THE RELATIONSHIP BETWEEN CO-MORBID CONDITIONS, CONTEXTUAL FACTORS, AND BREAST CANCER SCREENING MAMMOGRAPHY AMONGST OLDER AFRICAN-AMERICAN WOMEN

by

DONORIA EVANS

(Under the Direction of Marsha Davis)

ABSTRACT

INTRODUCTION: African-American women experience disparities in breast cancer mortality and are often diagnosed at later stages of disease resulting in poorer health outcomes. This study aims to explore the relationship of co-morbid conditions and breast cancer mammography intention. METHODS: Cross-sectional surveys and cognitive interviews were employed to test the psychometric properties of the Illness Perspectives scale, developed to describe affective mood or attitudes towards chronic illness burden, and determine participant mammography attitudes, knowledge and intention. Univariate, Bivariate, and multivariate linear regression were employed to assess predictors for mammography intention. RESULTS: Overall 242 respondents completed surveys with 149 surveys included in psychometric analyses and 201 in multivariate analyses. The Illness Perspectives scale was reliable instrument with two factors, Illness in the Foreground (α=.83) and Illness in the Background (α=.78). In multivariate analyses, having higher educational attainment (Some college or higher) (β=.826-1.055, *p*=.000) and having a more positive attitude towards mammography (Decisional Balance) (β=.296, *p*=.001) were statistically significant factors amongst women with higher mammography intention.

CONCLUSION: The Illness Perspectives Scale is a reliable tool to assess African American women's current attitudes towards chronic disease. Decisional balance and participant demographics, particularly education, can be used to predict mammography intention to tailor health education efforts.

INDEX WORDS: Breast Cancer mammography, African-American women, Co-morbid conditions, Chronic Illness

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DEDICATION

This dissertation is dedicated to my dear family for their unwavering love and support on this journey.

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Thank you to the wonderful women who participated in my research. They were honest and warm, and I left each encounter knowing that this work is important to and for others. I will continue to seek answers to reverse health disparities and lessen the impact on our communities.

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CHAPTER 1

INTRODUCTION

Background: Statement of the problem

Breast cancer has a significant impact on African American women. Despite a lower incidence of breast cancer than the general population, African American women are more likely to be diagnosed with advanced stage disease, aggressive tumor types, hormone dependent tumors and ultimately have higher breast cancer mortality. The tremendous decrease in population breast cancer mortality experienced in the last twenty years, has not occurred proportionally for older African American women (2006). However, breast cancer early detection methods, such as mammography, are effective in reducing breast cancer morbidity and mortality (Mandelblatt, 2007). Regular screening mammography is associated with reducing age-related disparities in breast cancer tumor size and stage at diagnosis, where older women who regularly utilize mammography are more likely to be diagnosed with smaller tumors and with an earlier stage of breast cancer (Randolph, Goodwin, Mahnken, & Freeman, 2002).

This dissertation is focused on the psychosocial and health system factors related to breast cancer and screening mammography. The impact of chronic disease is explored to identify its relationship to screening mammography among older African American women and to determine gaps in research and practice.

Introduction. In the United States, cancer of all types is the second leading cause of mortality, with approximately 582,607 individuals dying in 2012 (U.S. Cancer Statistics Working Group, 2015). As defined by the National Cancer Institute, cancer is a set of diseases defined by uncontrolled division of abnormal cells that can spread to surrounding tissues and organs (NCI, 2015). Cancer, if left untreated, will ultimately result in the death of an individual (ACS, 2015). While cancer can occur at any age, most (78%) cancer diagnoses occur in individuals aged 55 and older (ACS, 2010). Health disparities defined by disproportionate disease burden and outcomes continue to exist for cancer, particularly in mortality (Baquet et. al., 2008). Cancer incidence and mortality, amongst men, are highest for African-American males and mortality rates are highest for African American women (CDC, 2015b). According to the American Cancer Society, African Americans have a higher mortality rate (Males 29%; Females 14%) for all cancers (excluding kidney cancer), despite often lower incidence rates, than whites (ACS, 2015).

Breast, Cervical and Colorectal Cancers are among the top 3 diagnosed cancers and cancer-related causes of death for Asian American, Hispanic and African-American women (ACS, 2007). Although they are multi-faceted diseases, Breast, Cervical and Colorectal cancer survival can be linked to consistent screening and detection. However, cancer disparities continue with greater mortality, later-stage disease diagnosis and treatment inequities in minority communities (Anderson-Lewis, 2004). Cancer disparities have several overarching social determinants that impact screening, treatment and outcomes including socioeconomic status, access to care, and insurance coverage (ACS, 2015).

Epidemiology

Breast Cancer. Breast cancer is the "most commonly diagnosed cancer" (CDC, 2012) and one of the leading causes of "cancer-related death" (CDC, 2012) for women. However, breast cancer ultimately impacts both men and women, though males have a lower incidence. The American Cancer Society estimates that in 2016, 246,660 women and 2,600 men will be diagnosed with invasive breast cancer (ACS, 2016). Also estimated for 2016, more than 61,000 new in situ breast cancer cases in the United States will be diagnosed, including ductal carcinoma in situ (ACS, 2016). White women have the highest incidence of breast cancer as compared across racial/ethnic groups. Table 1 indicates the disproportionate burden of breast cancer mortality for African American women, despite lower breast cancer incidence than white women.

Table 1. Incidence and Mortality Rates of Selected Cancer Types by Demographic Characteristics in the United States, 2007-2011

	White	African-American	Asian/ Pacific Islander	Hispanic/ Latino	American Indian / Alaska Native
			Incidence Rate per 100,000		
Breast Cancer	127.6	123.0	86.0	91.6	91.7
Colorectal Cancer – Male	49.2	61.9	39.9	45.9	50.9
Colorectal Cancer – Female	37.4	45.6	30.0	31.6	41.1
Cervical Cancer	7.1	10.2	6.4	10.5	9.5
			Mortality Rate per 100,000		
Breast Cancer	22.2	31.4	11.3	14.5	15.2
Colorectal Cancer – Male	18.7	28.4	13.1	15.8	19.2
Colorectal Cancer – Female	13.2	18.9	9.5	9.9	15.6
Cervical Cancer	2.0	4.2	1.8	2.8	3.4

Source: American Cancer Society, Facts and Figures 2015. (ACS, 2015)

The stage at diagnosis is a critical component of cancer treatment and survival. Outcomes are markedly better for individuals diagnosed with localized disease. As noted in Figure 1, African-American and Hispanic women aged 50 and older had the highest rates of breast cancer diagnosed at regional and distant stages, indicating more aggressive treatment required and lower survival outcomes (ACS, 2015). The 5-year relative survival rate for breast cancer is currently an average of 89% for the general population attributed to increased utilization of early detection methods including screening mammography and treatment advances (ACS, 2015). Those individuals diagnosed with localized tumors have a 98% 5 year survival rate as compared to significantly lower survival with regional (85%) and distant (25%) tumors at diagnosis, indicating the importance of early detection and prompt treatment (ACS, 2015).

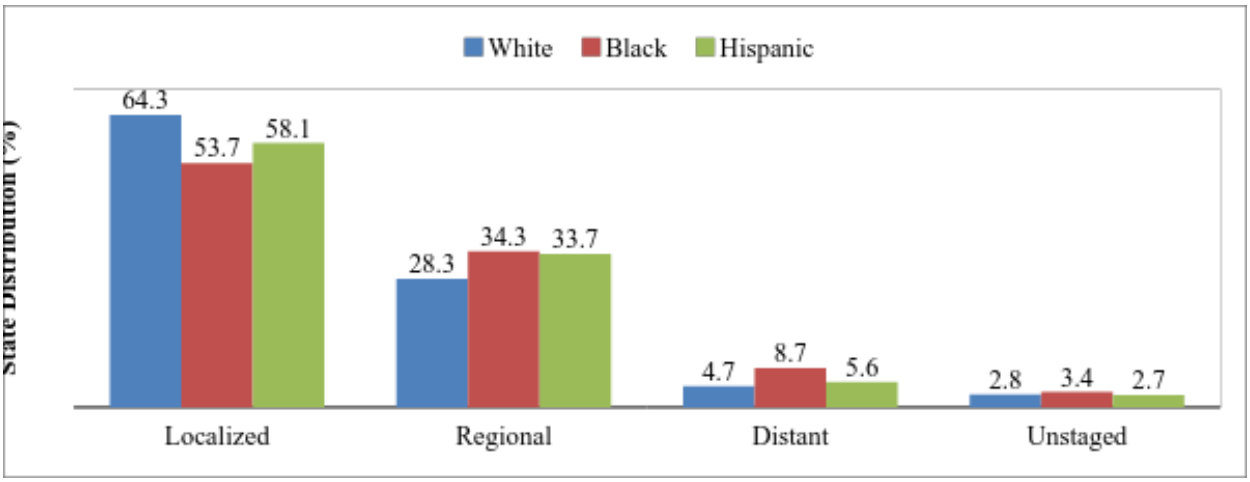

Figure 1 - Stage Distribution for Breast Cancer amongst Females aged 50 and older by Race/Ethnicity, 2000-2007 (ACS, 2009)

Breast cancer risk markedly increases with age, with approximately 8 in 10 cases occurring in women aged 50 and older (Intercultural Cancer Council, 2004; ACS, 2013). In

addition to the increased cancer incidence among older adults, older minority women face greater morbidity and mortality despite differential prevalence of cancers (see Table 2).

Table 2. Female Breast Cancer Incidence Rates per 100,000 in the United States stratified by Age and Race/Ethicity, 1995-2005

	White	African-American	Asian American/ Pacific Islander	Hispanic/ Latina	American Indian / Alaska Native
Age					
< 40	22.9	27.8	25.3	19.1	37.3
40-49	147.7	141.6	120.4	115.6	75.1
50-64	274.0	252.5	191.6	212.5	123.9
65-79	403.1	348.3	219.4	294.0	219.6
≥80	373.9	330.1	177.0	251.6	166.6

U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2005 Incidence and Mortality Web-based Report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2009. Available at: www.cdc.gov/uscs.

Modifiable risk factors for breast cancer, in general, include excess weight defined as being obese or overweight, "menopausal hormone therapy", not participating in regular physical activity, and daily alcoholic beverage consumption (one or more) (ACS, 2015). Additional risk factors include: age; extended menses (early onset or late cessation); "recent" use of oral contraceptives in the last 5 years; "never having children"; immediate family history of breast cancer; and first birth after age 30 (ACS, 2015).

Cervical Cancer

Epidemiology. An estimated 12,042 women aged 30 and older are diagnosed with cervical cancer annually (CDC, 2015). Early detection and screening methods, particularly Papinacolau smears, have contributed to significant declines in cervical cancer incidence and

mortality across the general population. Yet, African American and Hispanic women have the highest incidence and mortality rates for cervical cancer (see Table 1). However, the pap test screening rates reported across racial and ethnic groups are similar, with on average 80% of women aged 18 and older having a Pap test in the last 3 years (ACS, 2013).

A significant risk factor for cervical cancer is exposure to specific strains of the Human Papillomavirus (HPV). High risk sexual behaviors, including early initiation of sexual activity and multiple partners, increase the risk for HPV infection and subsequent cervical cancer. Additional risk factors include: suppressed immune system function; "high parity"; smoking cigarettes; and extended use of oral contraceptives (ACS, 2015).

The general population has a relatively high five year survival for cervical cancer (68%). 91% of those diagnosed with localized disease have survived at least five years. However, disparities in stage at diagnosis are meted by age and race/ethnicity. Fewer African American women (39%) and women aged 50 and older (33%) were diagnosed at a "early" stage when compared to women that were white (48%) or younger than 50 (59%). As well, Hispanic and African American women have higher incidence of cervical cancer at any stage than other race/ethnicities (ACS, 2015).

Colorectal Cancer

Epidemiology. The incidence of colorectal cancer for the general population has been declining since 1985. The observed decline has been credited to increased early detection and screening use, particularly colonoscopy coupled with polyp removal (ACS, 2015). Colorectal cancer incidence and mortality is disproportionately high amongst African-American males and

females as compared to all other race/ethnicities (see Table 1). Whites and Hispanics have a higher rate of colorectal incidence than Asian/Pacific Islander and American Indian/Alaska Natives among both men and women (see Table 1).

Colorectal cancer survival is lower than that of breast and cervical cancers. On average, the five year survival rate for colorectal cancer is 65%. For localized tumors the five year survival rate is significantly higher (90%) than tumors detected at regional (71%) and distant (13%) stages. However, few (40%) colorectal cancers are detected at the localized stage, indicating the need to improve the use of early detection methods (ACS, 2015).

The relationship between age and cancer risk is also present for colorectal cancer. More than 90% of colorectal cancer diagnoses occur in men and women aged 50 and older (Intercultural Cancer Council, 2004; ACS, 2015). Additional risk factors for colorectal cancer are family history of colorectal cancer or polyps, being obese or overweight, physically inactive, consuming a "diet high in red or processed meat, heavy alcohol consumption, long-term smoking, and possibly inadequate intake of fruits and vegetables" (ACS, 2015). As well, chronic inflammatory bowel disease medical history increases colorectal cancer risk (ACS, 2015). Furthermore, although the general population participation in colorectal cancer screening methods is low, disparities are prevalent considering race/ethnicity and income level. The Office of Minority Health reported in 2007 that Hispanics (8.1%) and African Americans (9.7%) were screened for colorectal cancer less than Whites (19.3%) in a Medicare sample (OMHRC, 2007). Additionally, the American Cancer Society indicates that only 53% of African-Americans aged 50 and older had received an endoscopic screening (flexible sigmoidoscopy within 5 year or

colonoscopy within 10 years) as compared to 59% of Non-Hispanic Whites (ACS, 2013). As well, a disparity is present for individuals utilizing a Fecal Occult Blood Tests (FOBT) within the past year and/or endoscopic screening within the past 5 to 10 years. Only 56% of African Americans were screened as compared to 62% of Non-Hispanic Whites (ACS, 2013).

Research Priority

Based on the current epidemiological and screening literature, African Americans have a markedly disproportionate burden of cancer morbidity and mortality across age ranges, racial/ethnic groups and genders. The overall colorectal cancer screening rates and mortality present a gap for further inquiry due to lower screening levels and late-stage diagnoses across racial/ethnic groups. However, breast and cervical cancers present the area of gravest concern. Access, knowledge and availability to breast and cervical cancer screenings have demonstrated continual improvement as public health and medical disciplines work to develop education and intervention programs addressing the obvious disparities; but despite these conscientious efforts and stated improvements in breast and cervical cancer screening and knowledge, African American women, particularly women aged 50 and older, continue to have higher mortality for both breast and cervical cancers. Yet, the screening rates for cervical cancer are higher than that for breast cancer, on average. The vast toll in terms of morbidity and mortality from late-stage breast cancer diagnosis warrants further action. Given the success of HPV vaccination and cervical cancer screening proliferation, breast cancer screening amongst African American women must be given priority. Therefore, further study is necessary to explore and define the factors that impact, both mediate and moderate, the relationship between knowledge and action

towards breast cancer screening mammography for older African American women. The proposed study will explore the relationship between theory-driven psychosocial constructs (i.e. knowledge), co-morbid illness characteristics, intention, and adherence related to breast cancer screening mammography.

