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Predicting Breast Cancer Screening Among African American Lesbians and Bisexual Women

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2011

Abstract

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by

Cheryl B. Fields

MPH, George Washington University 1996

BA, Marquette University, 1985

Dissertation Submitted in Partial Fulfillment

of the Requirement for the Degree of

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Abstract

In 2009, 713,220 new cases of cancer were diagnosed for women in the United States with more than a quarter million deaths. African American women and lesbians exhibit behavioral risk factors as well as diminished access to and utilization of breast cancer screening that reduces opportunities for early detection. This secondary analysis of a national convenience-based study examined screening compliance among 647 African American lesbian and bisexual women. Barriers to accessing screening represented the theoretical framework for this study. Bivariate chi square analysis was used to assess the association between independent variables: sociodemographic characteristics; participation in wellness activities; sexual orientation/gender identity; and experience with health care providers and the three dependent breast cancer screening compliance variables: breast self-examination (BSE), clinical breast examination (CBE), and mammography screening. Statistically significant associations between dependent and independent variables at the .05 level were further analyzed with logistic regression. Results of the ten regression models found that BSE was predicted by socioeconomic characteristics and participation in wellness activities. Compliance with CBE guidelines was predicted by sociodemographic characteristics, wellness activities, sexual orientation/gender identity and provider experience. Sociodemographic variables and provider experience also predicted mammography screening. Overall compliance was predicted by sociodemographic characteristics, namely insurance status. The social change implications of this research are an improved understanding of African American lesbian and bisexual women's screening behavior and guidance toward interventions that can improve and breast cancer screening compliance with guidelines.

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Dedication

I would like to dedicate this work to my mother Marie Fields who passed away while I was completing my doctorate and this dissertation. I had hoped that she would live long enough to see me graduate but I know that she was proud of me. There are so many people in my life who were supportive, understanding and encouraging to me during this process. I couldn't have done this without my wife Denise Pearson-Fields, and my dad Bernard. Without their love I could never have believed that I could do this, and I certainly never could have finished.

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Chapter 1: Introduction to the Study

Introduction and Overview

It is estimated that 658,800 new cases of cancer will be diagnosed in women in the United States in 2009 with more than a quarter million deaths (Jemal et al., 2009). Breast cancer is the most common cancer and the second leading cause of death among African American women (American Cancer Society, 2009). Surveillance, Epidemiology End Results (SEER) data published in 2003, the same year this study was completed, reveals that African American women had a higher breast cancer mortality rate (35.9/100,000) than any other ethnic group (Weir et al., 2003). In fact, 8.7/100,000 more African American women died due to breast cancer than European American women, whose mortality rate is 27.2/100,000 from breast cancer (Jemal et al., 2003; Bernstein, Mutschler, & Bernstein, 2002). The 5-year survival rate for African American women is lower than that of European American women (70% versus 86%). Mammography screening has been shown to be the most effective tool in identifying breast cancer early when it is most treatable (American Cancer Society, 2009).

Rates of mammography utilization are similar among European American and African American women (70% and 67% respectively) (Jemal et al., 2003; Bernstein, Mutschler, & Bernstein, 2002). However, breast cancer incidence is higher among European American women (123.5.8/100,000) than African American women (113.7/100,000) (American Cancer Society, 2009). Data from the past decade have shown that African American women are more likely to be diagnosed at later stages of disease, often after the cancer has metastasized to other parts of the body, and are

diagnosed with larger tumors than other women (American Cancer Society, 2009). Further only 30% to 50% of abnormal mammograms among minority women receive appropriate follow-up and treatment.

Explanations for the racial disparities in incidence, mortality and survival rates are complex. Differences in tumor biology have been implicated in explaining poor outcomes for African American women (Bauer, Brown, Cress, Parise, & Caggiano, 2007). Issues of education, housing, and poverty contribute to cancer disparities among African Americans (American Cancer Society, 2009). Access to health insurance also has a direct impact on breast and cervical cancer screening (Qureshi, Thacker, Litaker, & Kippes, 2000). A 1989 study showed that 20% of African American women were uninsured compared with 13% of European American women. These social determinants of health are not solely limited to race but cross numerous cultural characteristics including sexual orientation.

Relative to breast cancer data on heterosexual women, data on lesbians and breast cancer is limited. For example, breast cancer rates for lesbians are unavailable because questions on sexual orientation are absent from cancer registries. However, available research indicates that lesbians may be at increased risk for developing cancer compared with heterosexual women (Bradford, Ryan, & Rothblum, 1994; Solarz, 1999). These differences may be related to higher prevalence of behavioral risk factors such as smoking, alcohol consumption, nulliparity, obesity, and decreased frequency of breast cancer screening being more common among lesbians (Valanis et al., 2000; Denenberg 1995; Cochran et al., 2001). In a seminal address, Dr. Suzanne Haynes reported that based on these behavioral risk factors, lesbians may have twice the cancer risk of

heterosexual women (Haynes, 1995). Greene (1994) described a "triple jeopardy" (p.109) for African American lesbians based on their status as members of gender, racial, and sexual minority groups (Greene, 1994). African American lesbians may have increased risk of cancer based on behavioral risk factors; lesbians, in general, face challenges limiting their access to preventive cancer screening caused by low levels of health insurance and homophobia in the healthcare system (Gruskin, 1999). However, little research has documented the effect of this intersection of screening behaviors and cancer outcomes for African American lesbians.

The 2002-2003 Black Women 2 Women Spirit Health Study (Spirit Study), known herein as the original study to distinguish it from the current effort, was a comprehensive, descriptive national study of African American lesbians and bisexual women. This self-administered, cross-sectional survey examined African American lesbians' breast cancer risk factors, screening behaviors, and barriers to healthcare access. In addition the original study examined the impact of age, gender identity, and "outness", social support and family cancer history on screening behavior. The researcher conducted a secondary analysis of the data collected in the Spirit Study. The analysis focused on the impact of (a) demographic factors such as insurance, age, education, income level, (b) participation in wellness behaviors including tobacco use, body mass index (BMI), consumption of fruits and vegetables, physical activity, (c) and cultural factors such as sexual orientation, gender identity, *outness* with primary health care provider on breast cancer screening. Permission to utilize this dataset was granted by the Mautner Project, the national lesbian health organization's executive director. The Principle Investigator for the original study is also the researcher in this effort.

Background of the Problem

Although the medical community disagrees on the timing and efficacy of the breast cancer screening techniques, most women are aware that they should be participating in some type of breast cancer screening. However, research from the National Health Interview Survey reported in Healthy People 2010 showed that only 67% of women age 40 years and older in 1998 have had a mammogram within the preceding 2 years. This statistic is short of the 70% goal stated in Healthy People 2010 (U.S. Department of Health and Human Services, 2000). Not surprisingly, variations in screening mammography rates exist for women of color, poor women (50%), and women with less than a high school degree (50%). American Indian/Alaskan Native women have the lowest mammography screening rates of all women of color (45%). Other screening rates show that 66% of African American women and 61% of Latina and Asian/Pacific Islander women have had a mammogram in the past 2 years. These variations have given rise to a body of literature aimed at uncovering the predictors of screening utilization among minority populations. Much of this work has focused on the promoters of and barriers that limit access to health care.

The Institute of Medicine (IOM) defines access to healthcare as "the timely use of personal health services to achieve the best possible health outcomes" (Millman, 1993, p. 4). In its broadest sense, health services can be taken to mean both prevention and treatment for disease and illness. The availability of efficacious screening methodologies aimed at early detection, timely utilization of screening, and availability of quality treatment are all essential elements of a public health system. However, the factors that

diminish access to screening are myriad and greatly impacted by issues of culture, insurance, language, geography, and other factors.

Mammography, clinical breast examination (CBE), and breast self-examinations (BSE) have all been shown, to various degrees, as efficacious screening modalities to identify cancerous tumors in asymptomatic women (Smith et al., 2003). Availability of these screenings is enhanced through private and public health facilities and financing as well as public and private health insurance. Advocates and public health officials have made strides over the past several decades to make screening services and treatment more available through publicly funded programs such as the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and the Community Health Centers (Centers for Disease Control and Prevention, 2004).

Access to these services by lesbians and bisexual women is hampered by actual and perceived heterosexism and homophobia. In 1981, the American Medical Association (AMA) first recognized that physicians who harbor anti-homosexual attitudes may pose a threat to the care of gays and lesbians. In a resolution passed by the Council on Scientific Affairs, the AMA postulated that although a nonjudgmental attitude regarding homosexuality may be difficult for certain physicians to achieve, sick individuals deserved the best care possible (Schneider & Levin, 1999). In 1996, the AMA went further cited the "failure of the physician to recognize homosexuality or the patient's reluctance to report his or her sexual orientation and behavior can lead to failure to screen, diagnose, or treat important medical problems" (American Medical Association, 1996, p. 1357). Despite this position, only 50.6% of medical schools

addressed LGBT healthcare issues and those that did spent only 2.5 hours on the topic (Harrison, 1996). As lesbians become more visible within society so does their experiences of reflexive homophobia and heterosexism in response to this visibility (O'Hanlan, 1995). The lack of physician's awareness of the needs of lesbian patients as well as their personal belief systems contribute to a sense of exclusion from services felt by many lesbians.

In recognition of the barriers associated with homophobia and heterosexism in the health care system, the Centers for Disease Control and Prevention (CDC) added lesbians to its classification of priority populations of underserved women in 2000 and mandated specific outreach efforts be enacted for this population. In making this designation the CDC recognized the differential risk factors that impact lesbian's access to cancer screening. To overcome these barriers the CDC contracted with the Mautner Project, the National Lesbian Health Organization (formerly known as the Mary Helen Mautner Project for Lesbians with Cancer), to develop a training program in lesbian cultural competency for NBCCEDP health care providers. The goal of these training sessions is to increase capacity for lesbian cultural competence training at the state level within the NBCCEDP system thereby removing barriers that decrease screening among lesbians.

Statement of the Problem

In December of 2000, the United States Department of Health and Human Services (USDHHS) unveiled their health action plan for the next decade, Healthy People 2010 (HP2010) (US DHSS, 2000). For the first time, HP2010 identified sexual orientation as a marker of health disparities. This decision was undoubtedly built on

mounting research demonstrating homophobia in the health care system as well as the differential health risks exhibited by women who partner with women (WPW). As further exploration of health objectives specific to the lesbian, gay, bisexual, and transgender (LGBT) community, the Gay and Lesbian Medical Association (GLMA), in association with members of the gay and lesbian health advocacy community, developed the LGBT Healthy People Companion (Gay and Lesbian Medical Association, 2001). This document specifically addressed cancer among lesbians as a priority area in need of attention. The IOM also addressed the risk factors, behaviors, and unique needs of lesbians and WPW. The recently published IOM report on lesbian health comprehensively documented the barriers and health disparities that keep lesbians from receiving proper breast health education, screening, and treatment (Solarz, 1999).

In some cases, lesbians or WPW show increased behavioral risks for common health problems. In a sample of 96,000 women, lesbians and bisexuals were significantly more likely than heterosexuals to engage in the following health behaviors: heavy drinking, current or previous smoking, obesity, nulliparity, and eating fewer fruits and vegetables daily (Valanis et al., 2000; Bradford et al., 1994; Solarz, 1999). A study of lesbians of color found higher rates of obesity, tobacco, alcohol use, and lower utilization of health screenings among African American lesbians (Mays, Yancey, Cochran, Weber, & Fielding, 2002). Additionally, researchers have found that some lesbians delay seeking preventive health screenings for breast and cervical cancer (Diamant, Wold, Spritzer, & Gelberg, 2000; Aaron et al., 2001) due to heterosexism in the healthcare system (White & Dull, 1997; Roberts & Sorenson, 1995; Stephens, 1995), and lack of health care insurance (Valanis et al., 2000; Cochran et al., 2001). Numerous studies have shown low

rates of Pap smears, mammography, and BSE among lesbians (Burnett, Steakley, Slack, Roth, & Lerman, 1999; Cochran et al., 2001). Some evidence shows that lesbians are often discouraged from seeking a Pap smear by health care providers who incorrectly perceive them to be at low risk for HPV (O'Hanlan, Dibble, Hagan, & Davids, 2004). The combination of delaying or avoiding healthcare and possibly having higher risks for cancer can have disastrous personal consequences for lesbians.

Lesbian identity is not a monolith. Gender identity in the lesbian community, encompassing butch, femme, and androgynous, has been acknowledged as a genuine expression of one's authentic self (Levitt & Hiestand, 2005; Singh, Vidaurri, Zambarano, & Dabbs, 1999). Accepted definition of butch is a woman with a masculine gender identity, femme refers to one with a feminine identity; and androgynous refers to women who express equally both female and male gender identities (Singh et al., 1999). However, few studies have examined health behavior and barriers to care through the prism of gender identity. In one such study, Hiestand, Horne & Levitt (2007) found butch lesbians are more likely than femmes to be out to their providers and receive poorer treatment. A further understanding of the role of gender identity among lesbians, an already stigmatized group experiencing discrimination on the basis of sexual orientation alone, may uncover additional barriers to accessing cancer screening.

Although numerous studies have shown increased cancer risk factors and decreased access to care for both African American women and lesbians, few have addressed the health behaviors of African American lesbians. Most of the lesbian health studies conducted during the past two decades have collected data primarily on European American, urban women (Greene, 2000). Little to no data has been collected to describe

the behaviors of African American lesbians. Conversely, much is known about screening behaviors of African American women. Whether what is known about African American women and European American lesbians holds true for African American lesbians is unclear. Understanding the intersection of race, sexual orientation, and gender identity may have a profound impact on our knowledge of health behavior. This study examined a number of factors and their relationship to breast cancer screening utilization among African American lesbians and bisexual women as a way to better predict behavior and improve care for a vulnerable group of women.

Purpose of the Study

The researcher conducted a secondary analysis of data collected through the Spirit Study funded by the Susan G. Komen Breast Cancer Foundation. The original study assessed the impact of sociocultural domains previously identified in the literature as having a bearing on screening; including: (a) personal health history, (b) family health history, (c) age, (d) insurance status, (e) access to a primary health care provider, (f) risk factors, (g) social support and, (h) the impact of gender identity, delineated by butch, femme, and androgynous on screening behaviors. The purpose of this analysis was to examine the impact of age, gender identity, insurance status, and healthy lifestyle behaviors on breast cancer screening for African American lesbians and WPW.

Nature of the Study

While the gold standard in lesbian health research has advanced to population-based samples at the time of the original study, no other studies existed on breast cancer and African American lesbians. Therefore, an exploratory, non-probability sample represented the appropriate first step in describing behaviors among this population,

developing theories and hypothesis before further analytic studies can be undertaken. For this reason, it was critically important to distribute the survey as widely as possible. The investigator utilized organizational contacts, mailing lists and direct recruitment at gay and lesbian events and the internet to recruit study participants. The questionnaire focused on examining adherence to breast cancer screening, risk factors, and barriers to accessing healthcare. The project team used validated scales from existing questionnaires whenever possible. Pretesting was conducted locally, prior to fielding the instrument.

Hypotheses

The hypotheses tested in this analysis were:

- H1: Differences exist in adherence to breast cancer screening guidelines, which can be predicted by sociodemographic factors (age, education level, and insurance status), among African American lesbians and bisexual women.

- H2: Differential breast cancer screening utilization can be predicted based on participation in healthy lifestyle behaviors such as maintaining a normal weight, engaging in physical activity, refraining from smoking, moderate to no alcohol consumption, and regular access to a healthcare provider.

- H3: Gender (butch, femme, androgynous) identification among lesbians will predict on adherence to breast cancer screening guidelines among African American lesbians and bisexual women.

- H4: Experiences with primary health care providers (PHCP) including having a PHCP, being out to one's provider, previous negative

experiences (i.e., having been treated badly or discriminated against by a PHCP), anticipated negative experiences (i.e., afraid or worried about being treated badly or discriminated against by PHCP) can predict adherence to breast cancer screening guidelines among African American lesbian and bisexual women.

