourself?	<b>.62</b>	.01	-.11	.09	.09	.34
(63)How worried are you that if you found out you have breast cancer, your breast would be removed?	<b>.54</b>	.03	-.17	.13	.07	.33
(36)How sad would you feel if you had to tell a family member that you have cancer?	<b>.50</b>	.04	.08	-.04	-.10	.22
(43)How afraid are you of cancer treatment?	<b>.49</b>	-.12	.03	-.10	-.04	.22
(65)How afraid are you that a Pap smear will show you have cervical cancer?	<b>.45</b>	-.14	-.07	.18	.08	.28
(64)If you found out that you have breast cancer, how likely is it that you would die from it?	<b>.40</b>	-.05	-.04	.27	.15	.26
(6)How much do you trust doctors?	-.07	<b>.75</b>	-.02	-.02	-.06	.46

Table 5 (cont.)

Variables	Factor loadings					Communalities
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	
(7)How much do you trust doctors of a different race/ethnicity from you—or “who are not African American?”	.06	<b>.74</b>	.02	-.05	-.02	.43
(8)How much do you trust doctors who are African American?	-.07	<b>.63</b>	-.08	-.13	-.13	.36
(10)How effective are doctors at curing illness?	-.01	<b>.53</b>	.02	.08	.03	.26
(5)How much do you feel that doctors treat you differently because you are African American?	.17	<b>-.44</b>	.04	.10	-.02	.25
(70)How interested are you in learning more about cervical cancer?	-.14	-.07	<b>.96</b>	.04	.04	.89
(69)How interested are you in learning more about breast cancer?	-.11	-.02	<b>.95</b>	.05	.01	.89
(45)How likely are you to get cervical cancer?	.16	-.11	.04	<b>.84</b>	.04	.62
(44)How likely are you to get breast cancer?	.07	-.04	.05	<b>.83</b>	-.04	.59
(42)How likely are you to get a Pap smear even when you are feeling healthy?	.04	.02	-.02	.02	<b>.76</b>	.31
(40)How likely are you to get a mammogram even when you are feeling healthy?	.12	-.09	.05	.00	<b>.64</b>	.36

Table 6

“Not at All” to “Very Much” Anchored Scale Eigenvalues, Percentages of Variance, and Cumulative Percentages of Factors

Factor	Eigenvalue	% of Variance	Cumulative %
Physician Trust	2.07	11.51	11.51
Breast and Cervical Cancer Diagnosis	2.06	11.47	22.98
Cancer Education Interest	1.91	10.63	33.61
Cancer Risk Perceptions	1.58	8.76	42.37
Feeling Healthy	1.10	6.14	48.51

Table 7

“Not at All” to “Very Much” Anchored Scale Factor Inter-Correlations

Factors	1	2	3	4	5
1. Physician Trust	-				
2. Breast and Cervical Cancer Diagnosis	-.03	-			
3. Cancer Education Interest	.02	.05	-		
4. Cancer Risk Perceptions	-.02	.06	-.02	-	
5. Feeling Healthy	.04	-.06	.02	.01	-

Table 8

“Not at All” to “Very Much” Anchored Scale Item Mean, Standard Deviation, Skewness and Kurtosis

Variable	<i>M</i>	<i>SD</i>	Skewness	Kurtosis
Physician Trust				
(6)How much do you trust doctors?	3.79	0.81	-0.43	0.03
(7)How much do you trust doctors of a different race/ethnicity from you—or “who are not African American?”	3.64	0.89	-0.48	0.33
(8)How much do you trust doctors who are African American?	3.90	0.80	-0.56	0.71
(10)How effective are doctors at curing illness?	3.43	0.85	-0.59	0.50
(5)How much do you feel that doctors treat you differently because you are African American?	2.47	1.23	0.45	-0.69
Breast and Cervical Cancer Diagnosis				
(36)How sad would you feel if you had to tell a family member that you have cancer?	4.08	1.17	-1.24	0.63
(43)How afraid are you of cancer treatment?	3.41	1.19	-0.39	-0.54
(63)How worried are you that if you found out you have breast cancer, your breast would be removed?	3.11	1.35	-0.06	-1.21
(64)If you found out that you have breast cancer, how likely is it that you would die from it?	2.55	0.88	0.20	0.12
(65)How afraid are you that a Pap smear will show you have cervical cancer?	2.34	1.15	0.72	-0.19
(66)How worried are you that if you had cervical or breast cancer, you would not be able to take care of your family or yourself?	3.13	1.26	-0.10	-1.03
(67)How worried are you that if you found out you have breast or cervical cancer, you would not be able to pay for treatment?	3.00	1.42	0.01	-1.31

Table 8 (cont.)

Variable	<i>M</i>	<i>SD</i>	Skewness	Kurtosis
<b>Cancer Education Interest</b>				
(69)How interested are you in learning more about breast cancer?	2.32	1.11	0.62	-0.22
(70)How interested are you in learning more about cervical cancer?	2.29	1.06	0.63	-0.14
<b>Cancer Risk Perceptions</b>				
(44)How likely are you to get breast cancer?	2.63	0.95	0.11	0.3
(45)How likely are you to get cervical cancer?	2.52	0.89	-0.03	0.22
<b>Feeling Healthy</b>				
(40)How likely are you to get a mammogram even when you are feeling healthy?	1.92	1.12	1.14	0.54
(42)How likely are you to get a Pap smear even when you are feeling healthy?	1.73	1.05	1.54	1.76

Table 9

## “Not at All” to “Very Much” Anchored Scale Inter-Item Correlations

Items	1	2	3	4	5	6	7	8
1.How much do you feel that doctors treat you differently because you are African American?	-							
2.How much do you trust doctors?	-.33**	-						
3.How much do you trust doctors of a different race/ethnicity from you-or-who are not African American?	-.38**	.53**	-					

Table 9 (cont.)

Items	1	2	3	4	5	6	7	8
4.How much do you trust doctors who are African American?	-.34**	.50**	.51**	-				
5.How effective are doctors at curing illness?	-.16**	.47**	.34**	.29**	-			
6.How sad would you feel if you had to tell a family member that you have cancer?	.11	-.05	.10	-.01	.00	-		
7.How afraid are you of cancer treatment?	.11	-.15*	-.01	-.08	-.12*	.33**	-	
8.How worried are you that if you found out you have breast cancer, your breast would be removed?	.10	-.07	.04	-.03	-.02	.25**	.21**	-
9.If you found out that you have breast cancer, how likely is it that you would die from it?	.03	-.08	-.01	-.07	.04	.10	.12*	.36**
10.How afraid are you that a Pap smear will show you have cervical cancer?	.16**	-.09	-.11	-.13*	-.05	.13*	.17**	.34**
11.How worried are you that if you had cervical or breast cancer, you would not be able to take care of your family or yourself?	.08	-.04	-.01	-.03	.00	.26**	.29**	.37**
12.How worried are you that if you found out you have breast or cervical cancer, you would not be able to pay for treatment?	.16**	-.12*	-.11	-.13*	-.08	.27**	.32**	.37**
13.How interested are you in learning more about breast cancer?	-.01	.02	.02	.07	-.01	.00	.08	.20**
14.How interested are you in learning more about cervical cancer?	-.04	.06	.07	.11*	.02	.02	.07	.21**

Table 9 (cont.)