Study Purpose

The purpose of this study is to describe the relationship of co-morbid conditions and preventive health behaviors, particularly breast cancer screening mammography. The relationships of breast cancer screening mammography and co-morbid conditions amongst older African American women will be explored controlling for contextual factors such as age, socio-economic status and healthcare access. The study will test the expansion of the Health Belief Model to incorporate a co-morbid conditions construct that is related to mammography-specific intention. Specifically, the purpose of this study is to determine the manner in which several individual and contextual constructs relate to breast cancer screening in older African American women. It will provide an exploration of knowledge, attitudes, chronic disease and illness perspectives, history of breast cancer screening, and their influence on intention to have an annual mammogram.

Specific Aims

Health disparities continue to exist regarding breast cancer mortality for African American women. Despite advances in treatment and detection, African American women are often diagnosed at later stages of disease and have greater breast cancer mortality, as compared to age-matched white women. The constructs related to patient, provider and system components

of the screening issue have been documented in the literature. However, there remains a gap in the continuum from scientific knowledge to practice resulting in stagnant or minimal reductions in stage and mortality disparities. This study aims to explore the influence of chronic conditions on breast cancer screening mammography to develop recommendations for cancer control and prevention programs and practices.

The specific aims of this study are:

1. To determine the relationship between individual and sociocultural constructs in breast cancer screening for older African American women. The primary outcome will be mammography intention.

Hypothesis 1A: African American women who intend to have breast cancer screening will have fewer barriers, low fatalism, high prevention focus (health temporal orientation), and greater perceived benefit (decisional balance).

2. To determine the effect of chronic disease on preventive health behavior, particularly breast cancer screening.

Hypothesis 2A: Screening mammography utilization will be moderated by the presence of chronic disease, such that individuals with more co-morbid conditions will be less likely to intend to utilize screening mammography.

Hypothesis 2B: Individuals with attitudes focusing on illness (higher Illness Perspectives scores) will not intend to utilize screening mammography in the next year.

CHAPTER 2

REVIEW OF THE LITERATURE

Background & Significance

Breast Cancer Screening

Screening guidelines for breast cancer are developed by several entities including the American Cancer Society and the United States (US) Preventive Services Task Force (USPSTF). The American Cancer Society issues an annual review of cancer screening guidelines and identifies issues for further research and areas for physician-patient communication for informed, shared-decision making. In 2010, the breast cancer screening guidelines remained the same for women at average-risk for breast cancer, despite the recommended change in guidelines published by the USPSTF in that same year (Smith, 2010). The recommendations are provided in table 3 below.

Table 3: Breast Cancer Screening Guideline Comparison – USPSTF and ACS

Age Range	ACS Guideline to 2014	USPSTF
20-39	Clinical Breast Exam every 3 years	-
40-49	Clinical Breast Exam & Mammogram annually	Informed decision making - Mammogram
50-74	Clinical Breast Exam & Mammogram annually	Mammogram every 2 years
75+	Informed decision making – Mammogram	-

Mammography

Mammograms are recommended for women aged 40 and older annually to detect the presence of breast cancer. Mammography may detect asymptomatic, early-stage cancer tumors and therefore lends to its purported annual screening benefit (Smith, 2010). By detecting early-stage cancer, the overall benefits of mammography include decreased mortality risk, treatment options that include more options and fewer requirements for aggressive treatment (Smith, 2010). However, mammography has some drawbacks including imperfect specificity (false positive and negative), and detection does not prohibit potential treatment side effects and potential mortality risks associated with cancer tumors. (Smith, 2010) Additional risks associated with mammography are: exposure to radiation; affective issues due to false positive tumor detection (anxiety, fear, etc); additional testing and treatment for benign, non-cancerous or "nonprogressive" lesions (biopsy, radiation, surgery, etc).

The USPSTF revised their recommendations for breast cancer screening in 2009 after a systematic review of extant data and publications (Smith, 2010). The recommendations (see table 3) were in conflict with the previous widely accepted and adopted guidelines (Smith, 2010). For women aged 40 to 50, the recommendations strongly encourage "individual, informed decision making" regarding mammography screening. As well, for women aged 50 to 74 the recommended interval for mammography was lengthened to two years (Smith, 2010). Enhanced screening technologies such as digital mammography and MRI did not have sufficient evidence to warrant recommendations for or against their incorporation into a routine screening regimen. Also, there was not enough evidence to support or refute recommendations for screening of older

women (aged 75 and older). However, the American Cancer Society indicates that women should continue to screen based on individualized risk-benefit assessment and informed decision making, given that they are "in good health and would be a candidate for breast cancer treatment" (Smith, 2010). Therefore from a population-based screening standpoint, mammography breast cancer screening is an adequate form of early detection to improve morbidity and mortality outcomes.

Factors Related to Mammography Screening in Older Women

Age. In the 65 and older subset of the population, there are remarkably different screening behavior, beliefs and attitudes compared to other age cohorts. An inverse relationship has been reported between age and screening mammography regardless of race, where the oldest women are the least likely to screen (Kagay, Quale, & Smith-Bindman, 2006). Women aged 75 and older often do not utilize screening mammography at recommended intervals (Coughlin, Berkowitz, Hawkins, & Tangka, 2007; Sadler et al., 2007). In addition to age, race confounds the relationship and results in older minority women under-utilizing screening services(Bynum, Braunstein, Sharkey, Haddad, & Wu, 2005). According to Jones et al (2003), in a cross sectional sample of lower-income, older, African American women, only 48.8% of those aged 85 and older had received a mammogram in the past two years as compared to greater than 80% of the women aged 65 to 84. Also the oldest women, aged 85 and older, were less likely to perceive their own risk of breast cancer; nearly 60% reported that they "had no chance of getting breast cancer." They also were more likely to endorse myths such as "bruising the breast" as a risk factor (Jones, et al., 2003).

In addition, age is related to co-morbid conditions and functional impairment. As the number of co-morbid conditions increases, with decreasing functional status, women are less likely to utilize breast cancer screening (Kagay, et al., 2006). Therefore the impact of the inter-related factors of age, race and functional status is magnified for older African American women.

Perceived Barriers & Fatalism. In this context, barriers are the perceived or actual obstacles or costs associated with breast cancer screening. Individuals can report a multitude of barriers, but most are structural or behavioral as defined by Young and Severson (2005). Examples of structural barriers are access to care, having a usual source of care, time available for appointments, transportation, facility location, cost of screening, and physician recommendation. Noted behavioral barriers include fear or worry and being embarrassed by the screening process. Older women that report fewer barriers are more likely to complete screening mammography (Farmer, et al., 2007; Holt, et al., 2003; Russell, Champion, et al., 2006). Specifically, Russell et al (Russell, Champion, et al., 2006; Russell, Perkins, et al., 2006) found that perceived barriers were the only significant predictor of lower levels of screening behavior when sociocultural and demographic factors are controlled. The confluence of structural barriers with health system factors may heavily influence the screening behavior of older women. Fatalism also is considered a barrier to screening mammography. According to Farmer and Reddick (2007), it is associated with greater barriers and also decreased screening mammography utilization. Fatalism also impacts the perception of benefits from screening because if they "believe cancer is predetermined and out of their control," their perception of

screening may be negatively affected by "their fear of knowing they have cancer" (Farmer, et al., 2007).

Perceived Benefits. Using the Health Belief Model (HBM), one can also assess individual perception of benefits and positive results from adopting screening behavior. Older women who report more benefits associated with mammography were more likely to utilize screening for early detection (Farmer, et al., 2007; Jones, et al., 2003; Sadler, et al., 2007). Several reported benefits include "feeling good about oneself, reducing worry about breast cancer, and increasing the chances of finding a lump early, leading to better outcomes" (Farmer, et al., 2007). Multiple studies have shown that benefits and barriers are both influential components in breast cancer screening behavior. Interventions often attempt to increase the perception of benefits as well as decreased perceived barriers to improve screening attitudes and the probability that an individual will follow through with screening recommendations.

Knowledge. In the Health Belief Model, knowledge includes awareness and actual knowledge of facts related breast cancer risk factors, screening recommendations, and early detection methods. The construct of knowledge is directly related to mammography screening behavior. Those who utilize mammography screening often have greater knowledge of breast cancer and screening mammography (Russell, Champion, & Skinner, 2006).

Myths, beliefs and social norms often are used to bolster minimal knowledge about cancer, particularly breast cancer, in the African American community (Fowler, 2006). Older African American women are often miseducated about breast cancer risk factors and treatment options. The amalgam of mistrust, fatalism, cultural norms and beliefs work against the

information provided by health care workers and education specialists. For example, Jones et al (2003) found that the oldest of older women, aged 85 and older, were unable to identify multiple risk factors for breast cancer correctly. They also were less likely than those under the age of 85 to believe that early detection and treatment "could save a woman's life". Only 13% of the women in another sample knew that annual mammograms should begin at age 40 (Sadler, et al., 2007). An additional study found that older women, aged 60 and older, had less knowledge of their own risk, screening guidelines, and the behavioral barriers, especially fear, were a greater influence on screening behavior (Young & Severson, 2005). Also, older women may not have knowledge of the cost or availability of breast cancer screening, particularly mammography. Women who knew that Medicare covered annual mammograms were more likely to regularly utilize screening mammography (Eisner, Zook, Goodman, & Macario, 2002). However, African American women were less likely to know about the coverage offered by Medicare (66%) as compared to White women (77%) (Eisner, et al., 2002).

Self-efficacy. The construct of self-efficacy relates to the perception of control or confidence in one's ability to complete a health behavior. In terms of breast cancer screening, self-efficacy has been found to have a positive relationship with mammography. Sadler et al (2007) reported that individuals with higher self-efficacy were more likely to endorse early detection methods as a means to reduce risk for breast cancer. Also, Russell et al (2006) found that higher self-efficacy was significantly associated with an increased likelihood of screening behavior among older women.

Chronic Disease Burden and Preventive Health Behaviors. There have been multiple studies to show the relationship between cancer and chronic or co-morbid conditions (Extermann, 2007). For example, individuals with diabetes mellitus have a higher incidence of colorectal cancer than the general population. As well, those who are considered "prediabetic" or exhibit lower levels of insulin resistance also have a greater risk. Diabetes mellitus also is associated with an increased risk for pancreatic, breast and liver cancers. The cellular level mechanisms have not been determined but the most highly referenced is insulin-resistance related pathways. In addition, Gonzalez, et al (2001) found that the presence and severity of co-morbid conditions was associated with diagnosis at a later stage for breast, colorectal, prostate and melanoma cancer, regardless of patient demographics and possible confounding factors such as income and insurance status. In a survival analysis of each cancer type, the presence of co-morbid conditions was associated with greater mortality 5 years post incidence even after adjusting for stage at diagnosis. As well, Tammemagi et al (2005), showed that "comorbidity explained more than 40% of the survival disparity in patients younger than 70 years". In particular, they note the significant impact of controlling and preventing diabetes and hypertension on breast cancer survival outcomes. They also indicate that "control of co-morbidity" could be a pathway to decrease survival disparities for African American breast cancer patients. These are key articles in describing not only the impact of comorbid conditions on diagnoses but also its relationship to cancer survival.

The impact of co-morbid diseases on cancer risk, treatment and outcomes have been explored in numerous articles (Geraci, Escalante, Freeman, & Goodwin, 2005). However, there

are few articles that examine the relationship between co-morbid illness and cancer prevention. co-morbid conditions are a critical mediator for preventive health behaviors. It is proposed that disease burden and subsequent functional limitations impact an individual's intention to complete preventive health behaviors such as mammography.

Chronic diseases can create an additional health burden for individuals. Research in the literature is contradictory on the impact of chronic disease on health behaviors, particularly breast cancer mammography. However, several studies have shown that diabetes is associated with preventive health behavior, suggesting that greater frequency of medical care and office visits are directly related to cancer screening behavior (Heflin, Oddone, Pieper, Burchett, & Cohen, 2002; Kim, Tabaei, & Herman, 2006; McBean & Yu, 2007). Michels et al (2003) indicated that clinically diagnosed diabetic women were "more likely to be screened for breast cancer". But, there are very few studies whose specific outcome measures include mammography screening intention or behavior. However, Liscombe et al (2005) indicated that diabetic women in their study sample were significantly less likely (32%) to have had a mammogram in the last two years. In this case-control retrospective study, diabetes was a key factor in mammography receipt regardless of personal characteristics and socioeconomic factors such as income. However, the research was completed in Canada with universal health coverage and may not adequately generalize to older African American women in the United States with greater variation of income and health coverage. Additional conditions that impact breast cancer screening include, hip fracture, cognitive impairment, dementia, angina and gastrointestinal bleeding have been related to lower rates of mammography screening(Terret, Castel-Kremer,

Albrand, & Droz, 2009). Therefore, further work is necessary to explore the relationship between co-morbid illness characteristics and breast cancer screening amongst African American women.

Chronic Illness and Screening. Park et al (2010) explored health status as a factor in mammography intention among Korean women aged 40-69. Health status was measured using the EuroQol5, standardized with populations across Europe. Study results showed an inverse relationship between mammography intention and health status. Anxiety, depression, mobility impairment were among several key health status variables that exhibited statistical significance on intention to have a mammogram. However, a key limitation of the study is that its results are contrary to the existing literature (Blustein & Weiss, 1998; Burack, Gurney, & McDaniel, 1998; Walter, Lindquist, & Covinsky, 2004). As well, the social and environmental contexts of Korean health, including state-sponsored healthcare coverage, diet and other factors, may not be as comparable to African American women residing in the United States. Therefore, results may not be translational across national, ethnic and cultural milieus.

Schueler et al (2008) completed a meta-analysis of factors associated with mammography across multiple ethnicities. Among 221 studies, they assessed the likelihood of mammography with odds ratios and utilized random effects modeling to evaluate overall trends and develop summary scores. Physician and system access barriers including no insurance coverage (adjusted OR 0.47, 95% CI 0.39-0.57), not having a primary care provider (OR 0.41, 95% CI 0.32-0.53) and not having a physician recommendation for mammography (adjusted OR 0.16, 95% CI 0.08-0.33) . As well, previous screening behavior, including clinical breast examination (adjusted OR 9.15, 95% CI 3.49-23.98) and papinacoleau testing (adjusted OR 3.45, 95% CI

2.12-5.62) were strong predictors of mammography for most women.

Chronic Illness Characteristics. Chronic diseases are "illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely" (Stanton, Revenson, & Tennen, 2007). Chronic illness and disability is an exigent factor for quality of life in many older adults. According to Shadmi et al (2006) the majority of Medicare (65%) recipients have at least one chronic illness.