Theoretical/Conceptual Support for the Study

The overarching theme of this investigation is the acknowledgement that culture influences health behaviors and outcomes on multiple levels (Russell, Swenson, Skelton, & Shedd-Steele, 2003). It also recognizes that understanding the cultural milieu that African American lesbians inhabit will enhance our ability to address low levels of breast cancer screening (Safford, 2002). The conceptual support for the current study comes from the work completed by the IOM on the issue of access to health care. According to the IOM report entitled Access to Health Care in America, the realization of access to care allows individuals to receive the type of health care services necessary to maintain optimal health outcomes (Millman, 1993). The IOM report goes on to state "that access problems are created when barriers cause underuse of services, which in turn leads to poor outcomes" (Millman,1993, p. 35).Barriers to access and utilization vary by structural, financial, and personal/cultural factors. Several theoretical frameworks and models developed to describe and explain personal/cultural barriers. Some of the most useful models include the health belief model and locus of control. Each model seeks to illuminate the motivators for action.

The health belief model seeks to explain health behavior based on an individual's perceived susceptibility to disease, perceived barriers, and benefits of compliance with

behavior change (Champion & Menon, 1997). Several studies have used this theoretical model to explain and/or predict breast cancer screening utilization. For example, the perceived barriers such as cost, age, pain, too little time, and lack of physician recommendation for screening have all been identified as reasons for screening non-compliance. Victoria Champion, one of the foremost researchers in breast cancer screening adherence, noted that access barriers are the most powerful predictor of screening (Champion, 1991). Swan (2003) found that the lack of a usual source of care and lack of health insurance were the two most important reasons why women had not received a mammogram during the last two years. Other researchers have identified stated intent to be screened as a powerful predictor as well (Mandelblatt, Traxler, Lakin, Kanetsky, & Kao, 1993). Developing an understanding of the predictors for breast cancer screening behaviors is an important key to determining the types of intervention programs needed to address this issue.

The locus of control (LOC), and its derivatives multidimensional health hocus of control, (MHLC) and the God locus of health control (GLHC), provide additional frameworks that describe health beliefs. These frameworks seek to describe individual's beliefs about whether the control for one's health is seated internally, with others (externally), or can simply be ascribed to chance (Holm, Frank, & Curtin, 1999). Studies that have sought to determine the role of MHLC on mammography screening behavior have examined whether belief in personal responsibility, for example, is more highly correlated with utilization of mammography screening (Wallston, 2007). The GLHC was adapted from the MHLC to more clearly address the role of religiosity and spirituality in health behaviors. The GLHC scale is used by researchers to describe whether an

individual has an internal locus of control, meaning that they feel they are responsible for their healthcare, or an external locus of control, such as God or other higher forces. In a study of women with a familial BRCA1 mutation and therefore at high risk, researchers found that women who scored high on the GLHC scale, were less likely to adhere to mammography and clinical breast examination (CBE) recommendations (Kinney, Emery, Dudley &, Croyle, 2002). However, the use of the GLHC alone does not delineate the specific nature of a God locus of control. Holt and colleagues (2003) developed and tested a scale that further defined this relationship as either passive or active. Women who were classified as "passive" believed that God would take care of their health care, whereas women who were "active" felt that God empowered them to take care of their own needs. Developing an understanding of the belief systems of disparate populations is important in better understanding and ultimately improving health behaviors.

Numerous studies have been conducted on barriers specific to both African American women and lesbian and bisexual women. Barriers classified as structural or institutional, financial and personal mitigate the accessibility of healthcare services (Millman, 1993; Dean et al., 2000; Bibb, 2001). These barriers have a direct impact on utilization of breast cancer screening and health outcomes for African American women. Access barriers for lesbians are compounded by issues of heterosexism or heterocentricity in the delivery of healthcare services. An examination of the interplay of these barriers and screening behaviors for this vulnerable population will allow us to better develop interventions to address these needs.

The theoretical or conceptual support for this secondary analysis is the contribution of barriers in diminishing access to and utilization of breast cancer screening

among African American lesbian and bisexual women. Specifics on barriers to screening relevant to African American women and lesbians are presented in Chapter 2 of this document. Since the current study uses an existing data set some measures of barriers, service utilization, and mediators are not included in the analysis. Those that are available from the current data set are highlighted.

Definitions of Terms

The following terms are defined as used in this study.

Androgynous: Refers to women who express equally both a female and male gender (Singh et al., 1999).

Butch: Refers to a masculine gender identity. While butch is applied to both gay men and lesbians, this research project uses the word to refer to lesbians exclusively (Singh et al., 1999).

Femme: Refers to a feminine gender identity. Generally, femme identity is expressed through clothing, hair, use of make-up, but also manifests in psychosocial ideology (Singh et al., 1999).

Gender: Gender is a social construct of man and woman, as separate and apart from biologic sex. Gender is learned and adopted through public discourse, socialization, and observation of carefully agreed upon cultural norms (Anderson, 2003).

Gender expression: The external presentation of gender exhibited through dress, hair, make-up or lack of make-up, mannerisms, etc. Also referred to as "doing gender" (Anderson, 2003).

Gender identity: Gender identity refers to our perception of self and is rooted in the meanings we ascribe to the socially constructed role of man and woman. Gender and biologic sex may be discordant (Eyler & Wright, 1997).

Gender variant: An individual with a gender identity that is discordant with the individual's sex (Carroll, Gilroy, & Ryan, 2002).

Homophobia: Describes fear and hatred of individuals who are same sex attracted (Blumenfeld, 1992; Gruskin, 1999; Anderson, 2003).

Heterosexism: Refers to the assumption of heterosexuality unless proven otherwise (Gruskin, 1999; Dean et al., 2000).

Lesbian: Lesbian is a sociopolitical term that has been defined along three dimensions: behavior, affection and identity (Solarz, 1999). Other words that are used to denote a lesbian identity are *women who partner with women* (WPW), *same gender loving women*, and *queer*.

Sex: Refers to the biological distinction based on internal and external genitalia, hormonal levels, chromosomal make-up (i.e., XX, XY), and secondary sexual characteristics. Sex refers to male or female (Anderson, 2003).

Sexual Identity: Develops as a core-morphologic identity (i.e., self awareness of sex), subscription of gendered roles, and a development of sex object choice or sexual orientation.

Outness: Refers to the degree to which an individual has disclosed their sexual orientation to others (Mohr & Fassinger, 2000).

Assumptions

The following assumptions were made in the conduct of this secondary analysis:

- Issues of culture are important in predicting screening utilization.

- Heterosexism exists in the healthcare community.

- Respondents have answered questions truthfully.

Limitations

This study has several limitations that should be considered.

- Data were collected as part of a convenience sample and therefore will not yield results that are generalizable to the population of African American lesbians.

- Lack of randomized sampling may lead to self-selection bias which limits the ability to generalize findings to the population of African American lesbians.

- Data reported in this analysis resulted from self-report and therefore are subject to social desirability bias.

Although population based samples are necessary to produce generalizable data, much of the data published on lesbian health has relied on convenience sampling. In fact, the first study using a population based sample appeared in the literature in 2000 (Diamant et al., 2000). Until that time researchers had to rely on convenience samples or secondary analysis of data that just happen to include questions on sexual orientation and were therefore unable to shape the operationalization of sexual orientation and gender identity. Additionally, nationally derived population-based studies are costly and labor intensive. Therefore researchers were forced to depend on state or federal government agencies for the conduct of these surveys. However, since the number of lesbians in the

population is fairly small; these studies only generate small numbers of women who are willing to self-identify as lesbian. Furthermore, since African American lesbians are an even smaller proportion of the United States population, generating a representative sample of African American lesbians would be extremely difficult. Therefore, the original study utilized a nonprobability, convenience-based sampling methodology. Although the findings cannot be generalized to the African American lesbian population, the data offer a unique snapshot that illuminates the behaviors of a seldom studied group.

The African American lesbian community represents an often isolated and hidden population within a hidden population thus making recruitment of study participants difficult. Therefore, it was necessary to recruit respondents from lesbian-identified locations (recruitment is discussed in Chapter 3, Sampling Procedures). However, because women who are not "out" generally have limited contact with lesbian specific organizations and venues, alternative collection methods were necessary. The web-based survey was developed specifically make the survey more accessible to individuals who may not frequent lesbian specific organizations and venues and therefore mitigate this potential form of bias. Calculation of a response rate is not possible with this recruitment method.

Data collected in this survey were also subject to social desirability and self-report bias. Social desirability and self report bias are particularly relevant in measures of breast cancer screening utilization, intake of fruits and vegetables, physical activity, and calculation of obesity (Wyner, Cohen, & Winters, 1997). Additionally, respondents may have answered in ways they believed were more socially acceptable because the sponsoring organization was a well established lesbian cancer organization. However,

since this was the first major activity in the African American community for this sponsoring organization the community's organizational awareness may not be as great as with other communities. Findings from this study are confirmed by similar studies of lesbians.

Scope and Delimitation

The current study represents a secondary analysis of the data collected through the Black Women 2 Women Spirit Health Study that utilized a non-randomized sample of African American lesbians across the country. Inferences and correlations from these data are only descriptive of the participant pool. At the time of the study the Mautner Project had a 13 year history of providing direct services, outreach and education, advocacy, training, and research in areas of importance to the health of lesbians and WPW. The Mautner Project was the first organization to provided services to lesbians with cancer and has achieved national prominence for this work. The original study was conducted as part of the organization's research initiative on diversity within the lesbian community. It is assumed that the organization's credibility within the community had a positive impact on community member's willingness to participate fully and honestly in the study.

One of the major challenges in conducting research on lesbian health behavior and risk factors is in defining the population. Previous studies have differed in how a lesbian identity has been defined in terms of same-sex behavior, identity, and/or desire/attraction. Sexual identity and the linguistics used in the discourse of one's identity may be different for African American lesbians. For the purposes of this study, lesbian was operationalized to include both behavior and identity. Operationalizing lesbian differently may yield different results.

The original study recruited 666 African American lesbians and bisexual women (both self-identified lesbians, and women who have had a same-sex relationship, within the past 5 years), between the ages of 18-65. A variety of methods and venues were used to recruit participants. Assistance in distribution of questionnaires was received from nationally placed Outreach Consultants. These consultants had access to various mailing lists of AAL, through both organizational and personal contacts, throughout the country. Additionally, the project worked with the African American gay and lesbian faith community, national magazines, newsletters, and the worldwide web to recruit participants. Surveys were mailed from The Mautner Project using the Dillman method (Dillman, 2000). African American lesbian artwork was used as an incentive to participation. More details on data collection are presented in Chapter 3.

Lastly, over the past several decades breast cancer screening guidelines have changed based the availability of new effectiveness data. These guideline changes make it difficult to compare compliance over time. This data analysis used the screening guidelines promulgated at the time of data collection. Monthly BSE will be included in the breast cancer screening regimen because so much of the breast health education messages included messages of self examination.

Significance of the Study

The National Sex Study (NSS) conducted in 1994 by Laumman et al., estimated that 2% - 6% of women were lesbians. Lesbians include women who self-identify as lesbian or have same-sex sexual behavior without self-identifying. According to the 2002 U.S. Census,108 million women older than age 18 years live in the United States (US Census Bureau, 2002). Therefore, it is estimated that between 6.48 and 10.8 million

lesbians live in the U.S. The 2000 U.S. Census, for the first time, enumerated the number

of same-sex headed households in the United States. The U.S. Census found that 99.3%

of the counties in the United States contained same-sex headed households (Smith &

Gats, 2001). Although there were higher proportions in urban areas, almost every county

in the country has at least one LGBT couple that was willing to self-identify on the 2000

U.S. Census. Unfortunately, the 2000 Census does not include single LGBT individuals,

or individuals who do not wish to self disclose their sexual orientation on a government

form. According to the Human Rights Campaign, these omissions may result in an

undercount of LGBT of as much as 62%. Greene (2000) estimated 1.8 million African

American women in the United States identify as lesbian or bisexual.

Boehmer (2001) conducted an analysis of 3,822,822 English language articles on

human subjects published between 1980 and 1999 and indexed in Medline, a project of

the National Library of Medicine. At that time, only 1% (3,777) of the articles addressed

LGBT issues. The majority of articles (60%) were disease specific and primarily dealt

with HIV/AIDS. Gay men were the focus of 80% of the articles and another 39% of the

articles focused on bisexual men. Lesbians and bisexual women made up less than 27.6%

and 9.3% of the articles, respectively (Note: articles could focus on more than one

group). She also noted the alarming omission of race and ethnicity in 85% of the

published articles under review (Boehmer, 2001). Clearly, there is a dearth of information

on behavioral risk factors and screening behaviors of AAL. By addressing cancer

screening behavior among African American lesbians and bisexual women this study

contributes to the body of literature and knowledge base.

Social Change

The lack of data on African American lesbians relative to data available describing the health behavior of European American lesbians renders African American lesbians invisible in the development of health policy and health education programs. Compounding this data void is the lack of information specific to gender identity. If stigma has a compounding effect, then being, for example, African American, lesbian and butch-identified, could increase the perceived barriers to accessing breast cancer screening. The findings from this secondary analysis will have the ability to inform individuals who are actively engaged in program and policy development. Findings from the study will be shared with the Mautner Project, the sponsoring organization responsible for the original data collection. Plans for dissemination of the study findings include the following entities:

Women 2 Woman Spirit Health Study Community Advisory Committee (CAC)

Members of the CAC for the original study are on the front lines in providing services to African American lesbians. Data from this study will provide them with important information on the populations they serve to assist in improving existing services, identifying areas of additional need, and securing funding to meet those needs. Additionally, the study results can be used to develop interventions to increase African American lesbian's participation in breast cancer screening.

National Coalition of Feminist and Lesbian Cancer Projects.

Currently more than 40 grass roots organizations make up the Coalition. These organizations provide direct services to lesbians and bisexual women with cancer, cancer education, provider training, and referrals to health services. These organizations will be

able to use this data to develop programming that is specific to the needs of African American lesbians and bisexual women.

Lastly, the findings can be used to enhance the Removing the Barriers: Providing Culturally Competent Care to Lesbians WPW provider training. The Mautner Project currently administers this CDC-funded program. Currently, this training does not provide information specific to African American or butch identified lesbians. Data from this project could eventually be used to better prepare physicians to provide for their African American lesbian patients.

Summary

African American lesbians are at the intersection of the increased risk factors and barriers to health care that affect African American women, lesbians, and bisexual women. The ability to fully assess this intersection is limited by the paucity of breast cancer studies specific to African American lesbians. While many studies have linked screening behavior to ethnicity, newer studies have clarified this link further as a factor of socioeconomic status more than of racial or ethnic background (Qureshi et al., 2000). Additionally, factors impacting screening compliance for African American women include age, attitudes, beliefs, breast cancer knowledge, screening practices, and type of health care provider making the referral (Crump, Mayberry, Taylor, Barefield, & Thomas, 2000). Although access to care affects all socio-economically disadvantaged communities, focusing this study on the behaviors of African American lesbians will allow for a better understanding of the behaviors of this population and thereby enable more pointedly focused outreach efforts to a more well-defined community.

Chapter 2 contains a thorough examination of the available literature on breast cancer risk factors, screening methodologies and recommendations, as well as promoters and barriers to screening for African American women and lesbians. Chapter 3 explores the research design as well as a description of how the data were collected for the original study. Further, discussion of the data analysis plan data is also provided. Chapter 4 contains a description of the variables used in this study, variable coding and recoding, missing data, and how new variables were computed. Additionally, this chapter contains the bivariate, multivariate analysis, and statistical significance testing done for this analysis. Lastly, Chapter 5 presents a discussion of the study findings and their implication for social change, recommendations for action and future research.

Chapter 2: Literature Review

Introduction and Overview

Although cancer represents more than 100 different diseases affecting many parts of the body, breast cancer is the most frequently written about cancer. A search of Medline by this researcher revealed that breast cancer is mentioned in 207,600 articles compared with only 173,866 mentions of lung cancer, the second most commonly cited cancer. *Breast cancer* is defined as an uncontrolled growth of malignant cells in the breast (Barton, Russell, & Fletcher, 1999).