Items	1	2	3	4	5	6	7	8
15.How likely are you to get breast cancer?	.10	-.05	-.03	-.13*	.03	.00	.01	.17**
16.How likely are you to get cervical cancer?	.16**	-.13*	.08	-.21**	-.02	.08	.06	.14*
17.How likely are you to get a mammogram even if you are feeling healthy?	.05	.16**	.07	.11	.06	-.02	-.06	-.10
18.How likely are you to get a Pap smear even if you are feeling healthy?	-.01	.05	-.01	.12*	-.02	.09	.06	-.06

Note: Items renumbered for the purpose of this table and not reflective of item numbers within CLM-AA.

\*p < .05, \*\*p < .01

Table 9 (cont.)

Items	9	10	11	12	13	14	15	16	17	18
9	-									
10	.28**	-								
11	.31**	.30**	-							
12	.32**	.31**	.45**	-						
13	.04	.08	.17**	.14*	-					
14	.08	.10	.18**	.16**	.93**	-				
15	.25**	.11	.09	.10	-.09	-.06	-			
16	.24**	.25**	.20**	.18**	-.04	-.03	.69**	-		
17	-.10	-.13*	-.15*	-.23**	.04	.08	.03	-.10	-	
18	-.14*	-.07	-.11	-.09	.00	.03	-.01	-.02	.49**	-

Table 10

“Strongly Agree” to “Strongly Disagree” Anchored Scale: Factor Loadings and Communalities

Variables	Factor loadings				Communalities
	1	2	3	4	
(61)If you found out you have cervical cancer, you would feel nervous.	<b>.95</b>	-.03	-.01	.10	.94
(59)If you found out you have breast cancer, you would feel nervous.	<b>.94</b>	-.02	.03	.07	.93
(58)If you found out you have breast cancer, you would feel sad.	<b>.92</b>	-.04	-.03	.11	.94
(60)If you found out you have cervical cancer, you would feel sad.	<b>.90</b>	-.03	.00	.04	.92
(28)I would feel embarrassed checking my breasts for hard lumps when taking a bath or a shower.	-.03	<b>.93</b>	.19	-.14	.88
(30)I would feel embarrassed checking my breasts for hard lumps when I am lying in bed.	-.01	<b>.91</b>	.22	-.12	.87
(29)I would feel embarrassed checking my breasts for hard lumps when I look at myself in the mirror.	-.05	<b>.91</b>	.22	-.14	.87
(19)Cancer cannot be cured, even if it is caught early.	.02	.10	<b>.60</b>	.03	.33
(32)If I found out I have cervical cancer, I would probably die from the disease.	.05	.12	<b>.56</b>	-.05	.29
(26)If I found out that I have breast cancer, I most likely will die from the disease.	-.01	.16	<b>.54</b>	-.10	.30
(35)If I got cancer, I would feel like a burden to my loved ones.	.19	.04	<b>.45</b>	-.09	.24
(23)If I find out that I have cancer, I should keep it to myself and take it to the Lord in prayer.	-.13	.20	<b>.41</b>	.06	.24
(21)Cancer treatment is worse than the disease.	-.07	.04	<b>.41</b>	.01	.18

Table 10 (cont.)

Variables	Factor loadings				Communalities
	1	2	3	4	
(18)I often feel like a doctor does not respect me or shows little interest in me.	-.05	-.02	<b>.32</b>	-.22	.20
(17)My health is important to me.	.08	-.05	-.19	<b>.79</b>	.47
(15)It is important for me to have a doctor or nurse who shows respect and interest in me.	.04	-.09	-.04	<b>.71</b>	.41
(13)It is important for me to have a doctor who really pays attention to the pain I am feeling.	.10	-.17	.03	<b>.66</b>	.39

Table 11

“Strongly Agree” to “Strongly Disagree” Anchored Scale Eigenvalues, Percentages of Variance, and Cumulative Percentages of Factors

Factor	Eigenvalue	% of Variance	Cumulative %
Breast and Cervical Cancer Diagnosis	3.52	20.71	20.71
Breast Cancer Screening Embarrassment	2.67	15.71	36.42
Protecting One’s Health	1.80	10.58	47.00
Cancer Treatment Efficacy	1.71	10.06	57.05

Table 12

“Strongly Agree” to “Strongly Disagree” Anchored Scale Factor Intercorrelations

Factors	1	2	3	4
1. Breast and Cervical Cancer Diagnosis	-			
2. Breast Cancer Screening Embarrassment	.00	-		
3. Protecting One’s Health	.02	-.03	-	
4. Cancer Treatment Efficacy	.01	.07	.03	-

Table 13

“Strongly Agree” to “Strongly Disagree” Anchored Scale Item Means, Standard Deviations, Skewness and Kurtosis

Variable	<i>M</i>	<i>SD</i>	Skewness	Kurtosis
<b>Breast and Cervical Cancer Diagnosis</b>				
(60)If you found out you have cervical cancer, you would feel sad.	1.63	0.95	1.86	3.56
(59)If you found out you have breast cancer, you would feel nervous.	1.55	0.83	1.95	4.64
(61)If you found out you have cervical cancer, you would feel nervous.	1.61	0.92	1.88	3.86
(58)If you found out you have breast cancer, you would feel sad.	1.56	0.88	2.04	4.67
<b>Breast Cancer Screening Embarrassment</b>				
(29)I would feel embarrassed checking my breasts for hard lumps when I look at myself in the mirror.	4.56	0.78	-2.26	6.02
(30)I would feel embarrassed checking my breasts for hard lumps when I am lying in bed.	4.55	0.79	-2.24	5.81
(28)I would feel embarrassed checking my breasts for hard lumps when taking a bath or a shower.	4.58	0.76	-2.32	6.46
<b>Protecting One’s Health</b>				
(13)It is important for me to have a doctor who really pays attention to the pain I am feeling.	1.48	0.91	2.55	6.77
(15)It is important for me to have a doctor or nurse who shows respect and interest in me.	1.28	0.80	3.56	12.87
(17)My health is important to me.	1.43	0.90	2.72	7.61

Table 13 (cont.)