Among older adults with multiple co-morbidities, the "most worrisome" illness was indicated by the "perceived seriousness, presence of physical sensations, threat of functional decline and self-care demands"(Schoenberg, Leach, & Edwards, 2009). In particular, older adults tended to be more focused or vigilant on the condition considered to be "serious" as appraised by the individual. Much of the general literature focuses on the worry and fear associated with chronic disease diagnosis and progression over time. As well, perceived social norms of disease burden impact the individual's outlook on future functional capacity. As noted by Schoenber et al (2009), when individuals were asked to compare their current condition and functioning to that of individuals with more advanced symptoms or sequelae associated with the disease, most were not optimistic or "comforted" by their current state of health due to the view that their peers' condition was a "foreshadow … [of] their own impending functional losses" (Schoenberg, et al., 2009). Self-care produced a dual opportunity for worry and empowerment. The perceived capacity for self-care as well as the time required to care for multiple co-morbidities impacted worry associated with illness. As well, limitations and disability associated with the disease burden, such as limited mobility from "congestive heart failure or arthritis", negatively impacted

the ability of older adults to complete self-care tasks. This leads to increased time and difficulty with tasks as simple as "obtaining prescriptions and checking diabetic feet" (Schoenberg, et al., 2009). However, due to the prioritization of self-care, most older adults accommodated the regimens by changing and possibly replacing existing daily activities (i.e. "employment or fastidious housekeeping"), expenses and utilizing existing social networks for informal and formal assistance (Schoenberg, et al., 2009).

Susceptibility / Risk. Risk perception, in this context, is the individual's assessment of their own risk or susceptibility to get cancer. Perceived susceptibility is associated with mammography screening in older women, including older African American women. Approximately 30-40% of older African American women sampled across studies reported that their risk for breast cancer was minimal or not a concern (Eisner, et al., 2002; Jones, et al., 2003). Older women, aged 70 and older, were more likely to report a higher perceived risk for breast cancer (Eisner, et al., 2002). Several studies have shown that individuals at the extreme points of the risk perception spectrum are often least likely to have mammograms completed (Calvocoressi et al., 2004; Young & Severson, 2005). Those who reported that they "don't know" or are "very likely" to get cancer were not likely to receive a mammogram at follow-up after the initial assessment. In older women, those aged 50 and older, the effect of high perceived susceptibility was stronger on mammography screening than for younger women, aged 40-49. Calvocoressi et al (2004) postulated that the relationship between risk perception and screening may be mediated by other factors, such as fear. Therefore, the authors suggest that interventions should be aimed at increasing perceived susceptibility, but not to the highest point

in order to reduce the probability of also augmenting negative affect, fear or fatalism associated with cancer in older women.

Sociocultural & Health System factors. Personal relationships, socio-demographic and health system factors also impact mammography use by older African American women. Those who had "personal exposure" to breast cancer, for example friend or family member, were more likely to perform breast self-examination or have had a mammogram (Sadler, et al., 2007). However, personal exposure can also impact beliefs, attitudes and fatalism, as noted in the social support section. In addition, socioeconomic status is a critical component, despite the equity in coverage presented by Medicare. Older African American women with lower socioeconomic status have a "greater reliance on the traditions of significant others, which resulted in lower mammography screening" (Fowler, 2006). Additionally, access to care, having a usual source of care and recommendations for mammography by health care providers are greatly involved in influencing mammography use amongst older African American women. There is an established positive relationship between physician or health care provider recommendation for screening and mammography utilization for older African American women(Calvocoressi, et al., 2004). Access to care is often cited as a barrier and having a usual source of health care is positively related to attaining a mammogram (Coleman et al., 2003; Sadler, et al., 2007).

Social Support. As in the general population, social support is a critical component of preventive health activities in the African American community. Authors across disciplines have noted the impact of social support on choosing to participate in screening, coping with diagnosis, treatment, and ultimately cancer mortality. Farmer et al (2007), reported that older African

American women having "functional and emotional social support" at "higher levels" were more likely to have screening mammography. This cross-sectional study evaluated the association of several psychosocial attributes and current screening mammography behavior among older African American women. Those who had a mammogram in the last year were more likely to report higher social support than women who had not had a mammogram in the last year.

Spirituality / Religious Beliefs. Spirituality and religion are imbedded in traditional African American culture. Older women cite religious belief, prayer, and God as coping mechanisms and for healing. Mitchell et al (2002) found that older women were more likely to believe that "religious intervention," namely prayer, coupled with treatment would eradicate cancer. Older women frequently speak of the power of prayer and leaning on God for strength. In a qualitative study on the factors related to mammography screening and health in older African American women recruited from churches. They found that the women "asserted that health was rooted deeply in the social, spiritual, and mental dimensions" (Fowler, 2006). Particularly, the church and religion provided a source for "emotional and social support," and the social network from the church influenced health behavior (Fowler, 2006). They were influenced not only by peers but also by family members. They cite the health and longevity of family members and screening habits as factors in their own health decisions. For example, "My great-grandmother was 113 when she died. She didn't get a mammogram. She didn't need it … I must come from good stock, so I don't need a mammogram" (Fowler, 2006). Attitudes towards mammography were positively influenced by their peers through encouragement to screen and providing support by attending mammogram appointments (Fowler, 2006). Also having a

spiritual health locus of control, or belief that God empowers the individual or that God has control regarding a health disorder or behavior, is a significant predictor of perceived barriers. Those who felt that God empowers the individual, the active dimension, were more likely to report greater barriers and less perceived benefits to early detection. However, the sample included college students, who may differ greatly in beliefs and spirituality from older African American women.

Screening History. Women who regularly receive screening mammograms are more likely to continue to screen at recommended intervals (Calvocoressi, et al., 2004). Avis et al (2004) found that receiving a mammogram in the last year was the single largest predictor of screening mammography at follow-up. In addition, previous mammography in the last year was a significant predictor in the use of no- to low-cost mammography screening programs (Klassen et al., 2002). However, older African American women are the least likely to use mammography screening, either in their lifetime or at recommended intervals. In a recent study, only 55% percent of the African American women aged 60 and older had a mammogram in the last year (Sadler, et al., 2007). Mammography screening history, therefore, should be an important criterion in research and intervention development.

Chronic Disease Burden and Preventive Health Behaviors. Chronic diseases can create an additional health burden for individuals. Research in the literature is contradictory on the impact of chronic disease on health behaviors, particularly breast cancer mammography. However, several studies have shown that diabetes is associated with preventive health behavior, suggesting that greater frequency of medical care and office visits are directly related to cancer

screening behavior (Heflin, et al., 2002; Kim, et al., 2006; McBean & Yu, 2007). Contrarily, there are very few studies whose specific outcome measures include mammography screening intention or behavior. Therefore, further work is necessary to explore the relationship between co-morbid illness characteristics and breast cancer screening.

African American women being treated for breast cancer often have poorer outcomes including greater "recurrence/progression" and lower survival ("all-cause, breast cancer-specific, and competing-causes") (Tammemagi, 2005). Co-morbid conditions account for more than half of the disparate overall and "competing causes" survival outcomes for African Americans (Tammemagi, 2005). However, co-morbid conditions had no relationship to disease "recurrence/progression" or "breast cancer-specific survival" (Tammemagi, 2005). A study conducted by Tammemagi et al (2005) suggests that control of co-morbid conditions and associated sequelae, particularly diabetes and hypertension, may decrease breast cancer health disparities, particularly for survival rates. For women aged 70 and younger, co-morbid conditions accounted for more than 40% of the variance in outcomes (Tammemagi, 2005).

Co-morbid conditions in primary care settings requires consistent communication for care coordination, shared decision making and impacts the ability of physicians to address multiple issues during a single session (Shadmi, et al., 2006). Quality of care, care integration, and mitigation of disease-related complications are reduced particularly for older adults with multiple conditions (Shadmi, et al., 2006).

As well, overall patient care satisfaction and attitudes regarding care quality, communication, care coordination, and trust were significantly mediated by co-morbid status,

where an inverse relationship infers higher morbidity with lower ratings for each area representing health care system interaction (Shadmi, et al., 2006). This may be further explained by the "complexity" of their regimen and frequency, interaction and coordination of care with multiple providers, particularly when time is of the essence leaving patients feeling that provider interaction is "superficial, rushed, tense and impersonal" (Shadmi, et al., 2006). Further illustrated by a study of Medicare recipients, where those with "disabilities" significantly more likely to indicate inadequate physician-patient communication and limited healthcare access (Shadmi, et al., 2006). As well as the established link between health status (self-report) and patient satisfaction with care (Shadmi, et al., 2006). The constructs discussed above are critical components to understanding the impact of physician-patient relationships, communication and physician recommendations on preventive care behaviors. Particularly patient trust in their providers was directly linked to preventive health behaviors such as "influenza vaccination and mammography" (Shadmi, et al., 2006).

Competing Demands. The notion of competing demands has been addressed in the literature for psychological and preventive health service delivery, particularly as it relates to primary care visits. Competing demands are also a factor in consumer health decisions. In value expectancy theories, such as the Health Belief Model and Theory of Reasoned Action / Planned Behavior, competing demands are considered as barriers to the desired outcome or behavior. However, the interaction between these specific demands, beliefs, intentions and behavior should be conceptually defined to provide explicit opportunities for model testing.

For older African American women, critical health-related "competing demands" arise in the form of co-morbid conditions. The most cited chronic illnesses for African American women aged 60 and older include diabetes (33%) (Prevention, 2001).

As defined by Piette et al (2006), the diagnosis of breast cancer for diabetic patients presents as a "clinically dominant co-morbid condition" where the management of diabetes or other co-morbid conditions for "longer-term adverse events" is overshadowed by the immediate danger for significantly reduced life expectancy and health related quality of life.

The criteria developed by Piette and Kerr (2006) provide key latent constructs to define and determine the impact of co-morbid conditions. *Clinically dominant conditions* are considered those whose treatment is paramount to survival through short and long-term care coordination. Conditions that have been recently diagnosed ("breast cancer, rheumatoid arthritis"), have severe sequelae and symptoms ("Class IV chronic heart failure, severe depression), and have progressed to an advanced-stage ("Metastatic renal cell carcinoma, end-stage renal failure, severe cognitive impairment/dementia") surpass the attention and care to manage other diseases (Piette & Kerr, 2006).

Concordant diseases have similar "pathophysiologic risk profile" and are more likely to require a similar self-care and/or treatment regimen. Discordant conditions differ in their "pathophysiology" and treatment (Piette & Kerr, 2006). Several previous studies have indicated that concordance and discordance are not as critical to health behaviors and treatment compliance. However, it should be noted that the number and sequelae of chronic illnesses may

increase the interaction with the healthcare system and providers, thereby creating additional opportunities for improved disease management (Piette & Kerr, 2006).

Self-care for chronic disease is a symbiotic relationship between healthcare providers and patients. Self-care requires empowering patients with techniques, tools and knowledge regarding disease management and mitigation. However, little is known about specific illness-related factors and their impact on patient capacity and "willingness" to adhere to disease management strategies (Piette & Kerr, 2006). Piette & Kerr (2006) also identified a key gap in the literature includes identifying mechanisms patients use to adapt, prioritize and act on health needs and determine priority disease characteristics.

Summary

Health disparities continue to exist regarding breast cancer mortality for African American women. Despite advances in treatment and detection, African American women are often diagnosed at later stages of disease and have greater breast cancer mortality, as compared to age-matched white women. The constructs related to patient, provider, and system components of the screening issue have been documented in the literature. However, there remains a gap in the continuum from scientific knowledge to practice resulting in stagnant or minimal reductions in stage and mortality disparities. This study aims to probe the African American community for information to refine current cancer control and prevention research, programs and practices.

CHAPTER 3

METHODOLOGY

This study will utilize cross-sectional, observational study design with quantitative data collection methodology to explore the existence, strength, and direction of relationships between contextual factors, illness characteristics and breast cancer mammography among older African American women. The study was implemented in two phases – I) formative and II) implementation. The formative phase (Study I) entailed cross-sectional survey administration to identify psychometric properties and cognitive interviews to improve survey design for a newly designed scale, the Illness Perspectives scale. The implementation phase (Study II) expanded the survey with additional instruments for a cross-sectional survey administration to identify predictors of mammography screening intention in the target population. Research procedures and protocols were approved by the University of Georgia Institutional Review Board in 2014.

Study Design

Theoretical framework and guiding principles

Theoretical constructs from the Health Belief model provide a framework for research methods and design. The conceptual model regarding Breast cancer screening mammography

among older African American women particularly focuses on evidence-based explanatory constructs in this population, which were discussed in the background and significance.

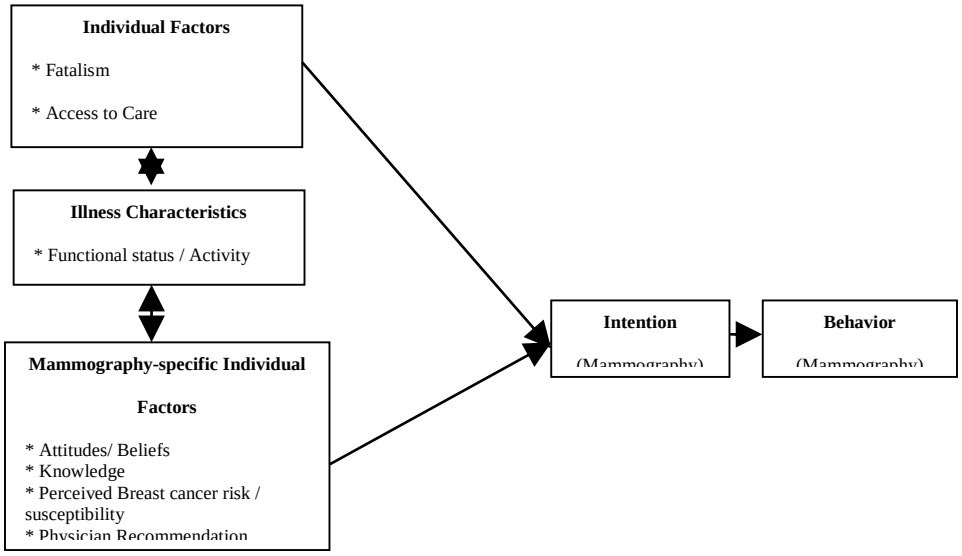

Figure 2: Conceptual Framework for Mammography in older African American women

The Health Belief model has been used extensively to guide public health research since its creation in 1950. It is based on the assumption that an individual will adopt a desired health behavior if negative results can be avoided (Underwood, 2007). In the breast cancer screening context, mammography and clinical breast examinations can be explored by identifying the perceived risk for cancer, perceived benefits and barriers for screening, knowledge, attitudes and beliefs about cancer and screening, as well as socio-demographic factors. The Health Belief model is the most widely used model, in breast cancer psychosocial research, with promising

results regarding health perceptions and mammography screening in African American women (Champion & Scott, 1997).

Interdisciplinary theoretical research was required to capture the appropriate nomenclature, operationalization and framing for this issue. Theoretical frameworks from health promotion, nursing and positive psychology expand the screening models traditionally used such as the Health Belief Model and the Theory of Planned Behavior. Particularly for this framework, exigent factors, such as co-morbid conditions, related to decision-making were critical to fully understand the relationship between affective mood states related to present chronic illness burden and preventive health behaviors and behavioral intention. In the proposed model, the "illness in the foreground, illness in the background" perspective provides a temporal marker for the strength of the relationship between co-morbid conditions and breast cancer screening mammography.