According to the American Cancer Society 150,090 new cases of cancer are estimated for African Americans in 2009 and 63,360 African Americans were expected to die from cancer (American Cancer Society, 2009). Breast cancer is the second leading cause of cancer deaths among African American women representing approximately 20% of cancer deaths. Although mortality rates for breast cancer have decreased over time, the level of decrease among African American women has not been as rapid. Breast cancer mortality among African American women exceeds that of European American women despite a lower incidence of breast cancer. African American women are more likely to be diagnosed with estrogen-receptor negative tumors that are less responsive to therapy (Stanford, Szklo, Brinton, 1987). Additionally, although the 5-year survival rates for breast cancer have improved for African American women, they are still less likely to survive after five years compared with European American women. In the early 1980s, disparities in mortality rates for African American women were non-existent. Subsequent diminished access to the advances in adjuvant therapy and access to widespread early

detection and screening experienced by African American women are directly linked to the divergence in mortality rates (American Cancer Society, 2007).

While breast cancer screening, i.e., searching for disease in asymptomatic individuals remains our most successful way to reduce cancer related mortality, there exist a myriad of access barriers and challenges that prevent women from utilizing this secondary prevention measure (Hewitt, Devesa, & Breen, 2002; Smith et al., 2003; USPTSF, 2002). This chapter focuses on identifying some of the internal and external challenges and promoters of screening behavior for African American women in general and lesbians and bisexual women specifically. The first part of this chapter outlines breast cancer risk factors, both as they relate to behavioral and non-behavioral issues. A brief discussion of the three breast cancer screening modalities, their effectiveness, and screening recommendations offered by several national health organizations will follow. A review of the literature on the factors that predict screening behavior in African American women are presented to set the stage for further discussions of screening behavior in the context of sexual orientation. Unfortunately, little information exists that elucidate the screening patterns of African American lesbians; therefore, findings from lesbian health research are presented to clarify the salient issues for this community. The chapter will conclude with a discussion of the possible barriers and facilitators of cancer screening for lesbians. Some hypotheses have been drawn to address the conflagration of race and sexual orientation on access to care for African American lesbians.

Literature for this review was identified through a Medline search and encompassed articles published during the past 30 years; several books and Federal

reports were also used to augment the literature search. Lastly, personal communications with experts in the field provided context that was unavailable from the literature.

Breast Cancer Risk Factors

Over the past several decades there has been increasing attention paid to identifying the causes of disparity in breast cancer mortality in African American women. Explanations generally fit into four categories: 1) sociodemographics; 2) behavioral risk factors; 3) access to care; 4) and physician recommendations. This section will briefly outline these differences and their potential impact on screening. Although a brief discussion of these factors has been presented herein, only screening, behavioral risk factors (i.e., healthy lifestyle behaviors), and demographics (i.e., insurance status, age, gender identity) are addressed in this investigation.

Sociodemographic Factors Related to Increased Risk

Several demographic factors are associated with increased risk of breast cancer. Among these are increasing age, low levels of education, low income, decreased access to health care insurance, and rural residence. Age takes on an interesting dimension for African American women. Although breast cancer incidence generally increases with increasing age, incidence rates cross over for African American women between age 45 and 49 years with African American women being diagnosed younger than European American women (Moormeir, 1996). Breast cancer in African American women tends to occur at younger ages than in European American women (American Cancer Society, 2007). Several studies have shown that African American women treated within the Military Health System (MHS) were more likely to be diagnosed at a younger age than their European counterparts (Wojcik, Spinks, & Optenberg, 1998; Bibb, 2001). These

studies suggest that even when access to care is equal as it is in the MHS, disparities in age at diagnosis remain for African American women. Education and income has also been associated with advanced stages of diagnosis of breast cancer in African American women (Merkin, Stevenson, & Powe, 2002).

Lifestyle and Behavioral Risk Factors

Health educators promote the view that the development of cancer is somewhat preventable based on healthy lifestyle behaviors that include adequate intake of fruits and vegetables, maintenance of a healthy weight, regular moderate physical activity, and routine access to healthcare screenings for early detection. According to the International Agency for Research on Cancer an estimated 25% of breast cancers are due to increased adiposity and lack of physical activity (McTiernan, 2003). However, few individuals are fully compliant with recommended levels of exercise and weight control (Bal, Woolam, & Seffrin, 1999).

Body Mass Index

Body mass index (BMI, kg/m^2) is often used as a measure of "fatness" and as such an approximation of risk for certain disease states such as cancer (Bianchini, Kaaks, & Vainio, 2002). BMI has been categorized as low (<18.5 kg/m^2) normal or ideal (18.5 to 24.9 kg/m^2), overweight (25 to 29.9 kg/m^2), and obese (30.0+ kg/m^2). Further classifications of obese, class I: 30 to 34.0 kg/m^2, class II: 35 to 39.9 kg/m^2, and class III: >40 kg/m^2, have been made to indicate progressive severity of risk for disease. The use of this as a proxy measure of risk is somewhat imprecise, given that individuals who exhibit high body fat or musculature may have a high BMI score. Additionally, individuals with a low BMI (<18.5) may also have high levels of body fat. Therefore, waist-to-hip ratios,

which more accurately approximate adiposticity, have been suggested as a better anthropomorphic measure. Data from the National Health and Nutritional Examination Survey III (NHANES III) indicates that 77.3% of African American women are overweight, and 49.7% of those can be classified as obese (≥ 30 kg/m^2).

BMI has generally been linked to increased risk of numerous conditions including respiratory disease, cardiovascular disease, high blood pressure, diabetes, breast and other types of cancer (Adderly-Kelly & Williams-Stephens, 2003). The association between obesity and breast cancer is more complex than originally thought (Stephenson & Rose, 2003). Numerous studies have linked obesity to poor prognosis; larger breast tumors; lymphedema; and less than efficient chemotherapy (Carmichael, 2006). The high rates of severe obesity among African American women may be linked to increased severity and late stage of diagnosis for breast cancer (Clark & Mungai, 1997). Obesity has also been linked to lower rates of breast cancer screening, (Wee, McCarthy, Davis, & Phillips, 2000). Additionally, overweight and obese individuals were less likely to be highly educated, insured, and have access to private health care insurance, all known barriers for accessing mammography screening. The authors also cited the lack of sensitivity of clinical breast examinations in overweight women as a potential challenge to early detection.

Nutrition

It is estimated that 16% or 400,000 deaths annually in the United States are attributable to poor nutrition and physical inactivity (Mokdad, Marks, Stroup, & Gerberding, 2004). A review of worldwide evidence on diet and cancer concluded that high intake of fruits and vegetables can reduce the risk of several types of cancer, yet

only 23.6% of African Americans consume five or more fruits and vegetables per day

(Bal et al,, 1999; CDC, 2003). Gorin & Jacobson (2001) found that 50% of African

American women consumed one or fewer fruits and vegetables per day. According to the

2005 Behavioral Risk Factor Survey only 27.3% of African American women reported

consuming five or more fruits and vegetables per day, the lowest proportion of all ethnic

groups (CDC, 2007). To date no study has found an association between fruit and

vegetable consumption and reduced risk of breast cancer (Smith-Warner et al., 2001; van

Giils et al., 2005). However, women who consumed more fruits and vegetables had more

recent mammograms and were more likely to engage in and adhere to cancer screening

recommendations than those who ate less healthy diets (Gorin & Jacobson, 2001).

Physical Activity

Moderate physical activity of at least 30 minutes or more on most days of the

week has been associated with a myriad of health benefits including the reduction of

cancer risk (Pate et al., 1995; US DHHS, 1996). A recent analysis of more than 20 studies

identified a dose response relationship between physical activity and breast cancer (Thun

& Furberg, 2001). A more recent study reported a decrease in breast cancer risk of 25%

for the most physically active women (Friedenreich & Cust, 2008). In one study

strenuous physical activity has been associated with cancer risk reduction in pre-

menopausal African American women (Adams-Campbell, Rosenberg, Rao, & Palmer,

2001). Other studies showed equal breast cancer risk reduction between moderate and

vigorous physical activity (Friedenreich & Cust, 2008). Although the preponderance of

the evidence shows the clear benefit of exercise, 55% of African American women were

physically inactive and only 7.1% participated in vigorous physical activity 5 times a week or more (Schoenborn, Adams, Barnes, Vickerie, & Schiller, 2004).

Tobacco and Alcohol Use

Although some studies have found an increased risk of breast cancer and active and passive tobacco exposure most have not (Ahern, Lash, Egan, & Baron, 2009; Bonner et al., 2005; Rollinson, Brownson, Hathcock, & Newschaffer, 2008). However, smoking has been a predictor or risk factor for non-adherence to mammography (McBride, Curry, Taplin, Anderman, & Grothaus, 1993; Schueler, Chu, & Smith-Bindman, 2008). Additionally, smoking has previously been associated with a decreased motivation for other types of cancer screening including cervical and colorectal (Vernon, Laville, & Jackson, 1990; Phillips, Johnson, Avis, & Whynes, 2003). Alcohol use, on the other hand, has been linked to an increased risk of breast cancer (Longnecker, 1994; Rosenberg, Levy, Rosenshein, Schottenfeld, & Engle, 1982). A meta-analysis conducted by McTiernan (2003) found a significant association between moderate to heavy alcohol consumption and breast cancer. Terry et al., (2007) reported that moderate alcohol intake was responsible for 30-50% of increased risk of breast cancer.

Reproductive Risk Factors

Reproductive factors, early age at menarche, and late age of menopause have been linked to increased risk for breast cancers (Moormeir, 1996). Data from the National Center for Health Statistics show that African American women begin menarche at an earlier age (12.5 years) than European women (12.8 years). Additionally, African American women reach menopause earlier (49.3 years) than European women (50.0

years). However, rates of surgically induced menopause are higher among African American women.

Nulliparity and age at first childbirth has also been linked to increases in breast cancer risk. Delay childbearing until after age 34 years confers the same risk for breast cancer as nulliparity (Hahn & Moolgavkar, 1989). Longer intervals between first and second birth has also been shown to increase risk for cancer in post-menopausal women (Paffenbarger, Kampert, & Chang, 1980). British researchers who examined data for more than 1 million women found that the age at first birth also impact tumor type (Reeves, Pirie, Green, Bull, & Beral, 2009). Additionally, breast cancer risk decreases as the number of full-term pregnancies increase (Ramon et al., 1996).

Breast Cancer Screening Modalities

Secondary breast cancer prevention, i.e., screening of asymptomatic women, represents our first line of defense in reducing cancer related mortality. Breast cancer screening is comprised of a triad of methodologies, including mammography, CBE, and BSE. Age appropriate use of these screening modalities can be effective in identifying early stage breast cancer (Smith et al. 2003).

Mammography Screening

Three generally recognized methodologies for conducting population based breast-cancer screening are mammography screening, CBE, and BSE. Mammography screening, which uses a low-dose radiography, is currently the most effective method of detecting breast cancer at its earliest stages, approximately 1 to 3 years prior to clinical detection (Bibb, 2001; National Cancer Institute, 2002; Wojcik, Spinks, & Optenberg, 1998). Digital mammography technology for breast cancer screening was approved in

2002 by the U.S. Federal Drug Administration (US FDA). Although digital technology has not been shown to be more effective than conventional analogue mammography, it does allow for more rapid access and portability of mammographic images.

Clinical Breast Examination

CBE, the second screening methodology, involves a health care provider palpating and inspecting the breast tissue of a patient in a supine patient to flatten breast tissue against the chest wall. This screening is generally performed during an annual physical examination, the precision of CBE is dependent on the skill and training of the health provider conducting the procedure, although factors such as age, lumpiness of the chest wall, tumor size and breast density may also affect results (Barton, Russell, & Fletcher, 1999). Although examination length has been established at 3 minutes per breast, studies have shown that physicians in clinical practice average about 1.8 minutes per breast (Barton et al., 1999). Researchers estimated the sensitivity, specificity, and positive predictive value of CBE as 58.8%, 93.4%, and 4.3%, respectively. Overall, 5.1% of cancers were detected by CBE but missed on mammograms (Bobo, Lee, & Thames, 2000). While its specificity alone is not sufficient to recommend CBE as a sole screening tool, the importance of CBE as part of a triad of screening modalities is clear (George, 2000).

Breast Self-Examination

The third screening modality is considered to be the BSE. While the ultimate efficacy of BSE in decreasing breast cancer mortality remains unknown, from a feminist perspective, it is an important component of women's overall self-care. *BSE* is defined as "a systematic method of self inspection and palpation of the breast and axilla" (Baxter &

Canadian Preventive Task Force, 2001, p. 1839). As a non-clinical procedure performed by women themselves, it offers an opportunity for women to get to know the contours of their breasts over time and identify any changes that may occur. Researchers have shown that women who perform BSE are more likely to identify breast cancers that are smaller and more localized (Weiss, 2003). While performing BSE may be empowering, women often do not perform it correctly, or with sufficient frequency. Although the practice of BSE has been much maligned over the past few years, the majority of breast cancer cases (79%) have been detected through BSE compared with 9% that were found through CBE and 20% through routine mammogram (Coates et al., 2001). However it has been noted that this detection rate does not have an impact on mortality (USPTSF, 2002).

Screening Recommendations

Barbara Rimer, a noted cancer behavioral research at the National Cancer Institute, described the "recommendations about mammography [as the] most contentious area of medicine" (Rimer, Halabi, Strigo, Crawford, & Lipkus, 1999, p. 509). In an article published in the Journal of Women's Health and Gender-Based Medicine, she outlines the controversies and vacillations that have occurred among the nation's leading cancer and health organizations, the American Cancer Society (ACS), National Cancer Institute (NCI), and the National Institutes of Health (NIH). The controversy over the benefits of screening mammography was re-energized by an article by Gotzsche & Olsen (2000) for the Cochrane Collective, an independent health review body. Based on a meta-analysis of breast cancer screening randomized trials, the researchers found insufficient evidence to justify mammography for the screening of breast cancer. The authors made this decision based on the belief that five of the seven studies included in the meta-

analysis were flawed (Smith et al., 2003). Many of the national bodies that promote

screening guidelines have since criticized their findings as inaccurate, stating that the

flaws noted by Gotzsche and Olsen (2000) were not of a sufficient magnitude to discount

the effectiveness of screening mammography. In fact, after a similar analysis of the same

data the USPSTF recommended screening mammography beginning at age 40 years at 1

to 2 year intervals based fair evidence of effectiveness (USPSTF, 2002). Seven years

later the USPSTF reversed that decision (USPSTF, 2009). The current recommendation

holds that given the relatively low number of breast cancers found in women under 50

years, routine screening for that age group is not recommended. However, the US PSTF

guidelines stipulate that women under 50 years who are at high risk for breast cancer

should continue to be screened. The CDC guidelines recommend an initial baseline

mammogram by age 30 years and yearly screening starting at age 40 years. The ACS

recommends screening mammography for women beginning at age 40 years (Smith et al.,

2003). While some providers make recommendations based on the risk profile of the

patient, patients and providers are still confused by when mammograms are warranted. In

fact some argue the benefit of screening women with a family history of breast cancer

before age 40 years (Smith et al., 2003). Although data presented here are relevant during

the timeframe the original study was conducted, it is interesting to note that the breast

cancer screening question continues to be raised. In 2009, the ACS reported that the

increase in mammography screening has lead to overtreatment of cancers that in all

likelihood would not lead to early mortality (Esserman & Shields, 2009). In fact, Danish

researchers cited an over diagnosis rate of 1 in 3 resulting in over treatment of cancers

that could be indolent or even regress (Jorgensen & Gotzsche, 2009).

The ACS recommends that CBE be performed every 3 years in otherwise healthy women to begin for women 20 to 40 years old (Smith et al., 2003). Green & Taplin (2003) found insufficient evidence that CBE actually increased breast cancer detection, but concluded that if providers increased the amount of time they spent performing the examinations and improved their techniques for conducting CBE, its ability to detect cancer may be improved. The USPSTF 2009 recommendation cites insufficient evidence to support or recommend against CBE for women 40 years and over (USPSTF, 2009).