Variable	<i>M</i>	<i>SD</i>	Skewness	Kurtosis
Cancer Burden				
(18)I often feel like a doctor does not respect me or shows little interest in me.	3.99	.89	-.97	1.30
(19)Cancer cannot be cured, even if it is caught early.	4.07	.99	-1.14	.92
(43)Cancer treatment is worse than the disease.	3.24	.98	.06	-.65
(23)If I find out that I have cancer, I should keep it to myself and take it to the Lord in prayer.	4.27	.92	-1.49	2.34
(26)If I found out that I have breast cancer, I most likely will die from the disease.	4.09	.99	-1.23	1.41
(32)If I found out I have cervical cancer, I would probably die from the disease.	4.07	.93	-.88	.48
(35)If I got cancer, I would feel like a burden to my loved ones.	3.39	1.24	-.23	-1.09

Table 14

## “Strongly Agree” to “Strongly Disagree” Anchored Scale Inter-Item Correlations

Items	1	2	3	4	5	6	7	8	9
1.If you found out you have breast cancer, you would feel sad.	-								
2.If you found out you have breast cancer, you would feel nervous.	.84**	-							
3.If you found out you have cervical cancer, you would feel sad.	.93**	.85**	-						
4.If you found out you have cervical cancer, you would feel nervous.	.78**	.93**	.88**	-					
5.I would feel embarrassed checking my breasts for hard lumps when taking a bath or a shower.	-.08	-.07	-.10	-.12*	-				
6.I would feel embarrassed checking my breasts for hard lumps when I look at myself in the mirror.	-.05	-.04	-.06	-.07	.91**	-			
7.I would feel embarrassed checking my breasts for hard lumps when I am lying in bed.	-.08	-.07	-.08	-.08	.92**	.92**	-		
8.It is important for me to have a doctor who really pays attention to the pain I am feeling.	.12*	.15**	.13*	.14*	-.22**	-.20**	-.22**	-	
9.It is important for me to have a doctor or nurse who shows respect and interest in me.	.07	.08	.13*	.14*	-.17**	-.16**	-.16**	.56**	-
10.My health is important to me.	.12*	.14*	.18**	.19**	-.19**	-.18**	-.20**	.56**	.56**
11.I often feel like a doctor does not respect me or shows little interest in me.	-.07	-.06	-.05	-.04	.06	.03	.05	-.20**	-.15*

Note: Items renumbered for the purpose of this table and not reflective of item numbers within CLM-AA.

\*p < .05, \*\*p < .01

Table 14 (Cont.)

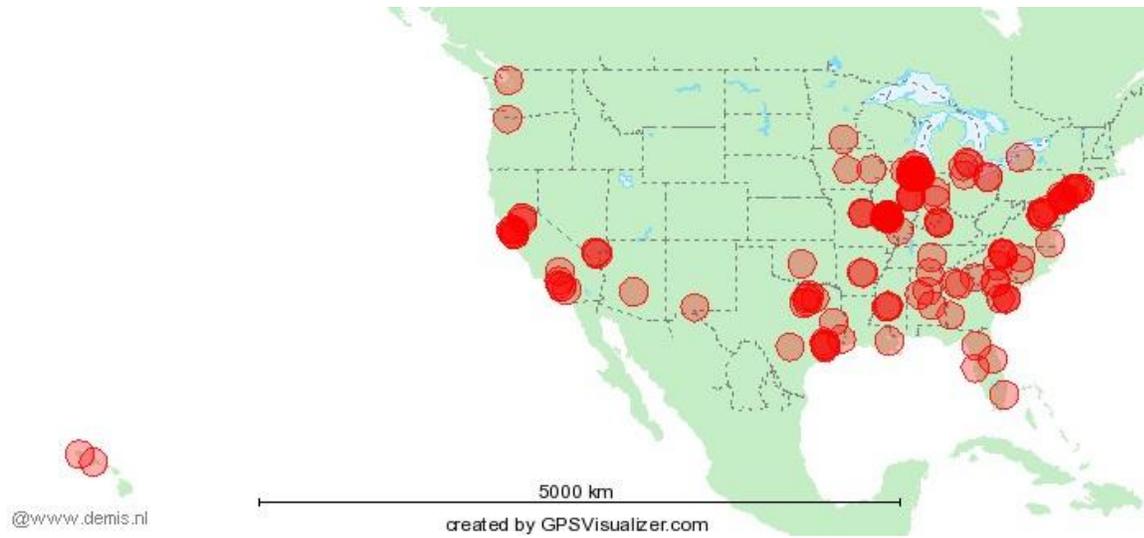
Items	1	2	3	4	5	6	7	8	9
12.Cancer cannot be cured, even if it is caught early.	-.01	.01	.01	-.03	.18**	.23**	.16**	.03	.03
13.Cancer treatment is worse than the disease.	-.06	-.03	-.06	-.04	.12*	.14*	.09	-.02	-.03
14.If I find out that I have cancer, I should keep it to myself and take it to the Lord in prayer.	-.15**	-.10	-.13*	-.15*	.31**	.27**	.28**	-.03	.03
15.If I found out that I have breast cancer, I most likely will die from the disease.	.00	.01	-.03	-.05	.24**	.22**	.24**	-.05	-.14*
16.If I found out I have cervical cancer, I would probably die from the disease.	.04	.03	.03	.01	.20**	.23**	.21**	-.07	-.02
17.If I got cancer, I would feel like a burden to my loved ones.	.17**	.18**	.13*	.12*	.12*	.09	.11	.01	-.04

Table 14 (Cont.)

Items	10	11	12	13	14	15	16	17
10	-							
11	-.29**	-						
12	-.12*	.08	-					
13	-.08	.19**	.34**	-				
14	-.01	.17**	.23**	.17**	-			
15	-.13*	.25**	.33**	.13*	.24**	-		
16	-.08	.10	.34**	.18**	.21**	.40**	-	
17	-.16**	.22**	.20**	.17**	.15**	.27**	.34**	-

Figure 1

Map of Participant Zipcodes



Note: Darker circles represent higher density of participants within the area.

**Appendix A****Sociodemographic Questionnaire**

1. What is your gender?  
 Female  Male
  
2. What is your race?
  - A. White
  - B. Black or African American
  - C. American Indian or Alaska Native
  - D. Asian
  - E. Native Hawaiian or Other Pacific Islander

If other, please identify your race. \_\_\_\_\_

Are you Latina?