Chronic Illness Perspectives. The Shifting Perspectives Model of Chronic Illness (Paterson, 2001) indicates that illness perspectives for people living with chronic diseases are temporal and shift along a continuum. As noted in the model, individuals regularly transition along a continuum of "illness in the foreground perspective" focusing on illness characteristics and sequelae, loss and burden, and the "wellness in the foreground (illness in the background) perspective" focusing on coping and adapting to the illness which provides an "opportunity for meaningful change in relationships with the environment and others… a revisioning of what [is] possible and normal" (Paterson, 2001). This reappraisal empowers the individual to define the self beyond the corpus and illness incorporating and developing knowledge of the illness,

structural supports, an intimacy with the body's "patterns of response" and their capability to share their experience and knowledge to help others (Paterson, 2001). The illness in the foreground perspective is critical to create behavioral and lifestyle changes to improve morbidity and quality of life due to a recent diagnosis or disease progression (Paterson, 2001). The prioritization and "switching" of attention across the continuum of life events and illness influences the overall focus of health decision-making and affect.

Chronic Disease & Stress and Coping Model. Stress and Coping Model (Folkman, Lazarus, Pimley, & Novacek, 1987) describes the process of affective and cognitive appraisal and subsequent coping and their impact on health-related quality of life in relation to stressful life events including chronic illness. The model focuses on two specific constructs with "appraisal of demands and goals" and "emotional and cognitive responses" directly impacted by "other life events, disease and treatment characteristics, disease related events, demographic characteristics" leading to specific coping behaviors modified by internal and external resources and health-related quality of life constructs (psychological, social and physical) (Peeters, Boersma, & Koopman, 2008). The model has been used to review psychosocial adjustment to chronic illness including asthma (Peeters, et al., 2008).

Theoretical Summary

Decision-making, intent and behavior do not occur in vacuum. Most health behavior models focus on the psychosocial individual level factors most closely related to intention and behavior. However, few provide a modifier to conceptualize the extent to which current illness characteristics and perspectives influence outcomes. Decisional balance occurs when an

individual has weighed options based on knowledge, social norms, affect (worry, fear, etc.), behavioral benefits and barriers, and the individual micro-environment. Chronic illness characteristics, sequelae, constraints and self-care are a part of the individual level micro-environment where the finite resources of vigilance and attention work to determine behavioral priorities. Therefore, the proposed theoretical model integrated illness characteristics as a factor related to behavioral intention in addition to individual knowledge, attitudes, and beliefs.

Study Population and Setting

Eligibility Criteria

The target population was African American women aged 50 and older due to the prevalence of breast cancer in their age group, the mortality disparity, and the documented disparity in breast cancer screening, knowledge and fatalistic attitudes prevalent in older African American women. The following criteria were required for study eligibility amongst potential participants.

Inclusion Criteria:

- Women aged 50 and older
- African-American
- Resident of Metropolitan Atlanta, Georgia
- Community Dwelling (living in own home / rental, assisted living facility, or with family members)
- Have not been previously diagnosed with breast cancer

Due to the nature of community and on-line recruitment, several respondents did not meet inclusion criteria. Therefore, surveys were removed from the final sample due to participant ineligibility (e.g. age, race/ethnicity, breast cancer history) (see Figure 3 for more details).

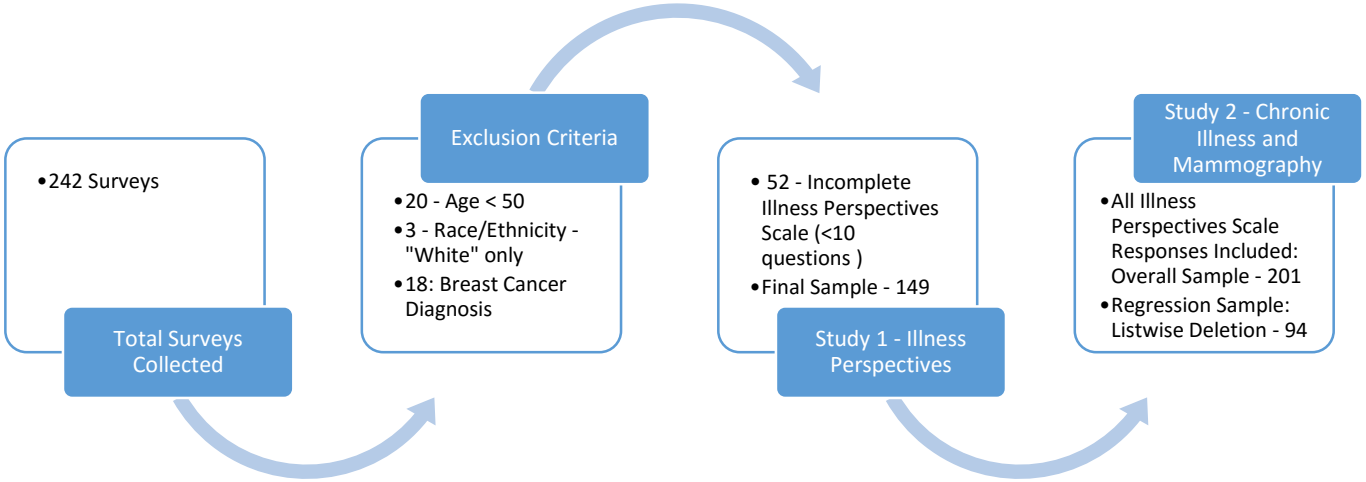

Figure 3: Survey Completion and Exclusion Criteria Applied to Determine Final Samples

Recruitment. Participants were recruited through on-site (e.g. in-person recruitment, study fliers posted) and virtual (e.g. listserv, email) methods. Recruitment locations included the Lou Walker Senior Center, H.G. Bowden Senior Center, New Life Baptist Church, Kroger grocery stores, and social clubs or private events. Electronic recruitment materials were shared through social networks including the Centers for Disease Control and Prevention's Delta Sigma Theta Sorority listserv. An online survey hosted by SurveyMonkey was available from January 2015 to August 2015. Each participant received health education materials for survey completion and an entry for a monthly drawing for a $25 gift card from January 2015 to August 2015. The general public was also eligible to enter the monthly drawing.

Participants. Surveys were completed by 242 women, from December 2014 to August 2015, for both Study I and II. 63 women completed the formative survey, and 179 completed the final survey. Due to the level of missing responses on the formative survey, Study I drew responses from the 201 completed final surveys. The sample ineligibility attrition is detailed in Figure 3. Study I had a total sample of 149 eligible respondents with complete data. Study II had a total sample of 201 cases for univariate and bivariate analysis and 94 cases for multivariate analysis after listwise deletion of cases with missing data in regression equation variables.

Materials and Methods

Study I: Formative Research: Survey Instrumentation Pilot Testing

Instrument Development. The constructs and content for questions on the Illness Perspectives Scale were identified through a literature review. Qualitative research focused on the impact of chronic illness, particularly articles citing the "Illness in the foreground, Illness in the background" theoretical framework were the basis for question development. 20 questions were drafted to cover each paradigm, focused on coping, perceived burden, perceived support, and illness symptoms. All questions were developed referring to the current date, acknowledging that disease states, symptoms and transitions on the illness perception continuum adjust over time.

The 20 questions were reviewed with an academic peer and two individuals with well-managed chronic illness to identify redundancies, improve question stem clarity and cull the overall instrument to 11 final questions.

Instrument Pilot Testing. A series of cognitive interviews (n=3) and one focus group (n=1; 7 attendees) were conducted between December 2014 and March 2015. Participants were instructed to mark unclear, repetitive or questionable wording and proceeded to "talk aloud" through the process of responding to each question. A pilot testing interview guide was developed to garner consistent participant feedback on the survey instrument (see Appendix B). Each interview or focus group was conducted after informed consent procedures were completed and recorded with moderator field notes.

Eligible participants in the pilot testing completed the self-report paper survey which included the drafted instrument and demographic questions. A preliminary analysis of the completed Study I survey, showed that although 63 women completed the formative survey, there was missing data for the instrument that could skew results. Therefore, the final analysis of the tool was completed at the end of the study, July 2015. 149 eligible women completed all of the Illness Perspectives scale items.

Measures. The Illness Perspectives scale identifies the focus of an individual's attitudes on wellness or their chronic illness, at the present time. The scale included eleven items developed to identify the perceived impact of chronic disease and respondent coping. A Likert scale was used for response options, ranging from 1 to 5, representing "Strongly Disagree" to "Strongly Agree". The survey is scored with six questions representing "Illness in the

Foreground (IF)" and four questions representing "Illness in the Background (IB)". Each factor is summed and the final Illness Perspectives scale score is derived by subtracting the "IB" subscale score from the "IF" subscale score. Appendix E includes a detailed table of the items and assigned factors.

Chronic Illness burden was measured with questions modified from the Behavioral Risk Factor Surveillance Survey and the National Health Interview Survey. Presence was assessed by "yes" or "no" responses to the question stem: "Has a doctor, nurse, or other health professional ever told you that you had any of the following?" for 21 common chronic illnesses (i.e. angina/coronary artery disease, asthma and back pain), see Appendices C & D for more details. Additional questions measured the time since diagnosis (How long ago were you diagnosed?) and disease impact on quality of life (If so, has it interfered with your daily activities) for each of the 21 chronic illnesses.

Additional questions were developed to measure the impact of chronic illness, based on the literature. The questions addressed six potential barriers, associated with chronic illness, to general medical care. The topics were time to get care for other illnesses, insurance coverage worry, healthcare provider time to discuss other illnesses, healthcare provider time to discuss screening tests, time for screening tests, and sick leave for those who are currently employed. Demographic questions included age, race, Hispanic/Latino ethnicity, marital status, employment and income (see Appendices C & D for the questionnaire).

Data Analysis and Management. Moderator field notes and marked surveys were evaluated to identify revisions for the final survey. Qualitative content analysis identified

common themes and recommendations to improve survey content and design. Content analysis was conducted with Microsoft Word. Participant confidentiality was addressed by using a three-digit number as the only identifier for respondents in all data entry and management tasks. Data collected in the field were entered in to SurveyMonkey through a data entry "collector" designated for manual entry. Overall, there were two collectors to differentiate data collection methods for web-based and field data. Data collected online were subsequently de-identified, with IP addresses and other identifying information deleted from the final analysis files. Data from the online repository were downloaded in a comma-delimited format (.csv) and converted to RData files with R software.

Exploratory factor analysis, psychometric tests of reliability and validity, and item correlations were completed using R with the graphic user interface, R Commander. Exploratory factor analyses allowed for eigen values greater than one to determine the overall number of factors. A final confirmatory factor analysis was completed after the exploratory analysis with the hypothesized factors 1) illness in the foreground and 2) illness in the background in a two factor solution.

Study II: Exploration of Screening Mammography Factor Relationships

The following measures were included in the final survey to complement the existing constructs and items in the formative survey. For more details on the survey items in both Study I and II, please refer to Appendices C & D.

Cancer Fatalism. Cancer fatalism was evaluated by the Betancourt Cultural Cancer Screening Instrument subscale entitled Cancer Screening fatalism (Betancourt, 2010). Three

items are included in the subscale, with potential responses ranging from 1 to 7 on a Likert scale, representing “Strongly Disagree” to “Strongly Agree”. Subscale scores can range from 3 to 21, with a higher score indicating higher fatalistic attitudes on breast cancer screening. The subscale had a reliability, indicated by Chronbach’s alpha, of 0.75 in a study population of Latina and White, Non-Hispanic women (Betancourt, 2010).

Breast Cancer - Screening Knowledge, Attitudes, Social Norms. Breast cancer screening knowledge and practices was measured using items from the literature. They include an items on mammography frequency (ever, last five years), knowledge of the recommended intervals for mammography, and history of breast cancer in family and friends. Item response options and references are included in Table 4.

Table 4: Study II: Survey Item Sources and Response Options

Question	**Response Options**	**Source**
Have you ever had a mammogram?	Yes, No	BRFSS
How often should you have a mammogram?	Never, Every year, Every two years, Every five years, Don’t know	Farmer, et al., 2007
Has anyone in your family ever had breast cancer? Have any of your friends ever had breast cancer?	Yes, No	Farmer, et al., 2007

Screening Mammography Decisional Balance. The Decisional Balance Scale developed by Otero-Sabogal, et al (2007), measures the positive and negative attitudes of participants regarding the perceived “pros” and “cons” for mammography screening. Response options were

on a 5-point Likert scale (Strongly Disagree to Strongly Agree). The subscale scores (Pros and Cons) were "standardized to a mean of 50 and a standard deviation of 10" (Otero-Sabogal, et al, 2007) in accordance with the authors' methodology. The final scale score is calculated by subtracting the subscale score for the "Cons Scale" from the subscale score for the "Pros scale". Higher scores indicate a positive attitude towards mammography screening, meaning that "Pros" are more strongly endorsed by the respondent. Negative scores reflect a more negative view of mammography screening, with "Cons" items garnering more agreement.

Health Temporal Orientation. The Health Temporal Orientation scale score was developed by Russell et al (2003) as a subscale within a larger instrument to explore the cultural beliefs associated with mammography screening for African American and Caucasian women. Health Temporal Orientation was found to be significantly associated with mammography screening, particularly with those who primarily identified early detection of health issues as important based on scale scores. Response options for the items range from Strongly Disagree (1) to Strongly Agree (5) on a 5-point Likert scale. A summary score is derived by adding the numerical responses, with higher scores representing a proactive, wellness focus regarding their health. Chronbach's alpha for this subscale is 0.79, while borderline represents a consistent instrument. Specific items are included in the questionnaire in Appendices C & D.

Health System Factors. Provider recommendation and access to care are measured using methods established in the literature. Modified items from the National Health Interview Survey 2005 will assess the provider recommendations for mammography as reported by participants (Sabatino, Burns, Davis, Phillips, & McCarthy, 2006). Specifically, participants can respond

"Yes" or "No" to the question "Has your doctor recommended that you get a mammogram?". Access to care was measured with four items from the Behavioral Risk Factor Surveillance Survey. Insurance coverage (Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs or government plans such as Medicare or Indian Health Services?) could be answered with "Yes" or "No" responses. Participants indicated the presence of a regular source of care ("Do you have one person you think of as your personal doctor or health care provider"; Response options: Yes, No). Visit frequency was also used as a metric of health system engagement, indicating the time since their last visit (measured in years: past year, 1-2 years, 2-5 years, 5 or more years ago).

Data Analysis and Management. Quantitative data analysis was completed using R software with the graphic user interface, R Commander. Univariate and bivariate analysis explored the individual items, scales, and relationships between contextual, illness characteristics, individual and mammography-specific constructs and mammography intention. Hierarchical multiple linear regression modeling was used to complete multivariate analysis to define predictors of screening mammography in the target population and test hypotheses. The dependent outcome variable was intention to utilize mammography screening. Linear regression was used to determine the nature of the relationships among the factors, particularly their influence on individual intention to utilize screening mammography, based on the a priori conceptual model. Covariance was accounted for in the model to provide better estimates of relationships and error. Covariance variables were age, income, employment status, and marital status, as appropriate.

Linear regression estimation techniques used measures that considered homoscedasticity and multicollinearity assumptions associated with general linear model techniques.

The equation representing the hypothesized full linear regression is below:

$\hat{y} = \beta_0 + \beta_1 x_1 + \beta_2 x_2 + \beta_3 x_3 + \beta_4 x_4 + \beta_5 x_5 + \beta_6 x_6 + \beta_7 x_7 + \beta_8 x_8 + \beta_9 x_9 + \beta_{10} x_{10} + \beta_{11} x_{11}$

Where y = Mammography Intention, x1=Breast Cancer Attitudes / Decisional Balance, x2 = Cancer Fatalism, x3 = Illness Perspective Score, x4 = Access to Medical Care, x5 = Office Visit Frequency, x6 = Social Norms, x7 = Co-morbidities / Disease Burden, x9 = Income/Employment Status, x10 = Age, x11 = Marital Status.