The controversy that has erupted over the benefit of BSE is arguably as contentious, if not more so, than the one that surrounds mammography. In 2001 the Canadian Medical Association Journal published an article stating that not only was BSE not efficacious in reducing breast cancer mortality but it was actually harmful to women (Baxter, N. & Canadian Preventive Task Force, 2001). The Canadian researchers based their findings on a meta-analysis of randomized clinical trials, quasi-experimental trials, and case-control trials. Although they admit that cancers are indeed discovered through BSE, they maintain that breast lumps are frequently found incidentally while women are engaged in other activities. Central to their concern is the belief that false positives strain the resources of the healthcare system by increasing unnecessary medical procedures. They also believe that these false positives result in unnecessary stress and worry among women. On balance, they believe, the cases of cancer that are correctly diagnosed are not worth the economic, psychological pain, and suffering caused. The USPSTF reenergized the debate on BSE in 2009 with their updated recommendation against the practice citing the same reasons as the Canadian researchers (USPSTF, 2009).

Predicting Screening Behavior

Even though mammography, CBE, and to some extent BSE save lives, there remains a substantial number of women that do not meet the recommended guidelines. This is particularly true of ethnic minority communities (Hiatt et. al, 2001). The barriers to accessing mammography and CBE can be characterized as personal, provider, and demographic barriers (George, 2000). Personal barriers refer to attitudes, knowledge and beliefs of the patient, where provider barriers are associated with a lack of continuity of care, diminished access to a primary care provider, and lack of provider recommendation. Age, level of education, and socioeconomic factors contribute to demographic barriers to screening (George, 2000).

Much of the literature has been devoted to identifying barriers to accessing healthcare, developing predictive models through theory testing, and evaluating breast cancer screening and educational interventions. The specific nature of the barriers identified has varied based on the demographics of the populations involved. For example, barriers that exist for African American or rural patients are different than those described for other populations and have often included education, income, and access to a primary health care provider (George, 2000). Barriers also diverge based on the screening method in question. Below is a brief discussion of the types of barriers that have been identified in the research literature for each screening modality. An understanding of the nature and variety of barriers has been helpful in setting the stage for the variables selected in this secondary analysis.

Predictors of Mammography Screening

Augustson et al. (2003) attempted to define predictors of mammography adherence among older, low-income women and identified the strongest predictor of mammography as participation in other clinical screenings such as Pap smear and fecal occult blood test (FOBT). Burnett and colleagues found a correlation between higher income and adherence to mammography screening (Burnett et al., 1999). Gorin and Jacobson (2001) identified number of fruits and vegetables consumed with adherence to screening recommendations.

Physician Recommendation

Studies have shown that one of the major predictors of mammography utilization is receiving a recommendation from a physician (Schueler et al., 2008). Crump, Mayberry, Taylor, Barefield, and Thomas (2000) found that the second most important reason for not having a mammogram, after not needing one (35%), was the absence of a physician recommendation (33%). Champion and Menon (1997), found that African American women who had a regular physician were more likely to be mammography compliant than women who did not have a regular physician. This finding further illustrates the importance of having access to regular primary health care as well as the importance of unbiased health care recommendations. African American women were the least likely to report that their physician encouraged them to have a mammogram (Frazier, Jiles, & Mayberry, 1996). More recent research in this area has identified perceived SES and not race as the significant factor that drives physician's recommendation of mammography. In a study by O'Mailley and colleagues (2001), after controlling for race and ethnicity, physician perceptions of SES and the potential for

patient compliance determined whether physicians recommended mammography. The authors, however, acknowledge that physicians are more likely to perceive African American women and older women as being of lower SES. A meta-analysis of breast cancer utilization research over time shows that the type of provider is also important with access to an obstetrician/gynecologist having the most impact on screening utilization (Schueler, Chu, & Smith-Bindman, 2008).

Family History

Several researchers have identified an association between positive family history of breast cancer, with adherence to mammography screening. Finney and Iannotti (2001) demonstrated significant differences in mammography utilization between women with and without a positive family history. In addition, the researchers found these women were more likely to be involved in cancer issues and be more responsive to breast cancer screening cues. Murabito et al., (2001) found that women with a familial history of breast cancer, who participated in the Framingham Offspring Study, were three times more likely to have ever had a mammogram and to have had a mammogram more recently than women without a family history. The study also identified a correlation between mammography screening, current smoking, and recent CBE with women who reported being a current smoker being less likely to have a mammogram, and women reporting a recent CBE being more likely to have a mammogram. Given the high rates of smoking among lesbians, this finding may have implications for encouraging screening among high-risk women.

Social integration, or the lack of isolation, has been identified in numerous studies, as a determinant of health, particularly among women (Ballentyne, 1999). Social

support has also been linked specifically to the access of mammography in African American Women. In a panel study of African American women conducted by Husaini and colleagues (2001) researchers found that women who had previously discussed mammography with family and friends, or who were married had a higher likelihood of mammography use than women who did not meet these criteria.

Predictors of Breast Self-Examination

One of the most important reasons for non-compliance with BSE screening recommendations is lack of proficiency and knowledge (Wood, Duffy, Morris, & Carnes, 2002). Despite being previously trained to conduct BSE, women often feel unqualified to identify a lump. Champion and Menon (1997) found that women who had the greatest knowledge and confidence in their ability to perform BSE had the highest reported frequency of BSE adherence. Being married was associated with a lack of BSE adherence. Additionally, many women believed that their health care provider would find their breast cancers during their physical examinations and therefore felt it was unnecessary to perform their own examinations. Unfortunately, women are best suited to identify changes in breast size, symmetry, texture and are more likely to identify changes in lump thickness or locations during palpation of their own breasts than a health care provider.

Predictors of Clinical Breast Examination

Use of CBE by African American women speaks to several issues related to access to health care, access to preventive health care, the role physicians play in encouraging screening behaviors, and the importance of CBE as a gateway to more intensive cancer screening. In a study by Pearlman et al. (1996), African American

women were more likely to use office based screenings such as CBE and pap tests than women of other ethnic groups. Mickey and colleagues (1995) further identified the link between access to CBE and mammography adherence. Women who did not have annual CBE also did not have regular mammograms or had them irregularly. However, the researchers found that having regular access to a physician was not enough to ensure CBE. In fact, in follow-up focus groups, it became evident that African American women often visit a health care provider for acute or chronic health care conditions and had limited access to or utilization of preventive health services. The lack of an annual physical has been linked to decreased CBE participation.

Access to Treatment

Access to appropriate treatment services facilitated by adequate insurance coverage for African American women has been cited as one cause of disparate survival rates. However, several studies have shown that access to treatment services does not fully explain survival differences. An analysis of the Department of Defense (DOD) Tumor registry showed that even with ready access to consistent medical services, breast cancer survival rates for African American military personnel, although higher than that of African American civilians, remains lower than European American military women (Wojcik et al., 1998). African American military women achieved a survival rate of 34.2% compared with 24.77% for non-military African American women. However, the rate for military and civilian European American women was comparable (18.08% and 18.4% respectively). A more recent study of the DOD system found similar results after adjusting for age and stage of diagnosis. Researchers speculate that differences may be explained, in part, by differences in obesity between African American and European

American women and differences in tumor phenotype, which limits availability of treatment (Jatoi, Becher, & Leake, 2003). Additionally, a study of members of 11 integrated health care organizations found that African American women with equal access to treatment still experienced worse survival rates compared with other groups (Field et al., 2005). Researchers in this study attributed some of the variance in survival to differences in levels of communications between providers and patients as well as pre-existing conditions or co-morbidities in African American breast cancer patients.

Impact of Sexual Orientation on Screening

The study of lesbians and African American lesbians in particular, is of interest for several reasons. As members of both a sexual and racial minority group, these women may experience multiple levels of oppression (Loiacano, 1998) that may have a cumulative effect that results in poorer health outcomes, particularly as they relate to breast cancer. As members of a racial minority, African American children have their parents as buffers to a hostile world. Having a shared experience allows African American parents to reassure and validate their children's perceptions of racism and experiences of difference or isolation, provide them with adaptive strategies for dealing with racism, and display a positive sense of identity known as cultural mirroring (Greene, 2000). However, young African American gay children do not have the same advantage in terms of their sexuality. Many learn early on that sexual behavior or orientation that deviates from the cultural norm jeopardizes the entire African American community. Additionally, according to Greene (2000) "African American women face challenges that result from sexism and racism in the dominant culture and from negative cultural stereotypes about Black sexuality" (p. 241). Greene (2000) goes on to state "African

American lesbians provide an example of women who face the challenge of integrating more than one salient identity in an environment that devalues them on all levels" (p. 246). Loiacano cites noted African American lesbian writer Audre Lorde's lament on the challenges of integrating multiple cultural identities by "constantly being encouraged to pluck out some one aspect of self and present this as a meaningful whole, eclipsing or denying the other parts of self" (Lorde as quoted in Loiacano, 1998). Audre Lorde lost her battle to breast cancer in 1992.

Gender Identity Development

The medical and health policy paradigm is permeated with the concept of gender essentialism (Wilson & Hammon, 2001). American history is replete with warnings to women who do not conform to appropriate roles. In the early 1900s, women who sought to expand their gender boundaries by demanding the right to vote or asserting their desire for equality were often discounted or institutionalized as a hysteric (Mayor, 1974). The essentialism of gender posits the inextricable link between sex (male/female) and gender roles (man/woman). For LGBT people, in particular, gender labels are often in conflict with the level of human diversity within the community.

There is a growing body of literature that confirms gender as a non-dichotomous social construct (Anderson, 2003; Butler, 1990; DeBeauvior, 1952; Garber, 1992; Kessler & McKenna, 1978; Lorber, 1994). The terms *male* and *female* refer to biologic sex, i.e., genitalia. Whereas the terms *man/woman* are social constructs and as such are linked to the adherence to cultural and societal norms of femininity or masculinity, and the psychological sense of being male or female. Gender identify refers to one's sense of gender (either man or woman), and can fall anywhere along the emerging ideation of the

gender continuum (Eyler & Wright, 1997). Gender role refers to performing behaviors that are culturally associated with gender identity. The expression of one's gender identity is often visible in choice of clothing, hairstyle, and activities. For example, people who are biologically female may have an identity as male, and dress and act accordingly. This is also true for gender roles, because choice of clothing or activities could reflect the idea that one is of a particular gender or that one wants to be seen by others as untied from traditional gender-specific roles. Individuals may identify as their biological sex but feel more comfortable with behaviors, perspectives, and ideas that are of the opposite gender. Individuals who experience gender variance fall within the umbrella of transgender, although this is a relatively new terminology in the gender lexicon. As an umbrella term, transgender can be inclusive of cross-dressers, butch lesbians, radical faeries, drag queens, drag kings, gender-blenders etc (Gender Education & Advocacy, 2001; Goodrum, 1998). Eyler and Wright (1997) refer to gender-blended and ungendered perspectives on gender. Gender identity and its impact on health behaviors is not well understood and should be addressed by empirical research.

The barriers to accessing health care services for lesbians have long been recognized to include structural, financial and personal/cultural barriers (Fields & Scout, 2001; Dibble, Vanoni, & Miaskowski, 1997; Schatz & O'Hanlan, 1994; Gay and Lesbian Medical Association, 2001). Gender identity or erotic role may intensify barriers experienced by lesbians. For example, research has shown that many lesbians utilize a construct or gender identity that includes butch, androgynous, and femme designations. These identities are not merely duplications of male and female roles but as Singh (1999) reported "authentic, lesbian-specific expressions of natural sexuality that, because of the

lack of alternative language, have simply been assigned heterocentric labels". Theorists have described the social contract ascribed to gendered behavior as "doing gender" (Anderson, 2003). Williams, Green, and Goodman (1979) have operationalized the concept of tomboy to refer to young girls who have an equal number of male and female friends, prefer to dress in boy's clothing, exhibit gender atypical play and other behaviors, and who are more likely to be involved athletically with boys than with their female peer group. Anderson goes on to note that research on tomboys has revealed that young girls who are classified as such are not merely imitating boys, but constructing a gendered identity that incorporates a conceptualization of both male and female. For butch-identified lesbians (BIL), expression of gender variation is most visible in style of dress, hairstyle, activities, and mannerisms. However, morphologic differences in waist to hip ratio, recall of atypical childhood behavior, desire to give birth and raise children, and salivary testosterone levels have also been noted (Singh et al., 1999). The outward expression of a gender that is incongruent with biologic sex can often be problematic in relating to the world, or more specifically mediating how the world relates to the individual, according to various theorists (Gruskin, 1999). It makes sense, therefore, that behaving and living as a BIL would create difficulty in accessing gynecologic cancer screening. In light of the previously identified homophobia in the medical community, this very visible expression of variance could potentially increase internal and external barriers to accessing healthcare. There are no data, however, that support this idea.

BIL who identify strongly as masculine may exhibit some level of anatomic dysphoria or extreme discomfort with the parts of their body that are most female. These feelings may cause them to deny their need for gynecologic care. Anecdotal reports

indicate that some BIL may not like to be touched in any ways that are related to female sexuality including the kind of penetration required for a pelvic examination or Pap smear. Therefore, accessing a clinical breast exam (CBE) or submitting to a Pap smear or any other gynecologic care can be anathema and traumatic to them. BIL accessing services at the Mautner Project have reported numerous negative experiences in obtaining gynecologic care ranging from panic attacks, crying during pelvic examinations to avoidance of gynecologic care at all costs (personal communication, K. Goodman, June 2003). An additional barrier is the negative responses providers BIL receive from healthcare when they do attempt to access gynecologic care. These range from inappropriate comments from providers regarding their clothing or appearance, or the difficulty or pain experienced by the patient as the speculum is introduced to rough treatment and assumptions about sexual orientation. Unfortunately, most of the data on BIL is anecdotal with few peer reviewed published articles addressing healthcare access for this community.

Access to Care

Access to and utilization of breast and cervical cancer screening is critically important in early detection of cancer (Hewitt et al., 2002). Lauver et al., (1999) identified barriers and facilitators of mammography utilization in two samples of older lesbians (aged 51-80 years). Through telephone interviews the researchers determined barriers and facilitators based on three modalities: personal factors, client-practitioner relationship factors, and system factors. For women who had not received mammography (Sample 2), lack of motivation (Personal Factor) was listed as the overall number one reason for not being screened. Women who had not been screened were more likely to

cite lack of trust in their practitioner/medical community (15%) and lack of risk for breast cancer or worth of mammography (26% and 10% respectively, compared with women who had had a mammogram (0% for both categories). Additionally, women who had not had a mammogram were more likely to suggest that lesbian specific outreach/education (3%) and openness/safety for lesbians in health care (3%) would facilitate their mammography utilization. Neither of these reasons was cited by women who had obtained a mammogram. System factors were more likely to facilitate mammography screening. The most often cited facilitator for screening among women who had not received a mammogram was scheduling/convenient hours (26%), compared with access/financial coverage (37%) which was the most cited reason for women who had received a mammogram. This data suggests a variety of motivators of and barriers to the utilization of mammography screening among lesbians and bisexual women. However, these studies fail to determine the possible impact of expectations of racism or the interaction of racism and homophobia on utilization of screening. The impact of perceived racism and heterosexism on health outcomes for this community is of great importance when one takes into consideration the differential risk proffered by tumor etiology, personal, structural, and financial barriers to care.

Personal/Cultural

Personal barriers refer to those barriers that occur at the individual level. Included in these barriers are age, knowledge, and attitudes towards cancer screening. Bassett, Maniikian, & Gold, (1990) cite mammography-screening barriers as being related to unclear benefits of screening, fear, cost, and physician related factors. For lesbians personal barriers include the fear of negative responses of health care providers. This

fear, based in previous personal negative experiences, and vicarious experiences from friends, often cause lesbians to delay seeking health care. Personal barriers also include bias and heterosexism on the part of health care providers (Dean et al., 2000).