- Yes  No

3. What is your zipcode? \_\_\_\_\_
  
4. What is the maximum years of formal education you have completed?
  - A. 0-1
  - B. 1-2
  - C. 3-4
  - D. 5-6
  - E. 6-7
  - F. 7-8
  - G. 9-10
  - H. 10-11
  - I. High School Diploma/GED
  - J. Some College
  - K. College Degree
  - L. 2-Year College Degree (Associates)
  - M. 4-Year College Degree (B.A., B.S.)
  - N. Some Graduate School
  - O. Master's Degree
  - P. Doctoral Degree
  - Q. Professional Degree (MD, JD)
  
5. What is your age?
  - A. Under 18
  - B. 18 – 25
  - C. 25-30

- D. 30-35
- E. 35-40
- F. 40-50
- G. 50-60
- H. 60-70
- I. 70 and over

6. What is your marital status?

- A. Single
- B. Married
- C. Cohabiting/Living Together
- D. Divorced/Separated
- E. Widowed

7. Do you have children?

- Yes  No

If yes, how many? \_\_\_\_\_

8. What is your sexual orientation?

- A. Heterosexual
- B. Lesbian
- C. Gay
- D. Bisexual
- E. Transgender

If other, please specify: \_\_\_\_\_

9. In the last 12 months, did you have a job for which you received income?

- Yes  No

10. What is your occupation?

---

11. What is your own yearly income?

- A. Less than \$10,000
- B. \$10,000-\$19,999
- C. \$20,000-\$29,999
- D. \$30,000-\$39,999
- E. \$40,000-\$49,999
- F. \$50,000-\$59,999
- G. \$60,000-\$69,999
- H. \$70,000-\$79,999

- I. \$80,000-\$89,999
  - J. \$90,000-\$99,000
  - K. \$100,000-\$149,000
  - L. over \$150,000
12. What is your total household income, including all earners in your household?
- A. Less than \$10, 000
  - B. \$10,000-\$19,999
  - C. \$20,000- \$29,999
  - D. \$30,000-\$39,999
  - E. \$40,000-\$49,999
  - F. \$50,000-\$59,999
  - G. \$60,000-\$69,999
  - H. \$70,000-\$79,999
  - I. \$80,000-\$89,999
  - J. \$90,000-\$99,000
  - K. \$100,000-\$149,000
  - L. over \$150,000
13. What kind of health insurance do you have?
- A. None
  - B. Private
  - C. Medicare
  - D. Medicaid

**If your answer is “none”, skip to question 17.**

14. Does your health insurance cover Pap smear exams?  
 Yes  No  I don't know.
15. Does your health insurance cover mammograms?  
 Yes  No  I don't know.
16. Do you have a regular health clinic you can go to for checkups and when you are sick?  
 Yes  No
17. Do you have a regular doctor that you see for checkups and when you are sick?  
 Yes  No

18. Have you ever attended a workshop on the importance of breast cancer screening?

Yes  No

19. Have you ever attended a workshop on the importance of cervical cancer screening?

Yes  No

20. Have you ever been diagnosed with cervical cancer?

Yes  No

21. Have you ever been diagnosed with breast cancer?

Yes  No

The following questions are about breast self-exams and mammograms. Please mark the box that most closely matches your behaviors. There are no right or wrong answers; we want to record your experiences.

22. Have you ever had a mammogram?

Yes  No

**If no, skip to question 30 on page 4.**

23. In the past 5 years, how many mammograms have you had?

- A. None
- B. 1
- C. 2
- D. 3
- E. 4
- F. 5 or more
- G. I don't remember.

24. When did you have your **LAST** mammogram?

- A. Less than 12 months
- B. 1 year
- C. 2 year
- D. 3 years
- E. 4 years
- F. 5 or more years
- G. I don't remember

25. Which of the following is true about your **LAST** mammogram?

- A. I asked my doctor for a mammogram.
- B. The doctor/nurse recommended it.
- C. I got a reminder card in the mail.
- D. Was part of my routine healthcare.
- E. I had a problem in my breasts.
- F. My church/spiritual community recommended it.
- G. A family member recommended it.
- H. A friend recommended it.

26. Which of the following is true about your **FIRST** mammogram?

- A. I asked my doctor for a mammogram.
- B. The doctor/nurse recommended it.
- C. I got a reminder card in the mail.
- D. Was part of my routine healthcare.
- E. I had a problem in my breasts.
- F. My church/spiritual community recommended it.
- G. A family member recommended it.
- H. A friend recommended it.

27. Do you have a gender preference for the healthcare provider who does your mammogram?

- Yes  No

28. Which gender do you prefer?

- Female  Male  No Preference

29. A healthy woman your age should receive a mammogram every:

- A. Few months
- B. 1 year
- C. 2 years
- D. 3 years
- E. 4 years
- F. 5 or more years
- G. I don't know
- H. I do not need a mammogram at my age.

30. Please mark the reasons that explain why you have NOT gotten a mammogram.

- A. I do not understand what the exam is about.
- B. A doctor did not recommend it.
- C. I am worried about the cost.
- D. I am afraid the mammogram will show that I have cancer.
- E. I have to wait too long for an appointment.
- F. I do not need a mammogram because I feel healthy.
- G. I have heard bad things about mammograms.
- H. I am afraid the mammogram will cause breast cancer.
- I. I do not have transportation.
- J. I forgot to get the exam.
- K. I do not have the time to get a mammogram.
- L. I am embarrassed to have that kind of exam.

31. Have any of the following people ever encouraged you to have a mammogram?

- A. Husband or partner
- B. Daughter/son
- C. Mother
- D. Sister
- E. Aunt
- F. Other family member(s)
- G. A doctor/nurse
- H. Another health professional
- I. Church/Spiritual Community
- J. Myself/I like to get regular checkups
- K. Friends
- L. No one

32. Do you know what a clinical breast exam is?

Yes No

33. A clinical breast exam is an exam where the doctor/nurse touches your breasts to feel for lumps. Do you have a gender preference for the doctor/nurse who does your clinical breast exam?

Yes No

34. Which gender do you prefer?

Female Male No Preference

35. About how long ago did you have your last clinical breast exam?

- A. Never
- B. Less than 12 months
- C. 1 year
- D. 2 years
- E. 3 years
- F. 4 years
- G. 5 or more years
- H. I don't remember

If your answer is "never", skip to question 38 on next page.

36. Which option is true about your last clinical breast exam?

- It was a part of my regular check-up
- I had a problem in my breasts

Other reason:

---

37. A healthy woman your age should have a clinical breast exam every:

- I. Few months
- J. 1 year
- K. 2 years
- L. 3 years
- M. 4 years
- N. 5 or more years
- O. I don't know
- P. I do not need a clinical breast exam at my age.