Bivariate significance determined factor inclusion in the final model for a parsimonious result. Therefore, the final model may differ from the proposed equation.

CHAPTER 4

RESULTS

Study I: Instrument Development Pilot Study

Sample Description

Ten (10) African-American women, aged 55 and older, participated in the cognitive interviews or focus group to garner their feedback on the Illness Perspectives instrument and five additional questions developed to describe chronic illness burden. Overall there were very few recommendations or comments provided in the qualitative inquiry to pilot the Illness Perspectives Instrument. The item "I feel that others judge me because of my chronic illness" was designed to elicit responses about perceived reactions to a respondent's chronic illness experience, primarily negative responses. Two respondents thought the item was negative and focused on "rejection or pity". For example, one respondent indicated that those with chronic pain may often hear others say "there she is with that again". Suggestions for revising the item are included in Table 5. The majority of respondents did not indicate that the item should be revised. Therefore, the item remained the same in the final version.

The item "It is easy to adjust my life for my chronic illness" was also identified by two respondents as a question that could be revised. Other items were only identified by one respondent (see Table 5). The items and suggested revisions were reviewed and no additional changes were made. The suggestions did not indicate substantive changes were necessary, and the overall responses to the interview guide were positive and supported that items were "straight forward" and "simple".

Table 5: Illness Perspectives Scale: Pilot Testing Participant Feedback

Item	Suggested Revision	Comment (n)
I feel that others judge me because of my chronic illness	Do people support me or judge/shun me Do others understand how living with a chronic illness impacts your daily life	… think they would want to explain it [qualify their responses] (*n*=2)
It is easy to adjust my life for my chronic illness.	Does chronic illness impact my daily life	If not seeing a need to make adjustments, [they] may not answer this question positively (*n*=2)
I don't pay as much attention to my illness now.		As compared to when … last year or [when they were] first diagnosed? (*n*=1)
I don't think I need the support aids or devices that my healthcare provider recommends for my chronic illness.		What about medicines? (*n*=1)

Study I – Illness Perspectives Psychometrics: Sample Description. A sample of 149 surveys were selected for psychometric testing, representing respondents that had not been diagnosed with breast cancer and completed every item of the final Illness Perspectives scale (*n*=10).

The majority of survey respondents in Study I, were African American with a secondary education or degree. Nearly a third of the study sample had an advanced degree (graduate or professional degree). Most of the respondents were retired (51.68%) or employed (31.54%). Annual income varied across the sample with a bimodal trend emerging. Most of the respondents

had incomes below $55,000 annually (51.67%) and 20% reported incomes greater than or equal to $75,000.

Table 6: Illness Perspectives Scale Pilot Testing Participants: Demographic Characteristics

Demographic Characteristics	**% (n)**
Hispanic/Latina	2.01 (3)
African American/Black	94.63 (141)
Education	
High School or Equivalent	12.75 (19)
Some College	24.83 (37)
Associate's or Bachelor's Degree	26.85 (40)
Graduate/Professional Degree	32.21 (48)
Employment	
Employed (full-time or part-time)	31.54 (47)
Studying or Training /Seeking Work	2.68 (4)
Not Employed	10.07 (15)
Retired	51.68 (77)
Annual Family Income ($)	
≤ 25,000	19.46 (29)
25,001-55,000	32.21 (48)
55,001-75,000	12.75 (19)
≥75,001	20.13 (30)
I prefer not to disclose my income	12.08 (18)
Marital Status	
Married	37.58 (56)
Divorced	30.87 (46)
Widowed	14.09 (21)
Separated	3.36 (5)
Never Married	11.41 (17)

A bivariate analysis showed that the proportions of respondents were similar across income categories, regardless of employment status. Table 7 details the sample proportions across potential combinations of income and employment status. An unexpected finding was that respondents who were training or seeking work had an annual family income greater than or

equal to $75,000. However, the number of respondents were small for this category and may not reflect population norms.

Table 7: Illness Perspectives Scale Pilot Testing Participants: Annual Family Income by Employment Status

	Employed (full-time or part-time)	**Not Employed**	**Retired**	**Studying or Training /Seeking Work**
≤ $25,000	3.36 (5)	5.37 (8)	9.40 (14)	
$25,001-$55,000	11.41 (17)	§	18.79 (28)	
$55,001-$75,000	6.04 (9)		6.04 (9)	
≥$75,001	8.72 (13)	§	8.05 (12)	§
I prefer not to disclose my income	§	§	8.72 (13)	§

§Data with fewer than five respondents were suppressed for data confidentiality.

Phase I – Illness Perspectives Psychometrics: Factor Analysis. An exploratory factor analysis resulted in two factors, detailed in Table 8, labeled Illness in the Foreground, Illness in the Background. Factor loadings for each item aligned with a priori factor assignments and within acceptable ranges. One item was removed from the analysis due to insufficient factor loadings ("I don't pay as much attention to my illness now"). With varimax rotation, the eigen values for the two factors are .295 and .230, supporting the proposed two factor structure which cumulatively explains more than half of the variance (52.5%). Two items had cross-loadings greater than .3 ("I am most concerned with managing my chronic illness symptoms today" "I don't think I need the support aids or devices that my healthcare provider recommends for my chronic illness"), however their directionality showed alignment with the Illness in the Foreground factor.

Table 8: Illness Perspectives Scale Exploratory Factor Analysis Results*

	Factor 1 Illness in the Foreground	**Factor 2 Illness in the Background**	**Communality**
I am most concerned with managing my chronic illness symptoms today.	.499	-.405	.413
I don't think I need the support aids or devices that my healthcare provider recommends for my chronic illness.	.444	-.408	.363
I find myself focusing on my limitations from my chronic illness.	.763		.585
I feel that others judge me because of my chronic illness.	.737		.549
I worry about my future because I have a chronic illness.	.812		.666
I have had to make significant life changes in the past 3 months because of my chronic illness.	.703		.498
I have accepted that my chronic illness is a part of my life.	-.449	.575	.532
I feel that my relationships with people have not changed since I was diagnosed with a chronic illness.		.708	.501
It is easy to adjust my life for my chronic illness.		.877	.772
I seek help or resources to deal with my disease symptoms if they worsen.		.591	.370

*Factor loadings less than .2 were removed from the table.

Table 9: Descriptive Statistics for the Illness Perspectives factors (n=149)

Subscale	Items	*M* (SD)	Skewness	Kurtosis	α
Illness in the Foreground	6	23.17 (5.52)	-.65	.11	.83
Illness in the Background	4	12.54 (4.60)	-.33	-.71	.78

Reliability. Internal consistency was assessed for each of the scales with results presented in Table 9. The resulting Chronbach's alpha statistics show that the items were closely related in each of the factors identified. The Illness in the Foreground factor (alpha = .83) had the strongest reliability. Reliability would not increase if items were reduced in either scale (Tables detailing the reliability if subscale items were removed are in Appendix E). The scales were not combined to provide an overall comprehensive reliability. The constructs that each factor measures are theoretically diametric and therefore reliability estimates for all items would be diminished.

Study I Summary: Illness Perspectives Scale

Respondents indicated that the overall structure and content of the Illness Perspectives scale items were adequate to elicit responses on African American women's attitudes towards chronic illness. After excluding an item with insufficient factor loadings, the final scale has 10 items. Two sub-scales were confirmed through factor analysis, Illness in the Foreground and Illness in the Background, to identify attitudes along the Shifting Perspectives continuum (Paterson, 2001). The sub-scales were reliable and exhibited internal consistency.

Study II: Breast Cancer Screening Mammography, co-morbid conditions, and contextual factors relationships

Sample Description

The average age for participants was 63 years old, ranging from 50 to 83 years. As in Phase I, many of respondents had higher educational attainment, with 55% completing an Associate's, Bachelor's or Graduate/Professional degree. Employment status was primarily retired (48%) or employed (32%) across the sample. In the overall study sample, a large proportion of respondents had an annual family income below $55,000 (49.25%). The sample was similarly apportioned amongst marital status categories, with married (34%) and divorced (30%) as the most endorsed. (See Table 10 for further details)

Univariate analyses were also conducted for the regression sub-sample population. Population characteristics were similar to the overall population. However, the regression subsample had more education (8% more in the Associate's/Bachelor's degree and 4% more in the Graduate/Professional degree category) and higher incomes (9% more in the highest income category). A greater proportion of the regression sample was married (8%). Table 10 also describes the demographic characteristics of the final linear regression sample with corresponding multivariate results in Table 16.

Table 10: Illness Perspectives Scale Pilot Testing Participants: Demographic Characteristics

	Overall Sample (*n*=201)	**Final Regression Sample (*n*=94)**
Demographics	**% (*n*)**	**% (*n*)**
Hispanic/Latina	1.49 (3)	3.19 (3)
African American/Black	94.03 (189)	100 (94)
Education		
High School or Equivalent	13.43 (27)	5.32 (5)
Some College	24.38 (49)	26.60 (25)
Associate's or Bachelor's Degree	23.38 (47)	31.91 (30)
Graduate/Professional Degree	31.84 (64)	36.17 (34)
Employment		
Employed (full-time or part-time)	32.30 (65)	35.11 (33)
Studying or Training / Seeking Work	1.99 (4)	4.26 (4)
Not Employed	7.96 (16)	10.64 (10)
Retired	48.26 (97)	45.74 (43)
Income ($)		
≤ 25,000	19.90 (40)	13.83 (13)
25,001-55,000	29.35 (59)	32.98 (31)
55,001-75,000	12.44 (25)	15.96 (15)
≥75,001	18.41 (37)	26.60 (25)
I prefer not to disclose my income	11.94 (24)	8.51 (8)
Marital Status		
Married	33.83 (68)	41.49 (39)
Divorced	30.35 (61)	28.72 (27)
Widowed	15.42 (31)	14.89 (14)
Separated	2.99 (6)	4.26 (4)
Never Married	10.45 (21)	9.57 (9)

Chronic Illness. The majority of the participants have a chronic illness (88.06%), with most having one to three co-morbid illnesses (55.72%). A small portion (7.96%) of the sample reported seven or more co-morbid conditions. Few respondents (23.88% of the most endorsed disease, Hypertension) completed subsequent questions on the length of time since diagnosis and

it's impact on quality of life, therefore these variables were not be used for further analysis. The most frequently selected chronic illnesses were hypertension (57.21%), cholesterol (41.79%), vision problems (42.29 %) and back pain (29.35%) (see Table 11 for additional details).

Table 11. Self-Reported Chronic Illness Prevalence

	%	***n***
Hypertension	57.21	115
Vision problem	42.29	85
Cholesterol, elevated	41.79	84
Back pain	29.35	59
Diabetes	23.38	47
Kidney disease	2.49	5
Stomach problem (e.g., gastritis, peptic disease)	11.44	23
Asthma	11.44	23
Osteoarthritis	11.44	23
Rheumatoid arthritis	9.95	20
Bronchitis, chronic/COPD	10.45	21
Thyroid disorder	9.95	20
Osteoporosis	7.46	15
Colon problem (e.g., diverticulitis, irritable bowel)	5.47	11
Other, specified:	6.97	14
Sickle cell / Sickle cell trait, Pituitary adenoma, Acromegaly, HIV, Sarcoidosis, Fibromyalgia, etc.		
Poor circulation (e.g., l vascular disease)	5.47	11
Stroke	3.98	8
Nerve condition	3.98	8
Angina/coronary artery disease	3.48	7
Congestive heart failure	3.48	7
Other Cancers (within the past 5 yrs)	§	§
Breast Cancer	0.00	0

§Cells with data representing fewer than five respondents is suppressed for data confidentiality.

Healthcare. A sub-set of the sample completed questions on their access and use of healthcare services. Insurance status was obtained for 119-122 respondents, with the majority reporting a source of health care coverage (95.04%). A primary care provider (e.g. personal doctor or healthcare provider) was identified by most of the respondents (94.96%). They also reported frequent engagement, with 90.16% visiting the doctor for a routine checkup within the last 12 months. A small portion of the sample had not had a routine physical in five or more years (3.31%). Despite the large majority reporting frequent engagement, some (14.05%) also indicated that cost prevented seeking care in the past year (12 months).

The majority of respondents did not indicate having major barriers in seeking healthcare caused by their chronic illness. As shown in Table 12, most respondents disagreed that time, insurance coverage, provider time, nor sick leave were an issue related to their chronic illness.

Table 12: Respondent Attitudes about the Impact of Chronic Illness on Healthcare Decisions

Item	*n*	Disagree (Strongly Disagree/Agree)	Neutral	Agree (Strongly Agree/Agree)	Not Applicable
I don't have time to get care for other illnesses because of my chronic illness	183	73.77	2.19	3.28	21.31
I worry about insurance coverage for other care because of my chronic illness	183	69.95	3.83	8.20	19.13
I do not have enough time to talk about my healthcare provider about other illnesses	183	77.60	3.28	4.92	15.30
I do not have time to talk with my healthcare provider about screening tests (like mammograms, pap smears)	183	80.87	3.83	4.92	11.48
I do not have time to go to screening appointments because of my chronic illness	183	79.23	3.28	§	16.39
I spend most of my sick leave away from work on my chronic illness	183	58.85	3.28	2.73	35.52

§Cells with data representing fewer than five participants are suppressed for data confidentiality.

Fatalism. The mean fatalism score was 5.02 (on a scale of 3 to 21, n=136), indicating that the respondents were not fatalistic about breast cancer screening. The majority of respondents had the lowest fatalism score (3, 73.53%) with a small proportion of the sample in the highest ranges (15-21, 7.35%).

Decisional Balance. On the Decisional Balance scale, the subscales represented two polar constructs of perceived "pros" and "cons" related to mammography screening. The means for each subscale were standardized to 50 with a standard deviation equal to 10, per the guidance from the authors (Otero-Sabogal, 2001). The interquartile range for the perceived "pros" subscale was 47.25-57.62, representing an overall range of 16.13-57.62. This shows a skewing of

the data towards higher scores on the scale indicating perceived "positive" attributes of screening mammography. On the "Cons" scale, scores ranged from 41.08 to 87.84 with an interquartile range from 41.08 to 53.83. The distribution indicates some outliers with high negative attitudes about screening mammography that are skewing the data.

The overall scale was calculated as the difference between the "Con" and "Pro" standardized subscales. Overall 46 respondents scored on the lower end of the scale (<0), indicating that the "Cons" or negative attitudes were the predominant beliefs regarding screening mammography. The sample mean for the overall Decisional Balance was -0.059 with a standard deviation of 14.91. The final standardized scale scores ranged from -44.08 to 16.55. The majority (60%) of responses indicated a neutral or positive overall perspective.