Structural Barriers

Institutionalized or structural barriers refer to health related systems such as office hours that are inaccessible, availability of transportation and childcare. For lesbians and bisexual women, these barriers are expanded to include heterosexism and homophobia of health care providers. While homophobia is the overt dislike or fear of homosexuals (Blumenfeld, 1992), often the subtler heterosexism is more pervasive. Heterosexism is used to describe situations in which the assumption of heterosexuality is absolute until proven otherwise. The term was defined further in the seminal work by Dean et al., (2000) as "characteristics of an ideological system that denies, denigrates, and stigmatizes any non-heterosexual form of behavior, identity, relationship, or community." Heterosexism in the American medical system is illustrated by denial of partner visitation in critical care settings, exclusion of partners from health care decision making, and the exclusion of gay, lesbian, and bisexual women's realities on medical intake questionnaires. For example, if a female patient is sexually active it is assumed that she uses or needs birth control (Gruskin, 1999). Marital status on intake forms is limited to single, married, widowed or divorced allowing little room for a same sex partnered woman to designate her relationship.

Financial Barriers

Although research points to high levels of income for some in the LGBT community, it does not hold true for lesbians or African Americans in general. A recent

analysis of same sex couples who participated in the U.S. Census Bureau revealed that African Americans in same sex relationships are more likely to hold public sector jobs than European American same sex couples (Dang & Frazer, 2004). Additionally, African American lesbians in same sex relationships have a median annual household income that is 17% lower than African American women in opposite-sex relationships. This decreased income and increased burden created by lesbians' inability to marry in most states can create a financial strain which may in turn impact care.

Lack of health care insurance is a significant barrier to accessing screening services. Numerous studies have demonstrated lower levels of health insurance among the LGBT community. Although many local governments and private organizations offer domestic partner benefits to its employees, those benefits are subject to taxation as income, unlike spousal benefits for married couples.

Lesbian Screening Behaviors

Bradford, Ryan, & Rothblum (1994) conducted the first national study of lesbians and women who partner with women in the late 1980's. This study, for the first time, detailed national data that addressed the preventive health behaviors of WPW. Although relatively few African American lesbians (6%) were included in the sample of 1,925, this study represented a benchmark in lesbian health research as the first study to document the underutilization of preventive cancer screening among lesbian and bisexual women. In the intervening two decades many other researchers have addressed preventive cancer screening including mammography, BSE, and CBE; behavioral risk factors such as smoking, alcohol use, obesity and exercise; and access to care including insurance, disclosure of sexual orientation and delays in accessing care for lesbians and bisexual

women. An early study of 1,362 lesbians and bisexual women found that lesbians were significantly less likely to participate in mammography screening than heterosexual women (Koh, 2000). In a study of lesbians in the Washington, DC Metropolitan area, almost 50% of all women surveyed had not received a clinical breast exam in the past year (Michaels, 2000). These findings have been repeated in multiple lesbian health studies.

Interestingly, the amount of time one spends as a lesbian seems to impact extent of barriers to care. Valanis and colleagues (2001) found differences in women who identified as lifetime lesbians and those that became lesbians at 45 years and older, classified as adult lesbians. Women who became lesbians as adults were more likely to have had mammography during the past year (69%) than all other groups including asexual adult women (65.2%), heterosexual women (66.7%) and bisexual women (65.2%) (Valanis et al., 2000). Lifetime lesbians, however, had the lowest utilization of mammography (62.6%) among all groups. These findings suggest that screening habits formed as a heterosexual woman, which are undoubtedly facilitated by the absence of structural and interpersonal barriers to care, may carry over once one becomes a lesbian. However, a lifetime of exposure to both internal and external barriers due to sexual orientation may have a lasting negative effect.

A recent study comparing breast and reproductive cancer risk factors for lesbians and their sisters found no significant differences in mammography utilization (Zaritsky & Dibble, 2010). Roberts & Sorenson (1999) found that lesbians had similar rates of preventive cancer screening as women in the general population. Forty-three percent reported occasionally doing BSE and 58% of women in their 40's and 79% of women in

their 50's reported ever having a mammogram. These findings were comparable to women who completed the National Health Interview Survey at the same time. However, lesbians reported higher levels of education than women in the general population, and based on our knowledge of the impact of education on utilization of cancer screening should have had higher screening rates than reported. Zaritsky and Dibble (2010) also found that lesbian sisters did significantly fewer BSEs than their heterosexual sisters.

Although these studies were based on convenience samples, their findings have in part borne out by population based studies. A population based study conducted in Los Angeles found that lesbians were less likely to use preventive health serves and more likely to suffer barriers to care such as lack of health care insurance (Diamant et al., 2000). Researchers found no differences in mammography screening based on sexual orientation although differences in clinical breast examination and Pap smear usage were found (Diamant et al., 2000). A population based study in New York City found that women who have sex with women (WSW) were 4 times more likely to have not a timely mammogram and 10 times more likely to have not had a timely Pap smear than non-WSW (Kerker, Mostashari, & Thorpe, 2006). Researchers also found that WSW were less likely to have health care insurance and a primary healthcare provider than non-WSW. It is unclear what role differences in definitions used to define the population, i.e., identity vs. behavior, may play in these two studies.

Lesbian Behavioral Risk Factors

Many of the behavioral factors that are associated with lower cancer risk are diminished among lesbians (Solarz, 1999). Numerous studies have demonstrated increased levels of obesity (Dibble, Roberts, Robertson, & Paul, 2002), alcohol and

tobacco use, and inadequate intake of fruits and vegetables (Valanis et al., 2000) among

lesbians, which may place them at increased risk of cancer (Aaron et al., 2001; Gruskin,

Hart, Gordon, & Ackerson, 2001; Cochran et al., 2001).

Obesity & Physical Activity

Data collected for the Women's Health Initiative found that 51% of lifetime

lesbians and 50% of adult lesbians were overweight or obese compared with 45% of

heterosexual women (Valanis et al., 2000). The community-based Epidemiologic Study

of Health Risk in Lesbians (ESTER), conducted in Pittsburgh, PA found that 47.8% of

lesbians were overweight or obese (Aaron et al., 2001). Interestingly, both of these

studies also showed lesbians to be more likely to exercise than heterosexual women.

Similar findings were discovered when lesbians were compared with their heterosexual

sisters (Roberts, Dibble, Nussey, & Casey, 2003). In fact, researchers in the ESTER study

found that when engaged in physical activities, lesbians are more likely to engage in

vigorous physical activity when compared with heterosexual women. Dilley et al., found

that while lesbians and bisexual women who participated in the Behavioral Risk Factor

Surveillance System (BRFSS) during a four year period reported the being more

overweight than heterosexual women, they had similar levels of physical activity (2010).

Although little data are available on obesity and other risk factors among African

American lesbians, one study found similar rates of obesity between this group and

European American lesbians (Yancy, Cochran, Corliss, & Mays, 2003).

Tobacco and Alcohol Use

Although, the link between tobacco use and increased risk for breast cancer has

not been fully clarified, the link between tobacco use and diminished screening utilization

is clear (McBride et al., 1993; Murabito et al., 2001; Schueler et al., 2008). As with other risk factors, strong evidence in both convenience and population-based studies suggests that lesbians smoke more than heterosexual women (Bradford et al., 1994; Ryan, Wortley, Easton, Penderson, & Greenwood, 2001; Skinner, 1994; Valanis et al., 2000). A 1984-1985 national survey of lesbians found that 41% of lesbians age 17 years and older were current smokers. A more recent meta-analysis of lesbian health studies conducted using data collected between 1987-1996 revealed that after standardizing for age, race, and geography, the prevalence of current and past smoking among lesbians greatly exceeded the national norms for women (Cochran et al., 2001). In another review of the literature Ryan, et al. (2001) also found an increase in smoking levels for gay and lesbian adolescents (38% to 59%) and adults (11% to 50%). Although few population based studies have examined risk behaviors among lesbians, a recent analysis of the Washington BRFSS supported data obtained in convenience samples (Dilley et al., 2010). Data collected between 2003-2006 revealed that lesbians and bisexual women are more likely to be overweight, drink and smoke heavier than heterosexual women.

These increased levels of tobacco use are thought to be related to a number of factors prevalent in the gay and lesbian community. For example, gays and lesbians are exposed to increased levels of stress caused by discrimination and heterosexism. Tobacco, alcohol and drugs are often used as mediators of stress (Skinner, 1994). In a population based study in California researchers found that 25% of lesbians smoked, 70% more than heterosexual women (Tang et al., 2004). The link between tobacco and alcohol use has long been established, particularly in bars. For many in the LGBT community bars have traditionally represented key social outlets (National Association of LGBT

Community Centers (NALGBTCC), 2004). Phrases like "can I have a light?" or "can I bum a cigarette" are frequently used as a vehicle for introductions. As one of the few places where gays and lesbians could safely meet, bars provided ample opportunity to combine multiple unhealthy behaviors: drinking and smoking (Goebel, 1994).

Nulliparity

A recent analysis of the 2000 census revealed that 61% of Black female same-sex households were raising children compared with 69% of married opposite-sex couples (Dang & Frazer, 2004). Although almost half (48%) of Black women in same-sex households reported being previously married [the same rate as European American women in same-sex households], 53% of Black women in same sex households report raising biologic children compared with 34% European American women. The similarity in rates of child rearing suggests similar pregnancy rates between Black lesbians and heterosexual women living in married or pseudo-married relationships. Pioneering work by Cochran & Mays (1988) in African American lesbian health revealed that 90% of African American lesbians reported heterosexual coitus, and were more likely to have previously been married and have mothered children than European American lesbians. Whether this finding is a result of heterosexual immersion is debatable; however, the health implications of a non-delay in childbearing are numerous. For example, childbearing prior to age 30 years may decrease the risk of breast cancer among women.

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Health Seeking Behaviors Among Lesbians

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Lesbians delay seeking health care and screening more than their heterosexual counterparts due to difficulty obtaining health care and communicating with a primary care provider (White & Dull, 1997). In their study of lesbians, 23% reported never

seeking care or waiting until their symptoms became severe to seek care. The researchers

were able to predict health seeking behavior based on ease of patient-provider

communication, ease of discussing health care issues such as depression and menopause

with their provider, and the general ease with which women could get needed health care.

In another study 50% of lesbians rarely or never sought routine medical care despite

being highly educated, insured, and having access to health care because of negative

experiences with health care providers (Harrison, 1996). Additionally, diminished access

to health care insurance for both African American women and lesbians may impact

utilization of breast and cervical cancer screening (Valanis et al., 2000).

A recent population based study using data from the National Health Interview

Survey found that women in same-sex relationships were less likely to use health care

services, have lower levels of health insurance coverage, and more likely to have unmet

health care needs (Heck, Sell, & Gorrin, 2006). The researchers concluded that the

disparities in care for individuals in same-sex and opposite sex relationships were most

likely due to a previous history of homophobic treatment by the health care providers.

This study validates a model for accessing health care which includes predisposing (age,

race, education, and some behavioral factors), enabling (income, employment, and health

insurance), and need-related factors previously described by Andersen (1995) as salient

to individuals in same-sex relationships. It also further supports the assertion that gay and

lesbians experience decreased access to health care services which may have an impact

on preventive care and screening.

Disclosure of Sexual Orientation

Disclosure of sexual orientation is another factor thought to impact access to care and health seeking behavior among lesbians. Numerous studies of primarily European American lesbians have demonstrated a reluctance to disclose sexual orientation. In a small ethnographic study of African American lesbians Mays, Cochran, & Rhue (1993) noted that African American lesbians use nondisclosure of sexual orientation as a coping strategy against possible homophobia. In a study of African American lesbians and bisexual women, Cochran & Mays, (1988), found that only a third (33%) of women surveyed had disclosed their sexual orientation to their primary care provider. This lack of disclosure on the part of African American lesbians is problematic in two regards. As mentioned previously, the benefits of disclosure include building a better rapport and relationship between provider and patient. The lack of disclosure impedes this relationship. However since a preponderance of the lesbian health literature addresses the behaviors of European American lesbians, disclosure by African American lesbians will undoubtedly prompt physicians to make assumptions based on a model of health behavior un-illuminated by cultural background. African American lesbians have remained virtually invisible in the literature thereby perpetuating the myth of ethnoheterosexuality.

Impact of Heterosexism on Access to Screening

Stevens (1995) points to barriers to health-seeking created by macro level heterosexist structuring within the health delivery system. This structuring is based on the presumption of heterosexuality in the way in which services are delivered. For example, preventative screenings are generally linked to the delivery of family planning services and are therefore deemed unnecessary by lesbians. The researcher also cited micro level

barriers that included heterosexist attitudes by individual providers. A thorough review of the literature by O'Hanlan (1995), a noted lesbian gynecologic oncology surgeon, listed numerous studies in which nursing students, medical students and physicians have exhibited homophobic and heterosexist views regarding their lesbian patients. Cultural competency training programs for physicians, nurses, and other allied health workers have emerged over the past decade to fill the gap left by traditional medical education. Although intermediate change in knowledge, attitudes, and beliefs have been observed immediately and three months post training, physician participation has been low (Scout, Bradford, & Fields, 2001).

The involvement of micro level structural barriers created by heterosexist and homophobic attitudes of health care providers cannot be ignored in describing health seeking behaviors among lesbians (Stevens, 1995). Even in the absence of overt homophobic comments, negative attitudes and feelings are still perceptible to the patient through provider's discomfort, and inability to maintain eye contact (Stevens, 1995). Additionally, for lesbians of color, particularly African American lesbians, it is difficult to disentangle the effects of perceived racism and heterosexism on access to care. Several experiences captured during in-depth interviews with lesbians of color revealed instances where physicians make assumptions about educational attainment, sexual history, and sexually transmitted disease (STD) status, even among disclosed lesbians (Hiatt et al., 2001). Heterosexist attitudes also interfere with patients' ability to include partners in health decision making, thereby removing supportive advocates from the health care discussion.

Summary

Ford and colleagues (2001) demonstrated the lack of compliance with the government's recommendations for healthy lifestyle behaviors in the United States population. This was particularly apparent among African American women. Few studies have examined the interrelationship of race, sexual orientation and gender identity (Safford, 2002). The lack of data on African American lesbian and bisexual women diminishes our ability to examine the impact of healthy lifestyle behaviors and behavioral risk factors in this population. The purpose of this study was to examine breast cancer screening and other health related behaviors of African American lesbian and bisexual women. We hypothesized that women who are actively engaged in self-care behaviors such as weight control, exercise, eating right, and routine physician visits are more likely to include breast and cervical cancer screening in their self-care regimen and that women who engage in unhealthy behaviors such as being overweight, smoking, not eating 5 or more fruits and vegetables a day are less likely to participate in breast and cervical cancer screening. Therefore, this analysis will examine the impact and predictive value of wellness behaviors on adherence to age appropriate breast cancer screening recommendations.

Chapter 3: Methodology

Introduction and Overview

The *Black Wome*n *2 Wome*n *Spirit Health Study* was a self-administered, cross-sectional, mail/internet based survey that examined African American lesbian breast cancer risk factors, screening behaviors, and barriers to healthcare access. The researcher conducted this secondary analysis of this dataset to examine the impact of age, gender identity, and access to healthcare, as well as the impact of healthy living behaviors, on screening adherence. Data from this study can be used to develop model interventions to increase breast cancer screening among AAL. Chapter 3 describes the research design used in the original study and provides a description of the target population and how they were recruited. Additionally, Chapter 3 contains a description of the instrument, variables chosen to answer the posed research questions, and an analysis plan.

Description of the Research Design

As a method of inquiry, quantitative research design is used to generate data to formulate theories and test hypotheses. This methodology differs from qualitative research in that its goal is not to develop a better understanding of 'context' and 'completeness of descriptions' but to select and collect indicators that can be used to explain actions (Harris, 1998). The Spirit Study used a quantitative research design to examine relationships, between indicators as a means of developing a model that is associated with or predictive of African American lesbian breast cancer screening adherence.

While the state of the art in lesbian health research has advanced to the use of population-based samples, only one study of this type had been published at the time this

study was conducted (Diamant et al., 2000). Through an extensive search of the literature it seems that no studies exist on breast cancer screening behavior specifically among AAL. Therefore, an exploratory, non-probability sample represented the most appropriate first step in describing behaviors and developing theories and hypothesis before further analytic studies can be undertaken.