38. Doctors recommend that a healthy woman your age should do a breast self-exam every:

- A. Not recommended for my age group
- B. Few months
- C. 1 year
- D. 2 years
- E. 3 years
- F. 4 years
- G. 5 or more years
- H. I don't know

39. Have you ever been shown how to do your own breast self-exam?

Yes  No

40. Have you ever examined your breasts?

Yes  No

The following questions are about Pap smears. Please answer with the option that most closely matches your behaviors. There are no right or wrong answers; we just want to record your experiences.

41. Have you ever had a Pap smear exam?

Yes  No

**If your answer is “no”, skip to question 46 on page 6.**

42. In the past 5 years, approximately how many times have you had a Pap smear?

- A. None
- B. 1
- C. 2
- D. 3
- E. 4
- F. 5 or more
- G. I don't remember.

43. When did you have your LAST Pap smear?

- A. Less than 12 months
- B. 1 year
- C. 2 year
- D. 3 years
- E. 4 years
- F. 5 or more years
- G. I don't remember

44. Which option is true about your FIRST Pap smear? (Mark ALL that describe you).

- A. It was part of a routine health checkup.
- B. I had a gynecological problem.
- C. It was part of the visit when I got my contraceptive prescription.
- D. It was part of my prenatal care.
- E. A doctor/nurse recommended it.
- F. Other reason

45. Please mark the reasons that explain why you have *NOT* gotten a Pap smear? (Mark *ALL* that describe you).

- A. I am embarrassed to have this type of exam done.
- B. A Pap smear might be painful.
- C. I do not need it at my age.
- D. I do not need a Pap smear because I feel healthy.
- E. I do not need a Pap smear because I am not sexually active.
- F. I do not need a Pap smear because I do not engage in risky sexual behavior.
- G. I am afraid the Pap smear will show that I have cancer.
- H. A doctor did not recommend it.
- I. I have to wait too long for an appointment.
- J. I am worried about the cost.
- K. I do not understand what the exam is about.
- L. I do not have transportation.
- M. I forgot to get the exam.
- N. I do not have childcare.

46. Do you have a gender preference for the doctor or nurse who does your Pap smear?  
 Yes  No

47. Which gender do you prefer?

Female  Male  No Preference

48. A healthy woman your age should have a Pap smear every:

- A. Not recommended for my age group
- B. Few months
- C. 1 year
- D. 2 years
- E. 3 years
- F. 4 years
- G. 5 or more years
- H. I don't know

49. Have any of the following people ever encouraged you to get a Pap smear exam? Mark all that describes you.

- A. Husband or partner
- B. Daughter/son
- C. Mother
- D. Sister
- E. Aunt
- F. Other family member(s)
- G. A doctor/nurse
- H. Another health professional

- I. Church/Spiritual Community
- J. Myself/I like to get regular checkups
- K. Friends
- L. No one

## **Appendix B**

### **Focus Group Interview Guide**

#### **Questions about Individual Survey Items**

1. Do you feel that this question could have been created in a clearer or different way that would have made it easier to answer?
2. Do you believe that this question is an accurate description of some women's beliefs about breast cancer (or cervical cancer)?
3. Do you believe that this question is an accurate description of some women's attitudes about breast cancer (or cervical cancer)?
4. Did this question fail to ask about an important part of obtaining health information about breast or cervical cancer?
5. Did this question fail to ask about an important part of using health information about breast or cervical cancer?
6. Do you have any comments about this question?

#### **Questions about Survey**

1. How was the experience of completing the questionnaire for you?
2. Do these questions describe important aspects of your experience obtaining and using cancer health information?
3. Do you feel that we failed to ask you something relevant about your experiences obtaining cancer health information? If so, could you tell us about it?
4. Do you feel that we failed to ask you something relevant about your experiences using cancer health information? If so, could you tell us about it?
5. Do you have any comments about the topics discussed?

## Appendix C

### Focus Group Informed Consent

**TITLE OF PROJECT:** Development and Validation of a Cancer Literacy Measure for African Americans

**NAME OF PRINCIPAL INVESTIGATOR:** Lydia P. Buki, Ph.D

**INVESTIGATOR:** Jennifer B. Mayfield, M.S.

**CONTACT NAME AND PHONE NUMBER FOR QUESTIONS/PROBLEMS:** Lydia P. Buki, Ph.D. at (217) 265-5491; Jennifer Mayfield at (773) 718-7405

You are invited to take part in a focus group. We hope to learn about the health needs of African American women. If you agree to participate in the study, you will be asked to fill out a background questionnaire and complete a cancer literacy survey about women's health issues, such as healthcare access, relationship with healthcare providers, and cancer screening. The primary purpose of the focus group is to review potential questions for the development of a cancer literacy measure. The researcher will ask you and the other women in the focus group to share your opinions about the topic and the researcher may take notes on your answers. The focus group will be audio-taped in order to make sure that none of the information is lost. However, your name will not be attached to direct quotes or included on any written materials about the results of the focus group. Furthermore, any transcriptions of audio materials will be kept on a password protected computer files. The focus group will last approximately 2 hours. The surveys and transcripts will be kept for at least 3 years. You will receive a \$25 gift certificate from Walmart for your time and participation upon your completion of the focus group.

The focus group is only for women 18 years of age or older. Since the focus group is an open forum for discussion, we ask that you respect the confidentiality of your fellow participants and not share individual responses with others outside of the focus group session. Unfortunately, the researchers cannot guarantee that fellow participants will maintain the confidentiality of the focus group. There are no known risks associated with participating in this study outside of what you may experience in everyday life when discussing women's health issues. Your participation in this research is voluntary. You may discontinue participation at any time or skip questions you do not want to answer without any penalties or loss of benefits to which you are otherwise entitled. You may also keep a copy of this consent form for your personal records.

If you have questions regarding this project, please contact Jennifer Mayfield (jmayfie2@illinois.edu; 773-718-7405) or Dr. Lydia Buki (buki@illinois.edu; 217-265-5491). If you have any questions about your rights as a participant in this study, please contact the University of Illinois Institutional Review Board at 217-333-2670 (collect calls accepted if you identify yourself as a research participant) or via email at irb@illinois.edu.

I have read and understand the above information and have received a copy of this consent form. I understand that the interview will be audiotaped and my responses to the interview will be kept confidential. I voluntarily agree to participate in the research project described above.

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Signature

Date

## Appendix D

### Survey Recruitment Email

Dear Potential Participant,

I would like to request your assistance in completing an online cancer literacy survey. My name is Jennifer Mayfield and I am a graduate student at the University of Illinois at Urbana-Champaign working on a dissertation study on women's health issues such as healthcare access, relationship with healthcare providers, and cancer screening. I am hoping to learn about the health needs of African American women.