Breast Cancer Screening Mammography. Most of the respondents (91.30%) reported receiving a doctor's recommendation for a mammogram. When addressing breast cancer screening mammography frequency knowledge, the majority (83.69%) of the sample indicated timing related to older recommendations ("Every year") with less than 13.48% choosing the currently recommended interval ("Every two years"). The majority of sample (98.68%) had received a mammogram in their lifetime ("Have you ever had a mammogram"). In the past five years, most (83.82%) had at least two mammograms, with 47.79% having five or more. Less than ten percent of the respondents had one (3.68%) or zero (3.68%) mammograms in the past five years. Mammography intention was assessed based on "how likely" respondents were to have a mammogram in the next year, on a scale from 1 (Not at all) to 7 (Very likely). The majority of respondents indicated that they were "very likely" to have a mammogram in the next

year (87.14%). Approximately 6% (5.71%) of the sample did not intend to have a mammogram (1 or 2). Other respondents were "neutral" about their mammography intentions (4 or 5, 6.43%). Social norms or exposure are also related to breast cancer screening mammography attitudes and beliefs. Nearly half of the sample had a family member diagnosed with breast cancer (44.20%). However, the majority of the respondents had friends diagnosed with breast cancer (73.76%). This indicates that the majority of the sample had been exposed to breast cancer by either a family member or friend in their lifetime.

Health Temporal. The average health temporal score was 29.61 with scores ranging from 12 to 45. Fewer participants completed items on this scale, with only 119 respondents. The responses were clustered around 29 to 31 points, representing the interquartile range.

Illness Perspectives. On the Illness Perspectives scale, respondents were on average (M = 0.081, SD = 5.76) in the illness in the foreground or Neutral range. The Illness Perspectives scale clusters were identified to create cut-points for data interpretation. Scores ranging from -14 to -1, align with "Illness in the Background", with scores at the lowest end of the scale (-14 to -6) having the strongest indication of active coping and attention to overall health. From 0 to 3, scores are neutral, indicating that there is nearly equal attention to both chronic illness and wellness. "Illness in the Foreground" is identified by scores ranging from 4 to 26 on the scale. Figure 4 details the proportions of the sample in each of the categories. Overall, the proportions were equally distributed across the sample, with slightly more (46.31%) scoring in the "Illness in the Background" range.

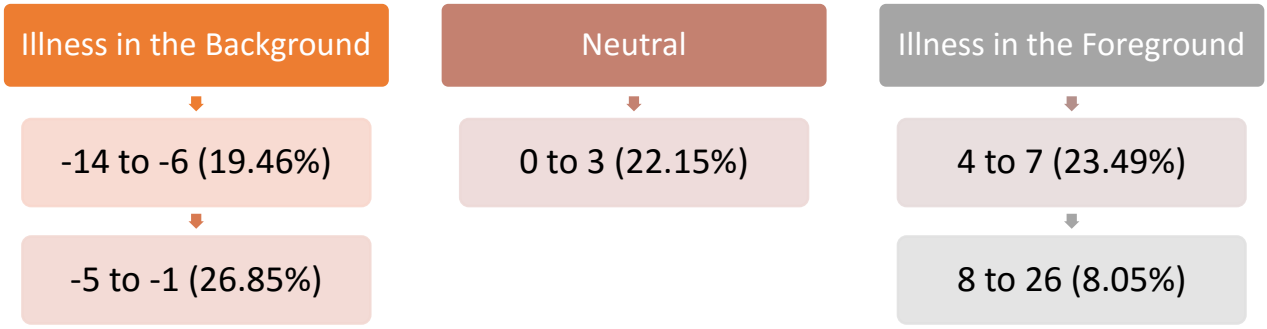

Figure 4. Illness Perspectives Scoring and Respondent Proportions

Each of the subscales were also scored to identify data trends. On average, the respondents scored lower on the "illness in the foreground" subscale (M=13.00, SD=5.56) than the "illness in the background" subscale (M=12.86, SD=4.45). The subscale scores align with the trends of the summary Illness Perspectives score.

Bivariate and Multivariate Analysis

Associations between mammography intention and related variables were evaluated with the appropriate correlational test based on the measurement level (i.e. dichotomous, ordinal, continuous) in the overall sample. Point-biserial correlations showed statistically significant relationships between intention and having a family member who has had breast cancer (r=-.170, p=.047), being uninsured (r=-.350, p=.000), and not seeking care due to cost in the last year (r=.280, p=.002).

Inverse relationships indicating lower mammography intention for individuals with higher fatalism scores (r=-.299, p=.000) and a health temporal orientation (r=-.224, p=.015). Higher scores on the decisional balance scale, indicating a more positive attitude towards

mammography, were associated with greater intention (r=.357, p=.000). Table 13 below details the variable correlations for the general population.

Table 13: Correlation Matrix of the Proposed Model Variables (*n*=201)

	Mammography Intention	Insurance	Some College	Associates Or Bachelors	Graduate or Professional	Decisional Balance	Fatalism Summary Score	Family Breast Cancer Diagnosis	Friend Breast Cancer Diagnosis	Health Temporal Scale	Illness Perspectives Scale	Chronic Illness presence	Access to Care
Mammography Intention	1	.350**	-0.091	0.145	0.106	.357**	-.299**	.170*	-0.133	-.224*	0.067	-0.121	.280**
Insurance	.350**	1	0.058	0.074	0.007	0.135	-.318**	0.019	-.235**	-0.13	0.036	0.018	.455**
Some College	-0.091	0.058	1	-.345**	-.430**	-0.132	0.046	0.096	0.136	0.119	.170*	0.092	-0.124
Associates Or Bachelors	0.145	0.074	-.345**	1	-.418**	0.059	-0.052	-0.001	-0.057	-0.087	-0.035	-0.018	0.123
Graduate or Professional	0.106	0.007	-.430**	-.418**	1	0.161	-.249**	0.018	-.180*	-0.144	-0.111	-0.098	0.098
Decisional Balance	.357**	0.135	-0.132	0.059	0.161	1	-.419**	-0.018	-0.045	-0.042	-0.166	-0.006	0.154
Fatalism Summary Score	-.299**	-.318**	0.046	-0.052	-.249**	-.419**	1	-0.16	.180*	.326**	0.093	0.032	-0.146
Family Breast Cancer Diagnosis	.170*	0.019	0.096	-0.001	0.018	-0.018	-0.16	1	-.329**	-0.069	0.145	-0.062	0.049
Friend Breast Cancer Diagnosis	-0.133	-.235**	0.136	-0.057	-.180*	-0.045	.180*	-.329**	1	0.155	0.059	-0.118	-0.115
Health Temporal Scale	-.224*	-0.13	0.119	-0.087	-0.144	-0.042	.326**	-0.069	0.155	1	-0.106	0.143	0.016
Illness Perspectives Scale	0.067	0.036	.170*	-0.035	-0.111	-0.166	0.093	0.145	0.059	-0.106	1	-0.147	-0.133
Chronic Illness presence	-0.121	0.018	0.092	-0.018	-0.098	-0.006	0.032	-0.062	-0.118	0.143	-0.147	1	-0.017
Access to Care	.280**	.455**	-0.124	0.123	0.098	0.154	-0.146	0.049	-0.115	0.016	-0.133	-0.017	1
Dr's Recommendation	-0.161	-.335**	0.031	0.007	-0.006	-0.097	0.059	-0.015	0.058	-0.058	0.007	-0.043	-0.021

Bivariate analyses were also conducted for the sub-sample of overall population in the regression analysis (n=94). Point-biserial correlations showed statistically significant relationships between intention and being insured (r=.265, p=.005). Lower mammography intention was indicated with an inverse relationship for individuals with higher fatalism scores (r=-.407, p=.000). Higher scores on the decisional balance scale, indicating a more positive attitude towards mammography, were associated with greater intention (r=.414, p=.000). For demographic factors, having an Associate's or Bachelor's degree was statistically significant (r=.227, p=.014) and associated with more intention. The correlation matrix for the regression sub-sample population is included below in Table 14.

Table 14: Correlation Matrix of the Final Linear Regression Model Variables (*n*=94)

	Mammography Intention	Insurance	Some College	Associate's/ Bachelor's Degree	Graduate / Professional Degree	Decisional Balance Summary Score	Fatalism Summary Score	Family Breast Cancer Incidence	Age
Mammography Intention	1.00								
Insurance	.265**	1.00							
Some College	-.114	.035	1.00						
Associate's/ Bachelor's Degree	.227*	.061	-.412**	1.00					
Graduate / Professional Degree	.153	.080	-.453**	-.515**	1.00				
Decisional Balance Summary Score	.414**	.145	-.144	..54	.138	1.00			
Fatalism Summary Score	-.407**	-.400 **	.233*	-.040	-.298**	-.432**	1.00		
Family Breast Cancer Incidence	.156	.032	.207*	-.093	.004	-.006	-.129	1.00	
Age	-.136	.249**	-.105	-.121	.155	.124	-.081	-.164	1.00

* $p<.05$; ** $p<.01$; *** $p<.001$

Multiple regression equations were developed using block entry to show the relationships and the way they may change as variable groups are incorporated into the model. Variables were selected for the final model if the bivariate relationship was statistically significant ($p<.05$). The multiple regression sub-sample was decreased with listwise deletion to 94 respondents. Imputation was not employed because more than 40% of the data across the variables were missing.

The analyses were initially completed to test the hypothesized model, with hierarchical linear modeling block entry to account for individual, health system and mammography-specific factors. Chronic Illness factors were entered in the first block with chronic illness presence (sum of chronic illnesses) and Illness Perspectives Summary Scale score as dependent variables. Health System/Individual factors assessed in the second block were health insurance, cost as a barrier to care (cost), and educational attainment, age. The final block entered for analysis represented breast cancer mammography attitudes and beliefs including family with breast cancer diagnosis, Decisional Balance summary score, and Breast Cancer Fatalism summary score.

Chronic illness presence was inversely related to mammography intention however this relationship was mitigated in subsequent models adding Health System/Individual and Mammography Attitudes/Beliefs. Education is the only Health System/Individual factor that remained statistically significant in the final model. Health System/Individual factors accounted for the greatest variance (36.2%) in mammography intention. The addition of both Health System/Individual and Mammography Attitudes/Beliefs factors improved the regression model

identified with a significant change in R^2, $F(6,65)=8.987$, $p<.001$ and $F(4,61)=4.377$, $p<.01$ respectively (see Table 15 for more details). Overall, the final model accounted for 63.0% of the variance in mammography intention.

Table 15: Mammography Intention Hierarchical Regression Analysis Results (n=74)

	Model 1 Standardized β	Model 2 Standardized β	Model 3 Standardized β
Intercept			
Chronic Illness Factors			
Chronic Illness Presence	-.343**	-.104	-.006
Illness Perspectives Summary score	.060	.012	.048
Health System/Individual Factors			
Insurance		-.173	-.004
Cost		-.030	-.014
Some College		.908***	.922***
Associate's/Bachelor's degree		1.175***	1.077***
Graduate/Professional degree		1.208***	1.116***
Age		-.181	.001
Mammography Attitudes/Beliefs			
Family Breast Cancer Diagnosis			.001
Decisional Balance Summary Score			.122
Fatalism Summary Score			-.249*
Mammography Adherence			.150
Adjusted R^2	.103	.465	.557
F	5.200	8.918	8.640
F for change in R^2	5.200**	8.987***	4.377***

**$p<.01$; ***$p<.001$

The final model was determined by excluding items that were not significant in the initial regression equation blocks, based on entry and bivariate analyses. The most parsimonious model included the following independent variables: age, fatalism, education, Decisional Balance, family incidence of breast cancer, and insurance status. Table 16 shows the statistically

significant factors include education and Decisional Balance. Women with a college (Associate's/Bachelor's degree) or advanced degree (Graduate/Professional degree) had greater mammography intention than women with a High School Diploma/GED, (β=1.055, p=.000) and (β=1.011, p= .000), respectively.

Table 16: Mammography Intention Final Linear Regression Results (*n*=94)

	Standardized β
Uninsured (referent: insurance access)	-.030
Education (referent: High School Diploma/GED)	
Some College	.826***
Associate's / Bachelor's Degree	1.055***
Graduate or Professional Degree	1.011***
Decisional Balance Summary Score	.296**
Fatalism Summary Score	-.120
No Family Breast Cancer Incidence (referent: yes)	-.045
Age	-.125
Intercept	5.155***
Adjusted R^2	0.456
F	10.747***

**p<.01; ***p<.001

CHAPTER 5

DISCUSSION

Overview of Research Aims and Methods

African American women bear a disproportionate burden of breast cancer morbidity and mortality. Despite population-level increases in mammography screening, gaps still exist for African-American women. The primary purpose of this study was to examine mammography intention and the influence of chronic illness, health system and breast cancer-specific attitudes and beliefs. This study also pilot-tested and established psychometric properties for the Illness Perspectives scale, a temporal measure of attitudes about the impact of chronic illness. Qualitative data (i.e. focus group, interviews) showed that the instrument elicited the appropriate attitudes during thinking aloud exercises. Psychometric testing established that the instrument was reliable and valid. Survey data analyses identified that older age, having a more negative attitude towards breast cancer mammography (i.e. Low Decisional Balance summary score), and lower educational attainment were predictors of lower mammography intention. While chronic illness presence was significantly associated with mammography intention, amongst other predictors the relationship weakens.

Research Conclusions

Illness Perspectives Scale

The Illness Perspectives scale is a reliable tool to measure current attitudes about chronic illness and respondent's temporal focus on "Illness in the Foreground" (α=.82) or "Illness in the Background" (α=.78). Previous research on "shifting perspectives" relied on time and resource intensive qualitative inquiry and meta-analyses to define the theoretical constructs and describe the common themes across the literature (Auduluv, et al, 2010; Paterson, et al, 2001). However, no survey instruments were available in the literature to assess an individual's attitudes on the continuum between Illness in the Foreground and Background. The instrument developed provides a brief assessment that could be utilized in the field by public health and clinical professionals to tailor health education and messaging. As noted in Auduluv (2011), the nuance in framing the illness impacts disease self-management and lifestyle decisions. In particular, individuals with a focus on wellness were more attuned to managing illness "to live life as they wished", while those with a focus on the illness were framing self-management in "disease control". Having a brief assessment will help tailor approaches to improve integration of preventive health behaviors into existing disease self-management and healthcare decisions.

The scale provides a temporal evaluation of individual attitudes, however it was not predictive of mammography intention in the current study sample, when adjusting for chronic illness presence, health systems and demographic factors. While the bivariate relationships were significant, the strength of the relationship may be weaker than other factors. In the literature, it is noted that chronic illness perspectives change often and the scale's focus on "today" identifies current attitudes about illness. This may impact the strength of the relationship detected, as the

strongest factors in the model seem to be "state"-based (e.g. insurance, education) or focused on attitudes that may develop over time (e.g. Decisional Balance).

Chronic Illness Burden. The number of chronic illnesses is related to less mammography intention but when accounting for socio-demographics and other screening-related behaviors the relationship diminishes. Therefore, it is not a direct predictor but may influence intention and behavior. In a sample of Korean women aged 40 and older, Park et al (2010) showed that health status was related to intention, specifically an inverse relationship with those with greater disease burden being less intent on seeking mammography. Also Study I found that having economic and social constraints such as not working due to family issues (ie childcare, health or disability) negatively impacted intention compared to those who are retired.

As seen in the literature, co-morbid conditions presence and its association with breast cancer screening can vary across study populations. There has not been any consistent trends. Yasmeen et al (2011) showed that women with more "stable co-morbid" conditions screened more often and were more likely to be diagnosed at an earlier stage. However, women with more "unstable" conditions or a greater number of multi-morbidities were at higher risk for more advanced stage breast cancer. The data presented in the literature (Fleming et al, 2005; Yasmeen et al, 2011) have used clinical data (i.e. SEER database records linked to health records, ICD-9 codes to define breast cancer diagnosis, healthcare engagement) to identify strong positive relationships between chronic illness burden and breast cancer screening mammography. Self-reported data, which were employed for this study, may not offer the same level of specificity or accuracy that clinical data offer which may explain the differing findings.