According to Laumann and colleagues, (1994) lesbians represent only 2-6% of the United States population. The authors made no estimates on the number of African American lesbians. It would, therefore, be extremely difficult to identify a probability-based, random sample of participants for this study who are both lesbian and African American. Hence, subjects for this non-probability study were recruited using convenience and snow-ball sampling techniques. Questionnaires were available at pride celebrations, bookstores, parties, and health centers, etc. Women who happen to come to those events or organizations were able to participate in the study. Additionally, respondents were asked to forward a questionnaire on to their friends or partners for completion. This increased the number of participants based on a respondent's social network. The study utilized a list sampling technique to distribute questionnaires through organizational mailing lists, and magazine subscriber lists (Dean et al., 2000). The study also utilized the world-wide-web to collect data as well as publicize the survey through web zines, websites, and listservs.

Validated scales from existing questionnaires were used to develop the Spirit Study instrument whenever possible. Pretesting was conducted locally prior to fielding the instrument. Additional psychometric testing was completed using an expert review

committee and AAL community leaders. These reviews established face validity of the questions and scales used in the instrument (Bryman & Cramer, 2009).

The overall purpose of any analysis of quantitative data is the quest to elucidate variations in behaviors, knowledge, attitudes or other indicators (Bryman & Cramer, 2009) as well establish a process for drawing inferences from those variations (Hazelrigg, 2009; Harris, 1998).The analysis of this secondary data focused on women 20 years of age and older who identified as African American and have had a same-sex sexual encounter over the past 5 years or who self-identified as lesbian or bisexual. To answer the research questions, data was analyzed for age appropriate screening behavior. This secondary analysis sought to determine correlations between the breast cancer screening compliance (dependent variables) and the hypothesized independent variables in the following categories: demographic data (Hypothesis 1: age, educational level, and insurance status); healthy lifestyle behaviors (Hypothesis 2: normal weight, engaging in physical activity, smoking, fruit, and vegetable intake); gender identity (Hypothesis 3: categorized as butch, femme, and androgynous); and experiences with the health care system (Hypothesis 4: having a primary health care provider, being out to a primary care provider, previous, and anticipated negative experiences with health care providers). Two aspects of screening adherence, ever participated in breast cancer screening and compliance with screening guidelines, were analyzed. Data from this study will be used to develop models that may explain and/or predict age appropriate screening adherence for this population. This study used the ACS screening guidelines, which recommends monthly BSE, CBE every 3 years for women between ages 20 to 40 years and annually after age 40 years, and annual mammography screening at 40 years (Smith et al., 2003).

Target Population

One of the major challenges in conducting research on lesbian health behavior and risk factors is in defining the population. Previous studies have differed in how lesbian identity is defined. Researchers have defined it based on the triumvirate of same-sex behavior, identity, and/or desire/attraction (Solarz, 1999). Sexual identity and the use of language to describe oneself may be different among African American lesbians. For example, the term lesbian is a sociopolitical construct that has been rejected by some African American women. Anecdotal data collected by the researcher revealed that African American lesbians are more likely to use terms like, same gender loving women than the word lesbian to describe themselves. The Community Advisory Committee for the study confirmed this information; therefore, in order to make the study more acceptable to this population the title was changed to specifically exclude the word lesbian. In order to be more inclusive, lesbian identity was operationalized for both the original study and secondary analysis to include both behavior and self identity. The use of the word Spirit in the original study title is culturally significant to the African American community.

Sampling Procedure

Sample Size

One of the reasons that most studies of lesbians have included few AAL is because these studies were done by European American researchers in bars and other social gathering places where an AAL presence was scarce (Gonsiorek, 1991). Participant recruitment was done in a variety of ways, and at a variety of venues. The project received assistance in distribution of questionnaires from nationally placed

Outreach Consultants. These consultants had access to contacts lists of AAL and AAL organizations throughout the country. Additionally, the project worked with the African American gay and lesbian faith community, national magazines, newsletters, and the world-wide-web to recruit participants. Six hundred and sixty seven surveys were returned in the original study. Twenty three cases that did not meet the study eligibility criteria or had more than 50% blank data were removed from the study dataset. A total of 644 eligible cases remained. G*Power was used to determine the study power. Given the sample size, the likelihood of committing a Type II error, rejecting the null hypothesis when the null hypothesis is true, ranges from 0.0876855 to 0.9509235 depending on the type of test used. The likelihood of accepting the null hypothesis when it is not true (alpha) is set to .05.

Eligibility Criteria

The data collected in the original study was intended to explore cancer and other health screening behaviors, personal and family health history, social support and community connectedness and "outness" among a subset of African American women. Therefore the eligibility criteria for study participation included the following:

- African American women living in the United States at the time of data collection.

- Lesbian or bisexual identity or same sex behavior within the previous five years.

- Attainment of 20 years of age at the time of data collection.

- Ability to read and write in English.

Instrumentation

The *Spirit Study* questionnaire was developed through a community based participatory process. A thorough literature search using Medline and Social Works Abstracts, two popular literature search engines, lead to several domains that addressed the behavioral determinants of cancer screening utilization among African American women and lesbian and bisexual women that were examined for their utility in the proposed research study. Clearly, predictors of breast cancer screening are multifaceted and encompass a wide variety of individual health behavior and health history. The recent Framingham Offspring study identified sixteen potential correlates to mammography screening alone. These included:

> "recent CBE, CBE ever, performance of BSE, self-reported breast disorder, self-reported breast surgery, age at first childbirth, age at menarche, oral contraceptive use, smoking, alcohol intake, use of routine check-ups, physician visits prompted by illness, marital status, education, subjective health, and self-perceived risk of breast cancer." (Murabito et al., 2001, p. 917)

Once the relevant domains were identified a research framework depicting the hypothesized relationships between domains was constructed. The goal of the data analysis is to determine what factors were highly correlated with screening adherence. The researcher believes that adherence to screening is impacted by a multidimensional cadre of factors, some that promote adherence and some that challenge adherence. The Spirit Study survey instrument can be found in Appendix A.

Demographic Data

Demographic data collected included date of birth, income level (in ranges), highest educational level attained, sexual orientation (lesbian, bisexual, heterosexual, other), gender identity (femme, butch, androgynous, other). Frequencies for demographic variables can be found in Chapter 4.

Description of Study Variables

The variables selected for this secondary analysis are based on available research on the predictors and barriers to adherence to breast cancer screening guidelines. Given that this is a secondary analysis, variables that were previously collected as nominal or ordinal may need to be recoded prior to analysis. Additionally, some variables such as body mass index and adherence scores were computed based on existing variables. Table 1 contains the independent and dependent variables examined in this secondary analysis.

Table 1

Description of Study Variables

Variable	Description	Measurement
Cigarette smoking	Independent	Nominal variable, "Do you currently smoke cigarettes?" coded as Yes/No.
Physical activity	Independent	Nominal data, multiple variables assessing type and frequency of activity.
Body mass index (BMI)	Independent	Interval data, calculated using height and weight.
Gender identity	Independent	Nominal data, "What word best describes your gender identity?" *Butch*, *Femme*, *Androgynous* (neither butch nor femme), *Other*.
Nutrition	Independent	Nominal, multiple variables assessing type of fruit/vegetables, frequency of consumption.
Health insurance	Independent	Nominal variable, type of health insurance including no insurance and nine insurance categories including public, health maintenance organization (HMO), private and military.
Income level	Independent	Ordinal variable.
Primary health care provider (PHCP)	Independent	Nominal variable, coded as Yes/No.
Out to PHCP	Independent	Nominal variable, coded as no PHCP, out and not out.
Anticipated negative experiences with health care providers	Independent	Nominal variable, coded as Yes/No.
Previous negative experiences with health care providers	Independent	Nominal variable, coded as Yes/No.
Mammography compliant	Dependent	Nominal variable, measured between past 12 months and 4 or more years ago. Recode to compliant, non-compliant.

(table continues)

Variable	Description of Variable	Level of Measurement
Clinical breast examination (CBE) compliant	Dependent	Nominal variable, measured between past twelve months and 4 or more years ago. Recode to compliant, non-compliant.
Breast-self examination (BSE) compliant	Dependent	Nominal variable, measured from within past 30 days to 4 or more months ago. Recode as compliant, non-compliant.
Breast cancer screening compliant – overall	Dependent	Nominal, computed from mammogram, BSE, CBE compliant scores.
Ever had mammogram	Dependent	Nominal variable coded as Yes/No.
Ever had CBE	Dependent	Nominal variable coded as Yes/No, don't know.
Ever done BSE	Dependent	Nominal variable coded as Yes/No, don't know.

Instrument Validation

The Scientific Advisory Committee for the original study assisted in the

identification of domains for the questionnaire, validated scales and face validity of

questions. Established questionnaires included the Georgetown University Lesbian Breast

Cancer Study (Burnet et al., 1999) the Boston University Black Women's Health Study

(Adams-Campbell et al., 2001); the University of Maryland Outness Inventory (Mohr &

Fassinger, 2000), multidimensional health locus of control (Wallston, 2007), and the

Human Rights Campaign (HRC) Black Pride Study 2001. In each case, permission to use

portions of the non-government instruments was obtained prior to their use. Additionally,

several government questionnaires were used to insure that data were compatible with

national statistics. These questionnaires included the CDC BRFSS, the National Drug

Abuse-Camp Household Survey, and the National Health and Nutrition and Exercise Survey (NHANES). Questions from the Sarasson social support scale were modified for inclusion in the survey. Additionally, questions were developed specifically for this study by the investigator. Once questions in each domain were selected or designed, the Community Advisory Committee established construct and face validity of the instrument. Their review ensured readability and understandability of the instrument. An expert review comprised of lesbian health researchers including Caitlin Ryan, Ph.D., Judy Bradford, Ph.D., Scout, Ph.D., Liz Gruskin, Ph.D., and others represented the third layer of review of face validity.

Psychometric testing was conducted through "talk aloud" pilot test interviews conducted by a trained interviewer who matched the study population. Participants were recruited from the Whitman Walker Clinic's Anacostia satellite office. This satellite office is located in a primarily African American inner-city neighborhood in Washington, DC. Nineteen pilot test interviews were conducted. Members of the project team reviewed piloted questionnaires and problem items were revised for clarity.

Data Collection

Data collection for the original study began in August of 2002 and continued through August of 2003. The recruitment strategy designed for the original study included the dissemination of study information on multiple levels through multiple sources. This is a common strategy employed by numerous lesbian health studies (Weber, 1996; Bradford, Ryan & Rothblum, 1994). The strategy included organizational outreach, advertisements, and individual referrals. The study used a purposive sampling technique to recruit study participants. Since African American lesbians are often not connected to

mainstream gay and lesbian organizations, the Principle Investigator of the original study identified Black LGBT organizations, websites, listservs, magazines, and newsletters to publicize the study. Information dissemination occurred primarily through press releases, advertisements, the Internet, and word of mouth. Additionally, the project team developed a study related information packet. The project's information packet was sent out to organizations such as LGBT community centers, health centers, and LGBT churches. This packet contained a cover letter, a copy of the questionnaire, a brochure, and a bounce back card to be used to request additional copies of the questionnaire. This was a useful tool in mailing large quantities of questionnaires to organizations.

Questionnaire packets consisting of an introduction letter, two consent forms, a thank you gift, questionnaire and a stamped, self-addressed return envelope were mailed to interested participants and distributed at various events. Additional letters of endorsement were mailed with the questionnaire packet in instances when the survey was mailed in collaboration with other organizations. In one case, the questionnaire packet was mailed with the Black Lesbian Support Group (BLSG) newsletter and an accompanying letter from the group's president. This allowed the study to absorb the cost of the newsletter mailing as a trade-off for using the group's mailing list. Organizational mailing lists were also shared with the project in the form of pre-printed address labels. This process, while allowing the partnering organization to safeguard their mailing list also necessitated a onetime only mailing of the questionnaire without the initial introductory letter.

Returned questionnaires were coded with a study identification number (SID). Introduction letters mailed to participants during the recruitment process informed them

that their information would not be linked to their name and that data from this study would only be reported in aggregate. No personal identifiers were keyed as part of the original study dataset. Completed questionnaires were keyed using Epi Info, a statistical analysis and data management package developed by CDC. Keyed data were then imported into SPSS for analysis (SPSS, Inc., 2002).

Mail Survey

As part of the project's purposive sampling strategy, the mailing list of a national African American LGBT magazine (*Venus Magazine*) was used to distribute questionnaires to female subscribers. The subscription base for this magazine at the time of study initiation was 1,200 individuals and organizations. Half of the subscribers were identified as female, producing a list of 502 women. The assumptions inherent in using this mailing list are: a) the majority of subscribers identify as gay, lesbian, or bisexual and b) subscribers identify as African American. Surveys mailed to Venus subscribers used a modified version of the Dillman tailored design method (TDM) (Dillman, 2000). First, an introductory letter signed by the magazine editor in chief and the investigator was sent to female subscribers to introduce the study and encourage participation. This letter was followed in two weeks by a questionnaire packet described further in the section on data collection. African American lesbian artwork produced by HoneyPot, Inc. served as the incentive for participation in the mailed survey. The project used a series of prints depicting African American lesbians purchased wholesale at .25 with a retail value of $10. The prints were suitable for framing. Subsequent reminder mailings to subscribers were not done based on an agreement with the magazine's editor. This eliminated the additional expense of mailing reminder cards and replacement surveys/return

envelopes/incentives to non-respondents. Of the original 502 mailed, 63 were returned with bad addresses, six were returned from the Post office with new forwarding addresses, and 4 were forwarded to new addresses by the post office. Therefore, it is presumed that 84% of the original list received a survey.

Internet Survey

The Internet represents a powerful tool in behavioral research in the 21st century. According to Nesbary (2000), web based surveys present the best of self-administered and interviewer surveys. Surveys conducted through the internet are relatively inexpensive, and allow for the collection of accurate data that can be stored and transmitted electronically. To capitalize on this technology the researcher developed a survey related website (www.spiritstudy.org). A web-based questionnaire developed using www.SurveyMonkey.com was incorporated into this website. The Survey Monkey application allowed for online development of questionnaires with skip patterns, required questions, and options for data storage, transport and analysis. The online questionnaire was developed to resemble the mailed survey and contained similar instructions on instrument completion. Differences in the nature of the instructions were based on whether respondents needed to fill in the circle or use a mouse click for the appropriate response. The Internet based survey went online in November 2002 and continued through August 2003. Questionnaires entered online were downloaded as an Excel spreadsheet, the program supported by www.SurveyMonkey.com then imported into SPSS. No incentive was given for participation in the Internet-based survey.

Data Analysis

There are more than 300 variables contained in the Spirit Study dataset. Analyses for this dissertation focused primarily on exploring the relationships of the independent and dependent variables. The first step consisted of descriptive statistics (frequencies, variance, and means) on all variables prior to the bivariate and multivariate analysis. Data completeness was tested to ascertain level of missing data for each variable of interest. Where appropriate, variables were recoded and or computed to support the analysis. For example, BMI was computed from data for height and weight. Additionally, measures of adherence to breast cancer screening were based on the 2002 breast cancer screening guidelines for women 40 years of age and older. Adherence for each of the three types of screening modalities (mammogram, CBE, and BSE) were coded into adherent and non-adherent, based on screening recommendations. For example, mammography and CBE adherence was coded into screened within 1to 2 years, and non-adherent was coded as screened more than 2 years ago. BSE adherence was coded as screened within past last month, and non-adherent as screened more than one month ago. A composite score was created to adherence to all three screening methodologies. An individual who was adherent to all methodologies has a maximum score of three.

Non-parametric testing included chi-square or logistic regression aimed at uncovering predictive value of the test models (i.e., sociodemographic variables, wellness activities, sexual and gender minority status, and experience with health care providers). The analysis focused on the entire respondent group stratified by age categories where

screening guidelines dictate such a distinction, gender identification categories, and sexual orientation.