Therefore, I am looking for African-American women who are over the age of 18 to participate in the survey. Participants who complete the survey will be entered in a raffle to receive one of 10 \$25 gift cards from Target.

The survey will take approximately 20-30 minutes to complete. Your participation is voluntary, so you may stop the survey at any time or skip a question that you do not want to answer. Your participation would be greatly appreciated.

To begin the survey: *Please click on the following web address or cut and paste it into your browser's address link to participate in this study:*

<web link here>

If you have any questions or concerns regarding this project, please contact Jennifer Mayfield (jmayfie2@illinois.edu; 773-718-7405) or Dr. Lydia Buki (buki@illinois.edu; 217-265-5491). If you have any questions about your rights as a participant in this study, please contact the University of Illinois Institutional Review Board at 217-333-2670 (collect calls accepted if you identify yourself as a research participant) or via email at [irb@uiuc.edu](mailto:irb@uiuc.edu).

Thank you for your time and consideration.

Best regards,

Jennifer Mayfield, M.S.  
Counseling Psychology Graduate Student  
University of Illinois at Urbana-Champaign

Lydia Buki, Ph.D.  
Associate Professor, Department of Kinesiology and Community Health  
University of Illinois at Urbana-Champaign

## Appendix E

### Survey Informed Consent Form

**NAME OF PRINCIPAL INVESTIGATOR:** Lydia P. Buki, Ph.D., University of Illinois at Urbana-Champaign, Department of Kinesiology & Community Health

**INVESTIGATOR:** Jennifer B. Mayfield, M.S., University of Illinois at Urbana-Champaign, Department of Educational Psychology, Counseling Psychology Division

You are invited to participate in a cancer literacy survey. The purpose of the study is the development of a cancer literacy measure for African American women. We hope to learn about African American women's health issues, such as healthcare access, relationship with healthcare providers, and cancer screening. Before completing the survey, please read the consent form below and click the "Yes" choice and "Submit" button at the bottom of the page if you understand the description of the study and consent to participate in the study.

You must be 18 years of age or older in order to participate in the study. If you agree to participate, you will be asked to fill out a background questionnaire and complete a survey about women's health issues. Your survey responses are anonymous, meaning that we will not collect any identifiable information from you including your name, address, and the IP address of the computer you are using to complete the survey. There are no known risks associated with participating in this study outside of what you may encounter in everyday life when discussing women's health issues. The possible benefits of this study for you may be to provide you with the opportunity to consider your health needs and to help researchers and healthcare providers learn about African American women's health issues.

The survey will take approximately 20-30 minutes to complete. After completing the survey, you may choose to be entered into a drawing for one of 10 \$25 gift cards to Target. Your contact information cannot be connected to your survey answers, so your answers will remain anonymous even if you choose to enter the lottery.

Your participation in this research is voluntary. You may discontinue participation at any time or skip a question you do not want to answer without any penalties or loss of benefits to which you are otherwise entitled. You may also print a copy of this consent form for your personal records. If you have questions regarding this project, please contact Jennifer Mayfield (jmayfie2@illinois.edu; 773-718-7405) or Dr. Lydia Buki (buki@illinois.edu; 217-265-5491). If you have any questions about your rights as a participant in this study, please contact the University of Illinois Institutional Review Board at 217-333-2670 (collect calls accepted if you identify yourself as a research participant) or via email at irb@illinois.edu.

I have read and understood the consent form and voluntarily agree to participate. (Please click "yes" and "submit" if you agree.)

[add links for "yes" and "consent" here]

## Appendix F

### Cancer Literacy Measure for African Americans Preliminary Draft

The following questions ask about your views about health. There are no right or wrong answers; we just want to know how you feel. Please mark the response that most closely describes you.

Below is an example of how to answer survey questions. For example, this would be the way you would answer if you enjoy eating ice cream, but you do not enjoy it “very much”:

**How much do you enjoy eating ice cream?**

Not at All   Very Little   Neutral   **Pretty Much (X)**   Very Much

	Not at All	Very Little	Neutral	Pretty Much	Very Much
1. How difficult is it for you to use the US healthcare system?	1	2	3	4	5
2. How much do you like talking about your health concerns with your friends?	1	2	3	4	5
3. How much would it bother you if a doctor seems in a hurry and spends only a little time with you?	1	2	3	4	5
4. How important is having a doctor or nurse who shows respect and interest in you?	1	2	3	4	5
5. How much do you feel that doctors treat you differently because you are African American?	1	2	3	4	5
6. How much do you trust doctors?	1	2	3	4	5
7. How much do you trust doctors of a different race/ethnicity from you - or "who are not African American?"	1	2	3	4	5
8. How much do you trust doctors who are African American?	1	2	3	4	5

9. How likely are you try traditional medicine (for example, traditional herbs, foods, rubbing alcohol) before seeing a doctor for a health problem?	1	2	3	4	5
10. How effective are doctors at curing illness?	1	2	3	4	5

**Please indicate how much you agree or disagree with the following statements.**

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
11. I have experienced racism with the healthcare system.	1	2	3	4	5
12. I prefer prayer over medication in order to be cured from sickness.	1	2	3	4	5
13. It is important for me to have a doctor who really pays attention to the pain I am feeling.	1	2	3	4	5
14. It is important for me to have an African American doctor.	1	2	3	4	5
15. It is important for me to have a doctor or nurse who shows respect and interest in me.	1	2	3	4	5
16. I pay more attention to the health of my family members or loved ones than my own health.	1	2	3	4	5
17. My health is important to me.	1	2	3	4	5
18. I often feel like a doctor does not respect me or shows little interest in me.	1	2	3	4	5

**The following questions ask about your beliefs about cancer and about physical exams. Please mark the choice that most closely matches how much you agree or disagree with each statement. There are no right or wrong answers. We want to know your opinions.**

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
19. Cancer cannot be cured, even if it is caught early.	1	2	3	4	5
20. Surgery can cause cancer to spread.	1	2	3	4	5
21. Cancer treatment is worse than the disease.	1	2	3	4	5
22. If I find out that I have cancer, there are things I can do to change my fate.	1	2	3	4	5
23. If I find out that I have cancer, I should keep it to myself and take it to the Lord in prayer.	1	2	3	4	5
24. If I find out that I have cancer, God will get me through.	1	2	3	4	5
25. I am likely to get breast cancer.	1	2	3	4	5
26. If I found out that I have breast cancer, I will most likely die from the disease.	1	2	3	4	5
27. I dislike talking about cancer.	1	2	3	4	5
28. I would feel embarrassed checking my breast for hard lumps when taking a bath or a shower.	1	2	3	4	5
29. I would feel embarrassed checking my breasts for hard lumps when I look at myself in the mirror.	1	2	3	4	5
30. I would feel embarrassed checking my breasts for hard lumps when I am lying in bed.	1	2	3	4	5
31. If I noticed a symptom of cancer, I would go to the doctor to get it checked.	1	2	3	4	5