Decisional Balance. Decisional Balance uses the Transtheoretical Model (TTM) as a model to determine stage of readiness to adopt mammography as a preventive health behavior (Otero-Sabogal, 2007). In Study II, the findings indicate that the scale score is a predictor of mammography intention, with respondents with higher scores being more likely to intend to complete screening mammography. The findings of this study align with the literature and contribute to confirming the relationship between this factor and mammography intention (Otero-Sabogal, 2007). While the relationship was significant, the overall strength of the relationship was small (β=0.296), as compared to other factors included in the model. The multifactorial nature of mammography decision making is further supported by these findings.

Sociodemographics and Social Norms. Education emerged as a prominent factor in mammography intention. Respondents with greater educational attainment were more likely to have higher mammography intention, particularly those with an associate's degree or higher. This was above the contribution that insurance may play in determining access to health systems, which was not statistically significant as other factors were added to the model. Jemal et al (2008) showed that, in general, cancer mortality was higher for the general population amongst those with less education due to "higher prevalence of risk factors such as smoking and obesity and limited access to medical services". These findings support education as an important proxy for identifying women who may have higher needs or risks associated with mammography uptake.

Women who had experienced a breast cancer diagnosis of a family member were more likely to have high mammography intention. This finding supports the literature (Sadler et al

2007) and aligns with positive social norms created by personal experience. These findings could be related to increased knowledge, awareness and perceived risk because of exposure during a family member's diagnosis. All of these factors have been shown to improve mammography uptake and influence adherence over time.

Limitations

Although this study examines the relationship between chronic illness and screening mammography, the temporal nature of the phenomenon and data collection methods preclude the definition of causality. This study does not directly account for structural, environmental and other community and neighborhood-level socioecological factors that can impact health care access and utilization. However, individual level factors are assessed. This study is limited to African American women residing in a metropolitan city; generalizability of results to other populations (i.e. race/ethnicity, gender, rural residents) will be limited. There may be inherent sampling bias due to the convenience sampling methodology and selected partners for recruitment. Self-reported data may also have bias due to being incomplete or not truly reflective of participant beliefs due to social desirability response bias, timing (participants may not have time to fully complete questionnaire) or participant motivation to complete the survey.

Delimitations

Due to the unique characteristics and burden of breast cancer mortality amongst African American women, the study sample was limited to women who self-identify as African American. Women residing in metropolitan Atlanta, Georgia, particularly DeKalb and Fulton

counties, comprise the study sample, therefore the study will only be generalizable for residents of urban and/or suburban areas. The study is limited to women with who self-identify as having no cognitive deficits that could impact survey self-administration.

Research and Practice Implications

Public health and clinical practitioners engage in health education, program interventions, and communications campaigns to change mammography attitudes and behaviors and improve breast cancer morbidity and mortality. The effectiveness of these activities are often influenced by the individual's existing knowledge, attitudes, beliefs, and health system (i.e. access, previous experiences), social contexts (i.e. social norms) and environmental factors (i.e. healthcare providers shortage per capita). Often these activities are tailored to participant demographic characteristics (i.e. race/ethnicity, age), language preferences, and social norms. As shown in this study, practitioners can assess an individual's Illness Perspectives, Education, and Decisional Balance to identify strategies to tailor health education and communication messages. This can include dovetailing disease self-management education with breast cancer mammography reminders, tailoring mammography messages to show how preventive healthcare fits into an overall chronic disease lifestyle improvement strategy, and framing brief patient clinical education interactions around integrated healthcare (i.e. preventive and disease-management strategies).

Conclusion

Chronic Disease burden influences health decisions, as noted by the relationship to mammography intention. However, the strength of that relationship is mitigated by factors more

closely related to mammography-specific attitudes and behaviors. The individual "micro-environment" of social, environmental and health competing demands should be considered when identifying health promotion strategies. Also, the Illness Perspectives instrument is a valid, reliable tool to assess African-American women's attitudes toward chronic illness. While scores on this instrument were not predictors of mammography intention in this sample, the instrument describes attitudes about chronic illness that could be addressed through health education and on efforts.

Future research should expand the sample to test the instrument with a more diverse group. A stronger study could be developed to include both self-report and clinical data with a larger sample to identify relationships in the larger population.

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Appendix A: Informed Consent Form

UNIVERSITY OF GEORGIA
CONSENT FORM
The Relationship between co-morbid conditions, contextual factors, and breast cancer screening mammography amongst older African American women

Researcher's Statement
I am asking you to take part in a research study. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. This form is designed to give you the information about the study so you can decide whether to be in the study or not. Please take the time to read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." A copy of this form will be given to you.

Researchers:
Donoria Evans, MPH, graduate student (Health Promotion & Behavior Department, dwilker@uga.edu, 770-648-7947)
Dr. Su-I Hou, professor (Health Promotion & Behavior Department, shou@uga.edu, 706-542-8206)

Purpose of the Study
The purpose of this study is to learn more about chronic illness and breast cancer screening mammography for African American women.

Study Procedures
If you agree to participate, you will be asked to complete one of two surveys. The first survey is about your perspectives on your illness. This short survey will take about 10 minutes to complete.
The second survey is about your attitudes and beliefs about your health. The survey will take about 20-25 minutes to complete. You may complete the surveys via paper or online.

Ten to twelve people will be invited to participate in one-on-one interviews. If you agree, you will be asked about the survey questions and recommendations to improve the survey. The interview will take no more than 35 minutes. The interview will be taped and notes will be taken so that we do not miss anything shared. Audio recordings will be transcribed without individually identifying information and the recording will be destroyed.

Risks and discomforts
This is an observational study and there is a minimal risk to participate. All information shared will be confidential and will not be identified by individual responses.

Confidentiality
Online surveys are confidential, however internet communications cannot be guaranteed. If you would prefer, you can print the survey to complete it and mail it to 3224 Quincey Crossing, Conyers, GA 30013. The Researchers will store study records and other information about you in a secure location and will grant access only to those with a need to know to lessen risks to your privacy. Identifiable information, such as your email address, will be kept in a password-protected electronic file which will be destroyed at the completion of this study. All survey data will be kept in a separate file with no identifiers assigned to responses (anonymous). The project's research records may be reviewed by departments at the University of Georgia responsible for regulatory and research oversight.

Benefits
There will be no direct benefits for participants. However, we hope to identify ways to improve women's health education for African American women and the community at large.

Incentives for participation
Survey and interview participants will receive health education materials. The general public, including all study participants, will be eligible to enter a monthly drawing for a $25 gift card or its monetary equivalent.

Taking part is voluntary
Participation in this study is voluntary. You may choose not to participate or stop at any time without penalty or loss of benefits to which you are otherwise entitled. You can refuse any interview or survey questions that you do not feel comfortable with or that you do not wish to answer.
If you decide to stop or withdraw from the study, the information/data collected from or about you up to the point of your withdrawal will be kept as part of the study and may continue to be analyzed.
If you have questions
The main researcher conducting this study is Donoria Evans, a graduate student, and Su-I Hou, a professor at the University of Georgia. Please ask any questions you have now. If you have questions later, you may contact Donoria Evans at dwilker@uga.edu, 770-648-7947 or Su-I Hou by email at shou@uga.edu *or* 706-542-8206. If you have any questions or concerns regarding your rights as a research participant in this study, you may contact the Institutional Review Board (IRB) Chairperson at 706.542.3199 or irb@uga.edu.

Research Subject's Consent to Participate in Research:
To voluntarily agree to take part in this study, you must include your name or email address below. Your name or email address indicates that you have read or had read to you this entire consent form, and have had all of your questions answered.

_____	_____	_____
Name of Researcher	Signature	Date
_____	_____	_____
Name of Participant	Signature	Date

Please sign both copies, keep one and return one to the researcher.

Appendix B: Pilot Study Interview Moderator Guide

Pilot-Testing Interview Guide

Moderator Script: I am here because I want to get your opinions and ideas on a survey that we will use with African American women aged 55 and older. With your honest input and opinions we hope to have a survey that will better help us understand what we want to know. There are no right or wrong answers—we want your opinions!

1. This interview will be taped but no one except the people in this room will know how you responded.

2. The information you share will be used to shape the survey going forward. We will not report what you have shared by individual names.

3. You can choose not to participate at any time.

Here is How this Process Will Work:

1. I do not want you to fill out the survey answers. As I read each question out loud and you read along, I want you to circle anything that is **not clear, confusing** or that you would **change**.
    a. If you have any comments, please write them next to each question.

2. Once we go through all of the questions, I will call out the number of each question and ask you to talk about anything that you have marked.

3. After this portion, we will talk about your general opinions about the questions, because this is important to us too.

Moderator Tips:

- *Read questions slowly allowing time for the participants to read and write comments*

- *Systematically remind that them we want to find out what is not clear, confusing or that they would change.*

- *The Moderator/Co-Moderator should be watching for non-verbal communication or reactions after each question and note these (looks of confusion, laughing, etc). These should be noted*

Step 1: "Now let's look at your surveys"

Read through each of the questions slowly asking the participant(s) to keep the following in mind:

- We want to find out what is not clear, confusing or that you would change.
- Let me know if the question was easy to understand?
- underline words/language that people might not understand
- *Probe for starred questions:* Was there an answer choice that you would have chosen?

Step 2: "Now we will begin to discuss each question"

Read each question and ask for comments on each:

- *For each question, ask respondents to* "Please explain what you believe was meant by this question"

Consider the following areas to make your comments about the survey questions:

- We want to find out what is not clear, confusing or that you would change.
- Let us know if the question was easy to understand?
    - Did you have to read the question more than once to understand what it was asking?
- Underline words/language that people might not understand
    - Are there any words/language in the question that people might not understand? Which ones? How do you think we should change?
- *Probe for starred questions:* Was there an answer choice that you would have chosen?
    - If not, which question would need another answer choice? Why?

- Were there any questions that made you wonder why they were there? Which ones? Why?

- Were there any questions that made you uncomfortable or that you felt were too sensitive? Which ones? Why?

- Is there anything you would change about the survey?

<u>Specific Questions:</u>

"Here is where we really need your help…"

- **For the questions about chronic illness, what do you feel comfortable sharing on a survey?**
    - What changes would you recommend?
    - Is there anything that made you uncomfortable or that you did not want to answer?

Step 3:

We have been talking about your opinions, ideas, and feelings about this survey and you have given us helpful information.

- Were there any *types* of questions that need to be changed? *Probe*: The types of questions could be about chronic illness or other things. Tell me more about these types of questions or others.

- How do you think your peers would feel filling this out for the first time? *Probe:* Tell me more about your answer.

- Is there anything else you would like me to take back about the survey that would help to improve it?

Thank you for your participation. We have a token of our appreciation for your time.

Appendix C: Instrument Pilot Testing Survey

We are conducting a survey with African-American women about chronic illness. Thank you for taking the time to complete this survey. We hope to learn more about the breast cancer and chronic illness needs in this community. There is no right or wrong answer so please answer as honestly as possible. The information you give will help us improve education and programs about breast cancer that can benefit you and your community.

The questions below are about you. Please write your answers to the following questions:

What is your age? _____

Are you Hispanic or Latino? ☐Yes ☐No

Which one or more of the following would you say is your race? (Check all that apply)

☐ White
☐ Black or African American
☐ Asian
☐ Native Hawaiian or Other Pacific Islander
☐ American Indian or Alaska Native
☐ Other [specify]_____

Please indicate your **marital status**.

☐ Married
☐ Divorced
☐ Widowed
☐ Separated
☐ Never married
☐ Living together

What is **your highest level of education**?

☐ Less Than High School
☐ High School Diploma
☐ Some College
☐ Graduate/Professional Degree
☐ Some High School
☐ G.E.D
☐ Associate's/Bachelor's Degree

What is **your work status now**? Are you...

☐ Employed full-time
☐ Employed part-time
☐ Employed full-time and studying
☐ Employed part-time and studying
☐ Studying (or training) full-time
☐ Seeking work/unemployed
☐ Other (specify below): _____
☐ Not employed: Caring for a relative
☐ Not employed: Can't afford childcare
☐ Not employed: Looking after children
☐ Not employed: Homemaker
☐ Not employed: Disabled / poor health
☐ Not employed: Retired

What is your **annual family income**?

☐ Under $10,000
☐ $10,001 - $25,000
☐ $25,001 - $40,000
☐ $55,001- $75,000
☐ $75,001 - $100,000
☐ Over $100,000

☐ $40,001 - $55,000 ☐ I prefer not to disclose my income

Please check below if you have ever been diagnosed with a chronic illness.

	Has a doctor, nurse, or other health professional **EVER told you** that you had any of the following?		How **long ago** were you diagnosed? (years)	If so, has it **interfered with your daily activities**?				
	Yes	**No**		**Not at all (1)**	**Slightly (2)**	**Moderately (3)**	**Very Much (4)**	**A Lot (5)**
Angina/coronary artery disease	☐	☐		☐	☐	☐	☐	☐
Asthma	☐	☐		☐	☐	☐	☐	☐
Back pain	☐	☐		☐	☐	☐	☐	☐
Bronchitis, chronic/COPD	☐	☐		☐	☐	☐	☐	☐
Breast Cancer	☐	☐		☐	☐	☐	☐	☐
Other Cancers (within the past 5 yrs)	☐	☐		☐	☐	☐	☐	☐
Cholesterol, elevated	☐	☐		☐	☐	☐	☐	☐
Colon problem (e.g., diverticulitis, irritable bowel)	☐	☐		☐	☐	☐	☐	☐
Congestive heart failure	☐	☐		☐	☐	☐	☐	☐
Diabetes	☐	☐		☐	☐	☐	☐	☐
Hypertension	☐	☐		☐	☐	☐	☐	☐
Kidney disease	☐	☐		☐	☐	☐	☐	☐
Nerve condition	☐	☐		☐	☐	☐	☐	☐
Osteoarthritis	☐	☐		☐	☐	☐	☐	☐
Osteoporosis	☐	☐		☐	☐	☐	☐	☐
Poor circulation (e.g., peripheral vascular disease)	☐	☐		☐	☐	☐	☐	☐
Rheumatoid arthritis	☐	☐		☐	☐	☐	☐	☐
Stomach problem (e.g., gastritis, peptic disease)	☐	☐		☐	☐	☐	☐	☐
Stroke	☐	☐		☐	☐	☐	☐	☐
Thyroid disorder	☐	☐		☐	☐	☐	☐	☐
Vision problem	☐	☐		☐	☐	☐	☐	☐
Other, please specify: _____	☐	☐		☐	☐	☐	☐	☐

Please check your answers to the following questions:

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a.	I don't have time to get care for other illnesses because of my chronic illness.	☐	☐	☐	☐	☐
b.	I worry about insurance coverage for other care because of my chronic illness.	☐	☐	☐	☐	☐
c.	I do not have enough time to talk with my healthcare provider about other illnesses.	☐	☐	☐	☐	☐
d.	I do not have enough time to talk with my healthcare provider about screening tests (like mammograms, pap smears).	☐	☐	☐	☐	☐
e.	I do not have time to go to screening appointments because of my chronic illness.	☐	☐	☐	☐	☐
f.	I spend most of my allotted sick time away from work on my chronic illness.	☐	☐	☐	☐	☐

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a.	I am most concerned with managing my chronic illness symptoms today.	☐	☐	☐	☐	☐
b.	I have accepted that my chronic illness is a part of my life.	☐	☐	☐	☐	☐
c.	I don't think I need the support aids or devices that my healthcare provider recommends for my chronic illness.	☐	☐	☐	☐	☐
d.	I find myself focusing on my limitations from my chronic illness.	☐	☐	☐	☐	☐
e.	I feel that my relationships with people have not changed since I was diagnosed with a chronic illness.	☐	☐	☐	☐	☐
f.	It is easy to adjust my life for my chronic illness.	☐	☐	☐	☐	☐
g.	I feel that others judge me because of my chronic illness.	☐	☐	☐	☐	☐
h.	I worry about my future because I have a chronic illness.	☐	☐	☐	☐	☐
i.	I have had to make significant life changes in the past 3 months because of my chronic illness.	☐	☐	☐	☐	☐
j.	I don't pay as much attention to my illness now.	☐	☐	☐	☐	☐
k.	I seek help or resources to deal with my disease symptoms if they worsen.	☐	☐	☐	☐	☐

Appendix D: Final Survey

We are conducting a survey with African-American women about chronic illness. Thank you for taking the time to complete this survey. We hope to learn more about the breast cancer and chronic illness needs in this community. There is no right or wrong answer so please answer as honestly as possible. The information you give will help us improve education and programs about breast cancer that can benefit you and your community.