Chi square goodness of fit tests are mathematically suited for variables that are at a different measurement level than the dependent variable in this study. For example, the dependent variables (mammography, CBE, BSE adherence and the overall breast cancer screening compliance score) are all dichotomous variables while independent variables such as age, BMI, sexual orientation, gender identity are categorical variables. The *chi-square* assesses statistically significant associations between the dependent and independent variables. Additionally, logistic regression was used to determine how the predictive value of the independent variables on screening adherence. Below is a discussion of the independent variables and the dependent variable (cancer screening adherence) and their possible association to adherence.

Gender Identification and Presentation of Self

The role of gender identity and expression in adherence to cancer screening and cancer risk behavior has been under researched. Most lesbian health studies do not include information on gender identity and therefore associations of this type have not been possible (S. Cochran, personal communication, November 12, 2002). The term gender identity is used in this study to denote where people fall along a continuum of gender. As described earlier, this continuum has included femme (lesbians who have feminine sex roles and or characteristics) butch (lesbians possessing more masculine qualities) and androgynous (possessing both masculine and feminine characteristics). One component of gender identity is how gender is expressed to, and read by the outside world. For example, femme lesbians may have an outwardly feminine expression –

wearing lipstick, dresses, etc. They are therefore less likely to be identified as lesbians by the outside world. A butch identified lesbian would have a more masculine outward appearance. That external expression of gender may place butch identified lesbians at risk of increased discrimination in accessing health care services because of how they look. This is supported by previous research conducted by this researcher on gender identity which shows that an expression of a gender that is discordant from one's biologic sex can create internal and external barriers to accessing healthcare, particularly cancer screening (Pearson-Fields & Scout, Qualitative Analysis of the Impact of Butch Identity on Access to Cancer Screening, unpublished data). Several questions were included in this survey to address gender identity as well as expression among participants.

Adherence to Cancer Screening by Age

Cancer screening guidelines for women over 40 years vary depending on the agency making the recommendation and have evolved over time. For the purpose of this analysis screening adherence levels were be set at monthly BSE, and CBE every 1 to 2 years for all women, and mammography screening every 1 to 2 years for women 40 years of age and older. A dichotomous variable was developed for each screening methodology and an overall screening score that encompasses compliance with all three screenings.

Protection of Human Participants

To insure confidentiality of data, no personal identifiers were either collected or keyed in the original study. All completed questionnaires were subsequently coded with a study identification number (SIN) by the original investigator. The questionnaire packet included two copies of the consent form, one to be signed and retained by the participant

and the other to be returned with the completed questionnaire. Since the only identifying information collected appeared on the consent form (printed name and signature), questionnaires that were returned without a consent form were accepted as consent by assent. A web version of the consent form was posted on the Spirit Study website. This consent form asked participants to click their assent to participant in the study. The secondary analysis for this dissertation was approved by the Walden University Institutional Review Board (Approval No. 03-10-11-0091625).

Summary

Scientific research has assiduously demonstrated the behavioral disparities and barriers prevalent among lesbian and bisexual women as leading to a decrease in access to and utilization of preventative cancer screenings and therefore may increase cancer risk. These barriers, which include insurance status, homophobia/heterosexism, behavioral or lifestyle risk factors have been well documented in the literature. However, much of the literature has been based on young, European American, middle class lesbians. Additionally, lesbians are often viewed as a monolith without examining the nuances inherent in a diverse community such as the impact of gender identity and racial identity. Therefore, a clear understanding of the impact these nuances play in access to cancer screening and to some extent cancer risk have been difficult to gauge. Data in this analysis will begin to shed light on the fact that all lesbians are not alike, and that those differences, when viewed within the rubric of gender identity, may play an important role in access to cancer screening services. Developing a clearer understanding of these differences has important implications for public health programming. No longer can we assume that "one-size-fits-all". It is not enough to develop public health programs that are

inclusive of lesbians and women who partner with women. Public health practitioners must go further and develop programs that recognize the diversity within the community, in terms of both racial and gender identity.

Chapter 4: Results

Introduction

This chapter reports the findings on breast cancer screening among lesbians and women who partner with women. This analysis utilized data on Black lesbian health behavior collected using the Black Women 2 Women Sprit Health Study (Spirit Study). Data on breast cancer screening were examined in relationship to healthy lifestyle behaviors such as healthy weight, smoking status, exercise behavior, and healthy eating. In addition the impact of gender identity was observed as was the characteristics that promoted and deterred utilization of breast cancer screening. A discussion of the sample and the testing of each research question are presented in this chapter.

Purpose of Study

The purpose of this study was to analyze variance in adherence to breast cancer screening among African American lesbians and bisexual women who differed based on sociodemographic factors, healthy lifestyle behaviors, gender identity, and previous experience with health care providers. A pre-existing data set was analyzed to address the following null hypotheses:

Null Hypothesis #1 Sociodemographic factors such as age, education level, health insurance status, and income do not predict breast cancer screening adherence.

Null Hypothesis #2: Breast cancer screening adherence is not predicted by utilization of healthy lifestyle behaviors such as maintaining a normal weight, engaging in physical activity, refraining from smoking, and being out to one's health care provider.

Null Hypothesis 3: Breast cancer screening compliance is not predicted by gender

identity (butch, androgynous, femme) or sexual orientation (lesbian, bisexual).

Null Hypothesis 4: Breast cancer screening compliance is not predicted by

experiences with health care providers including having a PHCP, being out to

one's provider, previously being discriminated against or treated badly by PHCP

(actual negative experiences), being worried or afraid of being discriminated

against or treated badly by PHCP (anticipated negative experiences).

Description of Sample

Demographic Data

Six hundred and sixty seven surveys were returned in the original study. Twenty-

three cases that did not meet the study eligibility criteria or had more than 50% blank data

were removed from the study dataset. A total of 647 eligible cases remained. Table 2

contains the frequency distribution for sociodemographic independent variables included

in this analysis. The vast majority of participants (N=644, 99.5%) considered themselves

Black or African American; however within group identities varied. Because participants

were allowed to select more than one racial/ethnic identity group, African American

participants also identified as Afro–Caribbean (*n*=59, 9.1%), African Immigrant (*n*=6,

.9%), Black Hispanic (*n*=25, 6.6%), Caucasian (*n*=32, 4.9%), Native American (*n*=36,

5.6%), and Asian Pacific Islander (*n*=5, .8%). Participants were able to select from within

race distinctions such as Black/African American and Afro-Caribbean, African

Immigrant, and Black Hispanic, as well as between groups, i.e., Black/African Heritage

and European American, Hispanic, Asian, and/or Native American to denote mixed race.

Since this study was designed to assess barriers that may be related to race and sexual

orientation, only individuals who identified as Black/African Heritage were selected for analysis. Participants were generally young, with a mean age of 38.72 years (*SD10.43).* Slightly more than forty percent (*n*=279, 44.1%) of participants were 40 years of age and older. More than half of the participants had a college degree or higher. More than 80% of women were employed (*n*=534), and the majority of those employed worked full time *(n*=431, 63.3%).* The high levels of employment may contribute to the large number of women who had health care insurance (*n*=514, 82.8%). The majority of participants reported a lesbian orientation (*n*=544, 84.9%).

Table 2

Sociodemographic Variables

Characteristic*	n	%
Age		
20 to 29 years	132	20.7
30 to 39 years	225	35.3
40 to 49 years	183	28.3
50+ years	98	15.1
Education		
Less than college	30	4.8
Some college	237	37.7
College degree	309	49.1
Graduate school	53	8.4
Gender Identity		
Butch	122	19.2
Femme	259	40.7
Androgynous	256	40.2
Sexual Orientation		
Lesbian	544	84.9
Bisexual	97	15.1
Income		
< $15,000	62	9.9
$15,000 - $29,000	107	17.3
$30,000 - $49,999	184	29.4
$50,000 - $69,999	131	21.0
$70,000 - $99,999	81	13.0
≥$100,000	59	9.4

Note. *Variables totaling less than 647 represent exclusion of missing data from frequency distribution.

Given the multiple methods of distribution of the survey instrument, it is difficult to determine the overall return rate. The majority of respondents received the survey through community-based organizations or from their subscription to Venus Magazine (17.6% and 17.2% respectively). Fifteen percent (15.3%) of respondents received a copy of the survey from a friend, 13.4% completed the survey through an internet link, and 10% received the survey at a public gathering such as Pride celebrations, conferences, and workshops. Table 3 depicts the distribution of survey sources.

Table 3
Survey Sources

Where did you receive this questionnaire?	n*	%
Organization	111	17.6
Venus Magazine	108	17.2
Friend	96	15.3
Internet/email	84	13.4
Public gathering	63	10.0
Church	62	9.9
Signed up for study	26	4.1
Toll free number	20	3.2
Therapist's office	16	2.5
Other location (not classified elsewhere)	8	1.3
Bar	8	1.3
Don't remember where	8	1.3
Newsletter	7	1.1
School	4	0.6
Book store	1	0.2

Note. *25 cases missing

Coding and Recoding of Dependent Variables

Three variables were selected from the dataset to describe adherence to breast cancer screening guidelines - mammography, CBE, and monthly BSE. Each screening methodology was assessed by three questions addressing lifetime utilization, last screening, and screening frequency. Women who responded 'No' to lifetime utilization, i.e., they had never received the test in question, skipped to the next set of questions. All

questions were closed ended. Dependent variables were recoded to compliant/non-compliant based on screening guidelines. This chapter contains a description of screening guidelines used, original coding for dependent variables, and recoding scheme.

Mammography

The ACS recommends mammography screening for women 40 years of age and older at intervals of 1-2 years (Smith et al., 2003). That recommendation was re-confirmed in a statement posted to the Deputy Chief Medical Officer for the national office of the ACS, Len Litchfield's blog on the ACS website (Litchfield, 2009) in response to the USPSTF updated recommendation against routine screening for women 40 – 49 years (USPSTF, 2009). This recommendation is particularly relevant for African American women who are more likely to be diagnosed younger than European American women and with more aggressive forms of cancer. Therefore, since the data analyzed herein were collected from African American women and according to pre-2009 mammogram guidelines, screening compliance was defined as having a mammogram every 1 to 2 years starting at age 40 years.

As noted earlier, respondents were queried as to the timing of their last mammogram. Answers were coded as 1 = 'Within the past 12 months' (I have had a mammogram since this time last year); 2 = 'Between 1 and 2 years ago'; 3 = 'Between 2 and 3 years ago'; 4 = 'Between 3 and 4 years ago'; and 5 = 'More than 4 years ago'. For the purpose of this analysis, mammogram compliance was recoded as 1 = 'Within the past 2 years' by combining responses of within the past 12 months and between 1 and 2 years. Non-compliance was coded as 0 and consisted of screenings between 2 and 4 or more years. Although 28.1% (n=98) of women under the age of 40 years reported having

a mammogram, only women 40 years of age and older were included in the analysis per ACS recommendations.

Clinical Breast Examination

Adherence to CBE was assessed using the same coding scheme used for mammography screening. Respondents who reported yes to ever had a CBE were queried to the timing of their last examination. Timeframes were recoded as 1 = 'Within the past 2 years' by combining responses of within the past 12 months and between 1 and 2 years. For simplicity of analysis, CBE compliance (coded as 1) was operationalized as within the past 2 years and non-compliance (coded as 0) was CBE 2 to more years ago.

Breast Self-Examination

The USPSTF recommends against monthly BSE (USPSTF, 2009). The ACS also recommends against routine BSE but is in favor of educating women about looking for changes in their breasts and reporting them to their healthcare provider. At the time of this study, women were still encouraged to perform monthly BSE as a way to identify changes in their breasts (ACS, 2001). Respondents were queried about the last time they did a BSE: 1= 'Within the past 30 days' ('I have done breast self-examination since this time last month'); 2 = 'Between 1 and 2 months'; 3 = 'Between 2 and 3 months'; 4 = 'Between 3 and 4 months'; and 5 = '4 or more months ago'. Compliance with BSE was coded as 1 = 'Within the past 30 days'; 0 = 'More than 1 month ago'.

Overall Screening Compliance Score

With the three breast cancer screening test variables recoded as compliant/non-compliant, an overall compliance to breast cancer screening score was created. Respondents received a maximum score of 3 by summing all three screening codes and a

minimum score of 0 for respondents who did not comply with any breast cancer

screening guidelines. In addition to the summary screening compliance score as the

dependent variable, individual compliance to screening recommendations was analyzed

for associations with study independent variables.

Coding and Recoding of Independent Variables

A total of 10 independent variables, not including sociodemographic

characteristics, were included in this study. Table 4 contains the frequency distribution of

independent variables and dependent variables. Variables were collected at various levels

of measurement, including categorical, ordinal, and continuous. Several continuous and

categorical independent variables were recoded into categorical variables to facilitate

analysis. Descriptive statistics for continuous variables can be found in Table 5.

Additionally, a description of how the independent variables were recoded is presented

below.

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Table 4

Descriptive Statistics for Study Variables

Characteristics	*n*	*%*
Smoking status		
No	505	78.7
Yes	137	21.3
Employed		
Yes	534	84.6
No	97	15.4
Body Mass Index (BMI)		
Underweight	5	0.8
Ideal weight	141	22.9
Overweight	165	26.8
Obese	195	31.7
Morbidly obese	109	17.7
Insurance		
Yes	520	82.9
No	107	17.1
Primary Health Care Provider		
Yes	499	78.2
No	139	21.8
Out to Primary Health Care Provider		
Yes	268	56.7
No	205	43.3
Fruits and Vegetables		
0-4	321	70.1
5+	137	29.9
Activity Level		
Non-Strenuous (light to moderate)	380	58.7
Strenuous	267	41.3
Anticipated Negative Provider Experience		
Yes	222	34.9
No	414	65.1
Actual Negative Provider Experience		
Yes	108	16.9
No	532	83.1

(*table continues*)

Characteristics	*n*	*%*
BSE Compliance		
More than a month ago	429	66.3
Within the last month	200	30.9
CBE Compliance		
More than a year ago	137	21.6
Within the last year	497	78.4
Mammography Compliance		
More than 2 years ago	87	24.6
Within the last 2 years	266	75.4

Table 5

Descriptive Statistics for Continuous Independent Variables

Variable Name	Range	Mean (SD)	Minimum	Maximum
Age	58	38.72 (10.43)	21	79
BMI	67.13	31.75 (9.06)	16.51	83.6

Weight and Body Image

Body Mass Index (BMI) is a computed variable from respondent weight (I3) and height (I4ft, I4in). Weight was captured in pounds. Height was originally captured in feet and inches and converted to inches in SPSS. The formula to compute BMI was also completed in SPSS:

$$BMI = \frac{(weight\ in\ pounds)*703}{(height\ in\ inches)}$$

Cases with either missing weight or height were coded as missing for BMI. BMI, a continuous independent variable, was binned and recoded into a categorical data (BMIGROUP): 1 = 'Underweight (>18.5 kg/m^2)', 2 = 'Ideal Weight (<18.5 to 24.9

kg/m^2)', 3 = 'Overweight (25 to 29.9 kg/m^2)', 4 = 'Obese (30 to 34.9 kg/m^2)', 5 =

'Morbidly Obese (35 kg/m^2 and over)'.

In addition to BMI, participants were asked about their self-image (I5).

Participants self-reported if they considered themselves 1 = 'Overweight', 2 =

'Underweight', or 3 = 'About the right weight'. Participation in weight control activities

during the past 12 months (I6) was reported (1-no, 1-yes) and is used as a way to assess

whether participants were actively participating in wellness activities in spite of excess

weight. Respondents who reported weight control activities specified what method of

weight control they used (I6OTHER).