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
32. If I found out I have cervical cancer, I would probably die from the disease.	1	2	3	4	5
33. God works through doctors to provide healing.	1	2	3	4	5
34. If I found out I have cancer, I would seek a second opinion about my condition and treatment options.	1	2	3	4	5

**For the next group of questions, the answers choices range from “not at all” to “very much.” Please choose the box that most matches how you feel.**

	Not at All	Very Little	Neutral	Pretty Much	Very Much
35. How sad would you feel if you had to tell a family member that you have cancer?	1	2	3	4	5
36. How embarrassed do you feel about examining your own breasts?	1	2	3	4	5
37. How embarrassed do you feel when a doctor or nurse you have not seen before touches your breasts?	1	2	3	4	5
38. How painful are mammograms?	1	2	3	4	5
39. How likely are you to get a mammogram if you are feeling healthy?	1	2	3	4	5
40. How much do you dislike getting a Pap smear?	1	2	3	4	5
41. How likely are you to get a Pap smear if you are feeling healthy?	1	2	3	4	5
42. How afraid are you of cancer treatment?	1	2	3	4	5
43. How likely are you to get breast cancer?	1	2	3	4	5
44. How likely are you to get cervical cancer?	1	2	3	4	5

**Please mark the choice the most closely matches your behaviors and thoughts.**

	Yes	No	I don't know.
45. It is possible to have breast cancer without symptoms.	1	2	3
46. A hard lump found in the breast is a definite sign of cancer.	1	2	3
47. A symptom/sign of breast cancer is a change in the texture of the skin of the breast.	1	2	3
48. A woman can feel the breast to find out if there is a hard lump.	1	2	3
49. The earlier a cancer is detected, the better the chances for survival.	1	2	3
50. As part of a breast self-exam, a woman looks at her breasts in the mirror.	1	2	3
51. As part of a breast self-exam, a woman squeezes her nipples.	1	2	3
52. A woman needs to have a mammogram only when something is wrong with her breast.	1	2	3
53. A mammogram is an x-ray of the breast.	1	2	3
54. A mammogram can find a small breast cancer lump before my doctor/nurse or I can find it.	1	2	3
55. A mammogram is done to see if there is a growing tumor in the breast.	1	2	3
56. Younger women have a higher risk of breast cancer than older women.	1	2	3

Please indicate how much you *agree or disagree* with the following statements.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
57. If you found out you have breast cancer, you would feel sad.	1	2	3	4	5
58. If you found out you have breast cancer, you would feel nervous.	1	2	3	4	5
59. If you found out you have cervical cancer, you would feel sad.	1	2	3	4	5
60. If you found out you have cervical cancer, you would feel nervous.	1	2	3	4	5
61. There are things you can do to keep from getting cervical cancer.	1	2	3	4	5

For the following questions, the answer choices range from “not at all” to “very much.” Please select the responses that most closely matches how you feel.

	Not at All	Very Little	Neutral	Pretty Much	Very Much
62. How worried are you that if you found out you have breast cancer, your breast would be removed?	1	2	3	4	5
63. If you found out that you have breast cancer, how likely is it that you would die from it?	1	2	3	4	5
64. How afraid are you that a Pap smear will show you have cervical cancer?	1	2	3	4	5
65. How worried are you that if you had cervical or breast cancer, you would not be able to take care of your family or yourself?	1	2	3	4	5

66. How worried are you that if you found out you have breast or cervical cancer, you would not be able to pay for treatment?	1	2	3	4	5
67. Please mark the answer "Pretty Much"	1	2	3	4	5
68. How interested are you in learning more about breast cancer?	1	2	3	4	5
69. How interested are you in learning more about cervical cancer?	1	2	3	4	5
70. How easy is it for you to identify someone who can provide you with information about breast cancer?	1	2	3	4	5
71. How important is it to get a Pap smear?	1	2	3	4	5
72. How painful do you think Pap smears are?	1	2	3	4	5

**For the following questions, please answer "Yes," "No," "I don't know."**

	Yes	No	I don't know.
73. It is possible to have cervical cancer without symptoms.	1	2	3
74. I know what HPV (Human papillomavirus) is.	1	2	3
75. A symptom/sign of cervical cancer is bleeding when a woman is not having her period.	1	2	3
76. A woman should have a Pap smear only after she has children.	1	2	3
77. Certain types of HPV (Human papillomavirus) can cause cervical cancer.	1	2	3
78. A woman needs to have a Pap smear only when she is sexually active.	1	2	3
79. A woman should get a Pap smear only when she has a gynecological (feminine or vaginal) problem.	1	2	3

80. A woman should get a Pap smear only when she is pregnant.	1	2	3
81. A woman who is past menopause needs to get a Pap smear.	1	2	3
82. A Pap smear is used to find cervical cancer.	1	2	3
83. A Pap smear is done to see if there is a growing tumor in the cervix.	1	2	3
84. Regular Pap smears help to keep from dying of cervical cancer.	1	2	3
85. There is a vaccine that protects against certain types of HPV that can cause cervical cancer.	1	2	3

**Cervical cancer risk increases by: (Mark ALL that describe you).**

- A. Having a family history of cervical cancer
- B. Having many children
- C. Having children very close to one another
- D. Taking birth control pills
- E. Not having children
- F. Having an abortion
- G. Having a sexually transmitted infection
- H. Having many sex partners
- I. Having sex during menstruation

**Through what kind of mass media do you usually get information about cervical and breast cancer? (Mark all that describe you).**

- A. Sharing experiences with my friends
- B. From family members
- C. Church/Spiritual community
- D. Alone with healthcare provider
- E. Attending a workshop
- F. Community health programs
- G. Television
- H. Radio
- I. Video
- J. Newspapers
- K. Brochures
- L. By mail
- M. Magazines
- N. Internet
- O. From someone who has been diagnosed with cancer

## Appendix G

### Cancer Literacy Measure for African Americans Preliminary Final Draft

The following questions ask about your views about health. There are no right or wrong answers; we just want to know how you feel. Please mark the response that most closely describes you.