The questions below are about you. Please write your answers to the following questions:

What is your age? _____

Are you Hispanic or Latino? ☐Yes ☐No

Which one or more of the following would you say is your race? (Check all that apply)

☐ White
☐ Black or African American
☐ Asian
☐ Native Hawaiian or Other Pacific Islander
☐ American Indian or Alaska Native
☐ Other [specify]_____

Please indicate your **marital status**.

☐ Married
☐ Divorced
☐ Widowed
☐ Separated
☐ Never married
☐ Living together

What is **your highest level of education**?

☐ Less Than High School
☐ High School Diploma
☐ Some College
☐ Graduate/Professional Degree
☐ Some High School
☐ G.E.D
☐ Associate's/Bachelor's Degree

What is **your work status now**? Are you...

☐ Employed full-time
☐ Employed part-time
☐ Employed full-time and studying
☐ Employed part-time and studying
☐ Studying (or training) full-time
☐ Seeking work/unemployed
☐ Other (specify below): _____
☐ Not employed: Caring for a relative
☐ Not employed: Can't afford childcare
☐ Not employed: Looking after children
☐ Not employed: Homemaker
☐ Not employed: Disabled / poor health
☐ Not employed: Retired

What is your **annual family income**?

☐ Under $10,000
☐ $10,001 - $25,000
☐ $25,001 - $40,000
☐ $40,001 - $55,000
☐ $55,001- $75,000
☐ $75,001 - $100,000
☐ Over $100,000
☐ I prefer not to disclose my income

Please check below if you have ever been diagnosed with a chronic illness.

	Has a doctor, nurse, or other health professional **EVER told you** that you had any of the following?		How **long ago** were you diagnosed? (years)	If so, has it **interfered with your daily activities**?				
	Yes	**No**		**Not at all (1)**	**Slightly (2)**	**Moderately (3)**	**Very Much (4)**	**A Lot (5)**
Angina/coronary artery disease	☐	☐		☐	☐	☐	☐	☐
Asthma	☐	☐		☐	☐	☐	☐	☐
Back pain	☐	☐		☐	☐	☐	☐	☐
Bronchitis, chronic/COPD	☐	☐		☐	☐	☐	☐	☐
Breast Cancer	☐	☐		☐	☐	☐	☐	☐
Other Cancers (within the past 5 yrs)	☐	☐		☐	☐	☐	☐	☐
Cholesterol, elevated	☐	☐		☐	☐	☐	☐	☐
Colon problem (e.g., diverticulitis, irritable bowel)	☐	☐		☐	☐	☐	☐	☐
Congestive heart failure	☐	☐		☐	☐	☐	☐	☐
Diabetes	☐	☐		☐	☐	☐	☐	☐
Hypertension	☐	☐		☐	☐	☐	☐	☐
Kidney disease	☐	☐		☐	☐	☐	☐	☐
Nerve condition	☐	☐		☐	☐	☐	☐	☐
Osteoarthritis	☐	☐		☐	☐	☐	☐	☐
Osteoporosis	☐	☐		☐	☐	☐	☐	☐
Poor circulation (e.g., peripheral vascular disease)	☐	☐		☐	☐	☐	☐	☐
Rheumatoid arthritis	☐	☐		☐	☐	☐	☐	☐
Stomach problem (e.g., gastritis, peptic disease)	☐	☐		☐	☐	☐	☐	☐
Stroke	☐	☐		☐	☐	☐	☐	☐
Thyroid disorder	☐	☐		☐	☐	☐	☐	☐
Vision problem	☐	☐		☐	☐	☐	☐	☐
Other, please specify: _____	☐	☐		☐	☐	☐	☐	☐

Please check your answers to the following questions:

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	N/A
g.	I don't have time to get care for other illnesses because of my chronic illness.	☐	☐	☐	☐	☐	☐
h.	I worry about insurance coverage for other care because of my chronic illness.	☐	☐	☐	☐	☐	☐
i.	I do not have enough time to talk with my healthcare provider about other illnesses.	☐	☐	☐	☐	☐	☐
j.	I do not have enough time to talk with my healthcare provider about screening tests (like mammograms, pap smears).	☐	☐	☐	☐	☐	☐
k.	I do not have time to go to screening appointments because of my chronic illness.	☐	☐	☐	☐	☐	☐
l.	I spend most of my sick leave away from work on my chronic illness.	☐	☐	☐	☐	☐	☐

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
l.	I am most concerned with managing my chronic illness symptoms today.	☐	☐	☐	☐	☐
m.	I have accepted that my chronic illness is a part of my life.	☐	☐	☐	☐	☐
n.	I don't think I need the support aids or devices that my healthcare provider recommends for my chronic illness.	☐	☐	☐	☐	☐
o.	I find myself focusing on my limitations from my chronic illness.	☐	☐	☐	☐	☐
p.	I feel that my relationships with people have not changed since I was diagnosed with a chronic illness.	☐	☐	☐	☐	☐
q.	It is easy to adjust my life for my chronic illness when I need to.	☐	☐	☐	☐	☐
r.	I feel that others judge me because of my chronic illness.	☐	☐	☐	☐	☐
s.	I worry about my future because I have a chronic illness.	☐	☐	☐	☐	☐
t.	I have had to make significant life changes in the past 3 months because of my chronic illness.	☐	☐	☐	☐	☐
u.	I don't pay as much attention to my illness now.	☐	☐	☐	☐	☐
v.	I seek help or resources to deal with my disease symptoms if they worsen.	☐	☐	☐	☐	☐

The next section is about breast cancer screening. Please check your answers to the following questions:

A **mammogram** is an x-ray of each breast to look for breast cancer. **Have you ever had a mammogram**?

☐ Yes ☐ No

In the past 5 years (since January 2010), **how many mammograms** have you had? _____

In the next year, **how likely are you to have a mammogram**?

1	2	3	4	5	6	7
Not at All			Neutral			Very Likely
☐	☐	☐	☐	☐	☐	☐

How **often should** you have a mammogram? (choose one answer)

☐ Never
☐ Every year
☐ Every two years
☐ Every five years
☐ Do not know

Has your **doctor recommended** that you get a mammogram? ☐ Yes ☐ No

Have any of your **friends** ever had breast cancer? ☐ Yes ☐ No

Has anyone in your **family** ever had breast cancer? ☐ Yes ☐ No

Please check your answers to the following statements:

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
a. You are too busy to have a mammogram	☐	☐	☐	☐
b. You will only get a mammogram if you have a breast problem	☐	☐	☐	☐
c. You are concerned that mammogram x-rays may be risky or dangerous	☐	☐	☐	☐
d. Mammograms cost too much for you	☐	☐	☐	☐
e. You do not like to have mammograms	☐	☐	☐	☐
f. You just never thought of getting a mammogram	☐	☐	☐	☐
g. Someone you know had a bad experience getting a mammogram	☐	☐	☐	☐
h. You do not want a mammogram because you are afraid to find out if you have cancer	☐	☐	☐	☐
i. You worry that you would not be able to pay for treatment if you got breast cancer	☐	☐	☐	☐
j. You would have a mammogram if your doctor told you that it is important	☐	☐	☐	☐
k. Having a mammogram every year will give you a feeling of control over your health	☐	☐	☐	☐
l. It will be good for your family if you have a mammogram	☐	☐	☐	☐
m. Yearly mammograms give you peace of mind	☐	☐	☐	☐
n. A woman should get a mammogram even if no one in her family has had breast cancer	☐	☐	☐	☐
o. Having a mammogram every 1 to 2 years decreases a woman's chance of dying from breast cancer	☐	☐	☐	☐

Please check your answers to the following statements:

	1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
a. It is not important to screen regularly because everyone will eventually die of something anyway.	☐	☐	☐	☐	☐	☐	☐
b. It is not necessary to screen for breast cancer regularly because it is in God's hands anyway.	☐	☐	☐	☐	☐	☐	☐
c. If nothing is physically wrong, then you do not need to screen.	☐	☐	☐	☐	☐	☐	☐

Do you have any kind of **health care coverage**, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare or Indian Health Services?

☐ Yes ☐ No

Do you have one person you think of as your **personal doctor** or **health care provider**?

☐ Yes, only one ☐ More than one ☐ No

Was there a time in the past 12 months when you needed to see a doctor but **could not because of cost**?

☐ Yes ☐ No

About how long has it been **since you last visited a doctor** for a routine checkup? A routine checkup is a general physical exam, not an exam for a specific injury, illness, or condition.

☐ Within past year (anytime less than 12 months ago) ☐ 5 or more years ago
☐ Within past 2 years (1 year but less than 2 years ago) ☐ Don‘t know / Not sure
☐ Within past 5 years (2 years but less than 5 years ago) ☐ Never

Please check your answers to the following statements:

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a.	Being healthy is important to my future.	☐	☐	☐	☐	☐
b.	It makes sense to take care of my health now so I can be healthy in the future.	☐	☐	☐	☐	☐
c.	It is important for me to take steps to prevent illness.	☐	☐	☐	☐	☐
d.	I only need to see my healthcare provider when I am sick.	☐	☐	☐	☐	☐
e.	Planning for regular health screenings is not important.	☐	☐	☐	☐	☐
f.	If I felt a lump in my breast, I would not worry about it.	☐	☐	☐	☐	☐
g.	As long as I am feeling good now, it is not important for me to have regular health screenings.	☐	☐	☐	☐	☐
h.	Finding health problems early is important to me.	☐	☐	☐	☐	☐
i.	It is important for me to plan to have a yearly mammogram.	☐	☐	☐	☐	☐

Thank you for your time. Please return your completed survey.

If you have any questions, please contact:

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Appendix E: Illness Perspectives Scale Psychometric Testing: Detailed Reliability Analysis Results

Table 1: Reliability Item Analysis: Illness in the Foreground Subscale (α=.83)

Item	α	Standardized α	Reliability if Item were dropped:
I am most concerned with managing my chronic illness symptoms today.	0.8306	0.8303	0.5043
I don't think I need the support aids or devices that my healthcare provider recommends for my chronic illness.	0.8297	0.8364	0.4677
I find myself focusing on my limitations from my chronic illness.	0.7811	0.7854	0.7253
I feel that others judge me because of my chronic illness.	0.7952	0.7992	0.6521
I worry about my future because I have a chronic illness.	0.7867	0.7932	0.6872
I have had to make significant life changes in the past 3 months because of my chronic illness.	0.8004	0.8075	0.6221

Table 2: Reliability Item Analysis: Illness in the Background Subscale (α=.78)

Item	α	Standardized α	Reliability if Item were dropped:
I have accepted that my chronic illness is a part of my life.	0.7654	0.7647	0.5250
I feel that my relationships with people have not changed since I was diagnosed with a chronic illness.	0.7273	0.7273	0.6008
It is easy to adjust my life for my chronic illness.	0.6844	0.6850	0.6813
I seek help or resources to deal with my disease symptoms if they worsen.	0.7469	0.7466	0.5617

Table 3: Correlation Matrix: Illness in the Foreground Subscale

	Q1	Q2	Q3	Q4	Q5	Q6
Q1. I am most concerned with managing my chronic illness symptoms today.	1	0.2988	0.4874	0.3395	0.4034	0.4159
Q2. I don't think I need the support aids or devices that my healthcare provider recommends for my chronic illness.	0.2988	1	0.4563	0.4543	0.3272	0.2978
Q3. I find myself focusing on my limitations from my chronic illness.	0.4874	0.4563	1	0.6083	0.5725	0.5401
Q4. I feel that others judge me because of my chronic illness.	0.3395	0.4543	0.6083	1	0.6146	0.4423
Q5. I worry about my future because I have a chronic illness.	0.4034	0.3272	0.5725	0.6146	1	0.6323
Q6. I have had to make significant life changes in the past 3 months because of my chronic illness.	0.4159	0.2978	0.5401	0.4423	0.6323	1

Table 4. Correlation Matrix: Illness in the Background Subscale

	I have accepted that my chronic illness is a part of my life.	I feel that my relationships with people have not changed since I was diagnosed with a chronic illness.	It is easy to adjust my life for my chronic illness.	I seek help or resources to deal with my disease symptoms if they worsen.
I have accepted that my chronic illness is a part of my life.	1	0.3908	0.4796	0.4291
I feel that my relationships with people have not changed since I was diagnosed with a chronic illness.	0.3908	1	0.6161	0.4407
It is easy to adjust my life for my chronic illness.	0.4796	0.6161	1	0.5031
I seek help or resources to deal with my disease symptoms if they worsen.	0.4291	0.4407	0.5031	1

Table 5: Correlation Matrix: Illness Perspectives Scale

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**11**
1	1.00	0.48	0.30	0.49	0.26	0.34	0.34	0.40	0.42	0.36
2	0.48	1.00	0.42	0.29	0.39	0.48	0.37	0.49	0.32	0.43
3	0.30	0.42	1.00	0.46	0.36	0.35	0.45	0.33	0.30	0.20
4	0.49	0.29	0.46	1.00	0.06	0.01	0.61	0.57	0.54	0.11
5	0.26	0.39	0.36	0.06	1.00	0.62	0.05	0.05	0.06	0.44
6	0.34	0.48	0.35	0.01	0.62	1.00	0.03	0.03	0.00	0.50
7	0.34	0.37	0.45	0.61	0.05	0.03	1.00	0.61	0.44	0.15
8	0.40	0.49	0.33	0.57	0.05	0.03	0.61	1.00	0.63	0.17
9	0.42	0.32	0.30	0.54	0.06	0.00	0.44	0.63	1.00	0.17
11	0.36	0.43	0.20	0.11	0.44	0.50	0.15	0.17	0.17	1.00