Below is an example of how to answer survey questions. For example, this would be the way you would answer if you enjoy eating ice cream, but you do not enjoy it “very much”:

**How much do you enjoy eating ice cream?**

Not at All    Very Little    Neutral    **Pretty Much (X)**    Very Much

	Not at All	Very Little	Neutral	Pretty Much	Very Much
1. How much do you trust doctors?	1	2	3	4	5
2. How much do you trust doctors of a different race/ethnicity from you—or “who are not African American?”	1	2	3	4	5
3. How much do you trust doctors who are African American?	1	2	3	4	5
4. How effective are doctors at curing illness?	1	2	3	4	5
5. How much do you feel that doctors treat you differently because you are African American?	1	2	3	4	5

**Please indicate how much you agree or disagree with the following statements.**

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
6. It is important for me to have a doctor who really pays attention to the pain I am feeling.	1	2	3	4	5
7. It is important for me to have a doctor or nurse who shows respect and interest in me.	1	2	3	4	5
8. My health is important to me.	1	2	3	4	5

**The following questions ask about your beliefs about cancer and about physical exams. Please mark the choice that most closely matches how much you agree or disagree with each statement. There are no right or wrong answers. We want to know your opinions.**

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
9. I often feel like a doctor does not respect me or shows little interest in me.	1	2	3	4	5
10. Cancer cannot be cured, even if it is caught early.	1	2	3	4	5
11 .Cancer treatment is worse than the disease.	1	2	3	4	5
12 .If I find out that I have cancer, I should keep it to myself and take it to the Lord in prayer.	1	2	3	4	5
13. If I found out that I have breast cancer, I most likely will die from the disease.	1	2	3	4	5
14. If I found out I have cervical cancer, I would probably die from the disease.	1	2	3	4	5
15. If I got cancer, I would feel like a burden to my loved ones.	1	2	3	4	5
16. I would feel embarrassed checking my breasts for hard lumps when I look at myself in the mirror.	1	2	3	4	5

17. I would feel embarrassed checking my breasts for hard lumps when I am lying in bed.	1	2	3	4	5
18. I would feel embarrassed checking my breasts for hard lumps when taking a bath or a shower.	1	2	3	4	5

**For the next group of questions, the answers choices range from “not at all” to “very much.” Please choose the box that most matches how you feel.**

	Not at All	Very Little	Neutral	Pretty Much	Very Much
19. How sad would you feel if you had to tell a family member that you have cancer?	1	2	3	4	5
20. How likely are you to get a mammogram if you are feeling healthy?	1	2	3	4	5
21. How likely are you to get a Pap smear if you are feeling healthy?	1	2	3	4	5
22. How afraid are you of cancer treatment?	1	2	3	4	5
23. How likely are you to get breast cancer?	1	2	3	4	5
24. How likely are you to get cervical cancer?	1	2	3	4	5

**Please mark the choice the most closely matches your behaviors and thoughts.**

	Yes	No	I don't know.
25. It is possible to have breast cancer without symptoms.	1	2	3
26. A hard lump found in the breast is a definite sign of cancer.	1	2	3
27. A symptom/sign of breast cancer is a change in the texture of the skin of the breast.	1	2	3

28. A woman can feel the breast to find out if there is a hard lump.	1	2	3
29. The earlier a cancer is detected, the better the chances for survival.	1	2	3
30. As part of a breast self-exam, a woman looks at her breasts in the mirror.	1	2	3
31. As part of a breast self-exam, a woman squeezes her nipples.	1	2	3
32. A woman needs to have a mammogram only when something is wrong with her breast.	1	2	3
33. A mammogram is an x-ray of the breast.	1	2	3
34. A mammogram can find a small breast cancer lump before my doctor/nurse or I can find it.	1	2	3
35. A mammogram is done to see if there is a growing tumor in the breast.	1	2	3
36. Younger women have a higher risk of breast cancer than older women.	1	2	3

**Please indicate how much you *agree or disagree* with the following statements.**

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
37. If you found out you have breast cancer, you would feel sad.	1	2	3	4	5
38. If you found out you have breast cancer, you would feel nervous.	1	2	3	4	5
39. If you found out you have cervical cancer, you would feel sad.	1	2	3	4	5
40. If you found out you have cervical cancer, you would feel nervous.	1	2	3	4	5

**For the following questions, the answer choices range from “not at all” to “very much.” Please select the responses that most closely matches how you feel.**

	Not at All	Very Little	Neutral	Pretty Much	Very Much
41. How worried are you that if you found out you have breast cancer, your breast would be removed?	1	2	3	4	5
42. If you found out that you have breast cancer, how likely is it that you would die from it?	1	2	3	4	5
43. How afraid are you that a Pap smear will show you have cervical cancer?	1	2	3	4	5
44. How worried are you that if you had cervical or breast cancer, you would not be able to take care of your family or yourself?	1	2	3	4	5
45. How worried are you that if you found out you have breast or cervical cancer, you would not be able to pay for treatment?	1	2	3	4	5
46. How interested are you in learning more about breast cancer?	1	2	3	4	5
47. How interested are you in learning more about cervical cancer?	1	2	3	4	5

**For the following questions, please answer “Yes,” “No,” “I don’t know.”**

	Yes	No	I don't know.
48. It is possible to have cervical cancer without symptoms.	1	2	3
49. I know what HPV (Human papillomavirus) is.	1	2	3
50. A symptom/sign of cervical cancer is bleeding when a woman is not having her period.	1	2	3
51. A woman should have a Pap smear only after she has children.	1	2	3

52. Certain types of HPV (Human papillomavirus) can cause cervical cancer.	1	2	3
53. A woman needs to have a Pap smear only when she is sexually active.	1	2	3
54. A woman should get a Pap smear only when she has a gynecological (feminine or vaginal) problem.	1	2	3
55. A woman should get a Pap smear only when she is pregnant.	1	2	3
56. A woman who is past menopause needs to get a Pap smear.	1	2	3
57. A Pap smear is used to find cervical cancer.	1	2	3
58. A Pap smear is done to see if there is a growing tumor in the cervix.	1	2	3
59. Regular Pap smears help to keep from dying of cervical cancer.	1	2	3
60. There is a vaccine that protects against certain types of HPV that can cause cervical cancer.	1	2	3

**Cervical cancer risk increases by: (Mark ALL that describe you).**

- A. Having a family history of cervical cancer
- B. Having many children
- C. Having children very close to one another
- D. Taking birth control pills
- E. Not having children
- F. Having an abortion
- G. Having a sexually transmitted infection
- H. Having many sex partners
- I. Having sex during menstruation

**Through what kind of mass media do you usually get information about cervical and breast cancer? (Mark all that describe you).**

- A. Sharing experiences with my friends
- B. From family members
- C. Church/Spiritual community
- D. Alone with healthcare provider
- E. Attending a workshop
- F. Community health programs
- G. Television

- H. Radio
- I. Video
- J. Newspapers
- K. Brochures
- L. By mail
- M. Magazines
- N. Internet
- O. From someone who has been diagnosed with cancer