Fruits and Vegetables

Consumption of fruits and vegetables was assessed through several questions

aimed at parsing out data by type of food. Three questions captured data on the number

of salads (I2C1), potatoes (I2D1), carrots (I2E1), and other vegetables (I2F1) consumed

daily. An estimate of the number of the aforementioned food items consumed per week

and per month was also asked. Fruit intake was determined by consumption of fruits

(I2B1) and fruit juice (I2A1) per day, per week and per month. A daily vegetable

(VEGIES_TOTAL) was computed of the sum of the four vegetable questions. Daily fruit

(FRUIT_TOTAL) intake was computed by summing the two daily fruit variables. A total

daily intake for fruits and vegetables (Daily_fruit_veg) was computed. Binning was done

to create a categorical variable (FRUIT_VEG_AGV) of 1 = '$\leq$ 4 fruits/vegetables', 2 =

'$\geq$5 fruits and vegetables'. Data were missing for 155 respondents due to a problem in the

online survey. Therefore, those respondents were excluded from this analysis.

Exercise

Physical activity during the past week was captured in levels of activity including light activity (i1a), moderate activity (i1b), strenuous activity (i1c), and very strenuous activity (i1d). When an overall activity variable was computed, the vast majority of participants stated that they did some type of exercise during the past week (n=631, 97.5%). Therefore, it was important to create a variable that distinguished between planned vigorous physical activity such as jogging, playing sports, running (coded as strenuous and very strenuous activity) and light to moderate physical activity which included cleaning house, soft ball, golf, walking etc. The original variables included time spent on each activity from none (1) to more than 10 hours on average per day (8). For the purpose of this analysis any strenuous or very strenuous physical activity of less than 1 hour (2) and above (3-8) was coded as 1 = 'Yes'. Light to moderate physical activity of any duration was coded as 0 = 'No'. Individuals who responded that they had engaged at multiple levels of activity were coded up to their highest level. For example, if a respondent engaged in one hour of light activity and less than one hour of strenuous activity they were coded at 1 = 'Yes' for engaging in strenuous activity.

Insurance Status

Respondents to the Spirit Study were asked about the specific type of health insurance they held. These insurances (C1) included 1 = 'Don't have any insurance', 2 = 'Medicare', 3 = 'Medicaid', 4 = 'Champus/Tricare/Chap-VA', 5 = 'HMO through job (like Kaiser Permanente)', 6 = 'HMO self-paid', 7 = 'HMO partner's policy', 8 = 'Private health insurance (like Blue Cross) through job', 9 = 'Private Health insurance, self-paid', and 10 = 'Private insurance, partner's policy'. Research on lesbian health demonstrates a

lack of healthcare insurance as a persistent barrier to accessing healthcare for this population. For the purpose of this analysis, data were recoded into INSURANC with a value of 0 = 'No', 1 = 'Yes' (includes all listed types of insurance 2 through 10). This computed variable foregoes the specificity of the impact of type of insurance on level of access and utilization of services.

Education

Educational attainment was captured in variable M6 in the original dataset. Overall educational attainment for this population was high with only .5% reporting having achieved the 6-11th grade (n=3), and only 4.2% responding high school or GED achievement (n=27). No respondents reported achieving less than a 6th grade education. The original education variable was recoded into EDUCATION. Educational level 2 = '6-11th grade' and 3 = 'HS or GED' were combined to reduce the number of cells under 5%. Additionally, 8 = 'Professional school' and 9 = 'Doctorate' both had responses of less than 5% and were therefore combined with masters level education to document graduate level education. The remaining education values were unchanged and were included in the analysis as asked in the survey.

Income

Total household income including alimony, public assistance and child support was assessed in the original study in the variable M10. Responses of $150,000 or more were limited to less than 5% (n=13, 2.1%), therefore responses were combined with $100,000=$149,900 to create a value of $\geq$$100,000. Other values remained unchanged. The original variable was recoded into INCOME.

Smoking

Ever smoked was determined by a response of 'Yes' to 'Have you ever smoked a whole cigarette'. Respondents who answered 'Yes' to having ever smoked a whole cigarette were then asked how old they were when they began smoking, if they currently smoked (K3), and if they had any desire to quit smoking. Responses were coded as 1 = 'No', 2 = 'Yes'. The variable K3 was renamed SMOKNOW to be more easily identifiable.

<div align="center">

Data Screening

</div>

This section describes data screening activities aimed at assessing the dependent and independent variable distribution and collinearity between independent variables (Table 6). The analysis of skewness is aimed at identifying variables that lack symmetry around a central point. The closer the skewness is to 0, the more that sample represents a normal distribution. Kurtosis measures outliers in the data but describing the "peakness" for each variable. A kurtosis that is close to 0 represents few outlying data points. Data collected in this study had the following distribution pattern. Although understanding the distribution around the mean is important, since this study is not drawn from a random sample it is not surprising that some variables may be skewed to the left or right of the mean.

Table 6

Summary of Skewness and Kurtosis for Dependent and Independent Variables

Dependent Variables	**Skewness**	*Kurtosis*
BSE compliant	-1.182	-.607
CBE compliant	.784	-1.390
Mammography compliant	-1.383	-.088
Compliance with breast screening	.404	-1.019
Independent Variables		
Age	.418	-.419
Education	-.091	-.212
Income	.172	-.705
Insurance	-1.755	1.084
Activity level	.356	-1.879
Fruits and vegetables	.880	-1.230
BMI	-.044	-1.070
Smoking status	1.402	-.034
Sexual orientation	1.950	1.810
Gender identity	-.358	-1.116
Out to PHCP	-.650	-.925
Have a PHCP	-1.307	-.123
Anticipated negative experience with care provider	.635	1.773
Actual negative experience with care provider	-1.602	1.147

An examination of the within model correlations between independent variables is an important measure to assess the impact this correlation may have on the overall predictive value of the model. The hypotheses tested in this study incorporated independent variables that are related to each other, i.e., sociodemographic status, wellness, sexual/gender minority status, and health care experience. As anticipated, a test of multicollinearity between independent variables found several that were positively associated. For example, income was found to be positively correlated with age, educational attainment, and insurance status. Additionally, being out to one's health care provider was positively correlated with having a care provider, and gender identity was positively associated with sexual orientation. Conversely, BMI was negatively associated with physical activity level. Other correlations between independent variables across models existed as well, however, these relationships are outside of the scope of this analysis. Table 7 contains the Pearson correlation coefficient for each variable pair for the models being tested.

Table 7

Summary of Multicollinearity of Independent Variables

Independent Variable Pairs		Pearson Correlation Coefficient	*Sig (2-tailed)*	*n*
Anticipated neg. exp.	Actual Neg. Exp.	*.367	**.000**	630
Out to PCP	Has PCP	**.662	**.000**	625
Gender identity	Sexual Orientation	*.098	**.014**	633
BMI	Physical Activity	-.196	**.000**	615
Income	Insurance	**.256	**.000**	608
Income	Education	**.311	**.000**	622
Income	Age	*.159	**.000**	620

Note. * Correlation is significant at the 0.01 level (2-tailed)
　　 ** Correlation is significant at the 0.05 level (2-tailed)

　　　　Data for this study were analyzed using logistic regression with SPSS Version 12.0. Since logistic regressions are not hampered by normality of distribution, no changes need to be made to variables included in this analysis (Stolzenberg, 2004).

Exploratory Data Analysis

Missing Data

　　　　An analysis of missing data was completed to assess potential impact on the overall analysis. Only one variable (VEGAVDG) had greater than 5% missing cases. Since this variable was part of the wellness theoretical framework, a missing variable mean was calculated in SPSS to be used in the analysis. No independent variables were excluded due to missing data (Table 8). The complete list of dependent and independent variables after cleaning and recoding is presented in Table 9.

Table 8

Variables with missing data

Variable	Variable Label	# Missing	% Data Missing
VEGAVDG	Fruits and Vegetable Intake	189	29.2
BMI	Body Mass Index (BMI)	32	4.9
BMIGroup	BMI Grouped	32	4.9
INSURANC	Insurance Status	20	3.1
INCOME	Household Income Grouped	22	3.4
EDUCGRP	Education Attainment	18	2.8
OUTPHCP	Out to Primary Care Provider	13	2.0
C4	Anticipated negative experience with PHCP	11	1.7
PHCPYES	Have a Primary Care Provider	9	1.4
C10	Actual negative experience with PHCP	7	1.1

Table 9

Revised List of Variables

Variable Name	Label	Value	Type
MAMM_COMPLIANT	Last mammography screening	0=Mammogram more than 2 years ago 1= Mammogram 1-2 years ago	Dependent
CBE_COMPLIANT	Last clinical breast examination	0=CBE more than 2 years ago 1= CBE 1-2 years ago	Dependent
BSE_COMPLIANT	Last Breast Self-Examination	0=BSE more than 1 month ago 1= BSE within last month	Dependent
COMPLIANT_SCORE	Combined breast cancer screening score	Range: 0-3	Dependent
INCOME	Household income	1 = <15k, 2 = $15-29.9k, 3 = 30k-49.9k, 4 = 50K-69.9K, 5 = $70-99.9k 6 = ≥$100k	Independent
PHCPYES	Out to Primary Care Provider	1=Yes, 0=No	Independent
INSURANC	Insurance Status	1=No, 0=Yes	Independent
EMPLOYD	Employed	1=Yes, 0=No	Independent
EDUCATION	Educational Attainment	1= less than college, 2= some college, 3=college degree, 4=graduate degree	Independent

(table continues)

Variable Name	Label	Value	Type
BMIGROUP	Body Mass Index Grouped	1=underweight (>18.5 kg/m^2), 2 = Ideal Weight (<18.5 to 24.9 kg/m^2), 3 = Overweight (25 to 29.9 kg/m^2), 4 = obese (30 to 34.9 kg/m^2), 5 = Morbidly Obese (35 kg/m^2 and over)	Independent
EXERCISE2	Level of Exercise	0=no activity, light to medium activity, 1=strenuous to very strenuous activity	Independent
FRUIT_VEG_AVG	Daily fruits and vegetable intake	0=0-4, 1=5+	Independent
SMOKNOW	Current smoker	0=no,1=yes	Independent
OUTPHCP	Out to primary care provider	1=no primary care provider, 2=no, 3=yes	Independent
BUTCH_FEMME	Gender Identity	1=butch, 2=neither, 3=femme	Independent

Dependent Variables

The dataset for this analysis contained seven dependent variables, including six dichotomous nominal variables and one interval variable. The value for each variable depicts whether the respondent was compliant with recommended screening guidelines; therefore 'Yes' for MAMM_Compliant meant that respondents had had a mammogram within the past two years, etc. Ever tested for CBE, mammogram, and BSE are also included in the list of dependent variables. The overall screening score (interval variable) represents the number of compliant screening tests the participants had. Table 10 illustrates the distribution for each dependent variable.

Table 10

Characteristics of Dependent Variables

Variable	Description	No *n* (%)	Yes *n* (%)
MAMM_COMPLIANT	Last mammography screening	43 (17.2)	*207 (82.8)
CBE_COMPLIANT	Last clinical breast examination	137 (21.6)	497 (78.4)
BSE_COMPLIANT	Last BSE	429 (68.2)	200 (31.8)
D1_MAMM	Ever had a mammogram	26 (9.4)	*250 (90.6)
D7_BSE	Ever performed a BSE	42 (6.6)	591 (96.4)
D15_CBE	Ever had a CBE	44 (6.8)	**591 (91.5)

Note. *women age 40+ years
    **$n=11$ (1.7%) responded 'Don't know'

The seventh variable is a summary score of the three breast cancer screening methodologies. None of the tests were weighted. Table 11 contains the distribution of the summary screening score.

Table 11

Characteristics of Dependent Composite Variables

Combined breast cancer screening score	*n*	%
One compliant test	226	41.2
Two compliant tests	229	35.4
All three compliant tests	93	17.0
Missing	99	15.3

Independent Variables

Twelve independent variables were included in the analysis. Independent variables have been grouped into categories that describe activities or phenomena of interest in predicting breast cancer screening adherence. For example, insurance status, age, income, and education have been grouped into the category, *sociodemographic characteristics*. Sociodemographic characteristic variables were analyzed in relation to Hypothesis 1. Similarly, smoking status, intake of fruits and vegetables, physical activity, BMI, and out to one's primary health care provider (PHCP) have been grouped under the category of *wellness activities*. Although sexual orientation and gender identity can be considered sociodemographic in nature, they comprise a separate group to facilitate study under the category of *sexual/gender minority status*. Finally, since barriers for lesbians are thought to be partially related to their experiences with the healthcare system,

independent variables collected that fit that description including having a PHCP, being out to one's PHCP, previous negative experiences with a health care provider, and anticipated negative experiences with a health care provider were studied together as *provider experience*.

Confirmatory Data Analysis

Bivariate Analysis

Bivariate analysis was conducted using chi-square to explore positive relationships between independent and dependent variables in each of the four hypotheses. The level of significance for this analysis was set at $\geq .05$. Dependent variables in each hypothesis included: a) ever received BSE, CBE, and mammogram screening; b) compliance with BSE, CBE and mammogram screening recommendations; and, c) breast cancer screening composite scores. Relationships between dependent and independent variables that achieve significance at the .05 level have been added to the regression models for further analysis. This technique of model building for logistic regression is reported by Hosmer and Lemeshow (1989).

The following section describes the bivariate and regression analysis for Null Hypothesis #1 which states that sociodemographic factors such as age, education level, insurance status, and employment status do not predict of breast cancer screening adherence.

Breast Self -Examination

Recently, BSE has been questioned as an effective method of breast cancer screening (USPSTF, 2009). However, almost all the women who participated in this survey had performed BSE at least once (93.4%, *n*=591). Adherence to BSE within the

last month was much less frequently cited with less than one third of participants

(31.85%, *n=200*) reported performing BSE within the past month. Participants who were

insured and had attained an education at a college level or above were more likely to have

ever used BSE (Table 12). Additionally, ever performed BSE was more likely to be

associated with income levels between $30,000 and $49,900 per year (34.3%). Age was

significantly associated with ever BSE *(X^2 [4, N=626], = 14.214, p = .007)* with younger

women being less likely to have ever performed a BSE.

Of participants who adhered to monthly breast cancer screening, few variations

were noted among the independent variables with the exception of age (Table 13). Forty

percent of women age 50-59 years reported being compliant with monthly BSE while

only 15% of women in their twenties reported BSE compliance *(X^2 [4, N= 622], =*

21.083, p = .000).

Table 12

Bivariate Association Between Ever Performed Breast-Self Examination and Sociodemographic Variables

Independent Variable	Dependent Variable n (%)	X^2	p value
Insurance	**Ever Performed BSE**	.236	.627
No	95 (92.2)		
Yes	478 (93.5)		
Education	**Ever Performed BSE**	5.234	.155
Less than college	27 (93.1)		
Some college	154 (89.5)		
College degree	221 (94.4)		
Graduate school	174 (95.1)		
Income	**Ever Performed BSE**	7.132	.211
<$15K	55 (88.7)		
$15K – $29.9K	94 (90.4)		
$30K – $49.9K	172 (95.0)		
$50K – $69.9K	119 (92.2)		
$70K – $99.9K	78 (97.5)		
≥$1000K	56 (94.9)		
Age	**Ever Performed BSE**	14.214	**.007**
20 – 29	115 (88.5)		
30 – 39	211 (95.5)		
40 – 49	171 (95.5)		
50 – 59	72 (93.5)		
60+	15 (78.9)		

Table 13

Bivariate Analysis Between Breast Self-Examination Compliance and Sociodemographic Variables

Independent Variable	Dependent Variable n (%)	X^2	p value
Insurance	**BSE Compliance**	.132	.716
No	34 (17.5)		
Yes	160 (82.5)		
Education	**BSE Compliance**	2.335	.506
Less than college	12 (6.2)		
Some college	49 (25.5)		
College degree	55 (39.6)		
Graduate school	192 (28.6)		
Income	**BSE Compliance**	4.783	.443
<$15K	16 (26.2)		
$15K - $29.9K	33 (32.0)		
$30K – $49.9K	62 (34.3)		
$50K – $69.9K	43 (33.9)		
$70K – $99.9K	18 (33.5)		
≥$1000K	19 (32.2)		
Age	**BSE Compliance**	21.083	**.000**
20 – 29	20 (15.5)		
30 – 39	79 (35.9)		
40 – 49	62 (34.8)		
50 – 59	31 (40.8)		
60+	6 (31.6)		

Clinical Breast Examination

Overall, 91.5% (*n*=591) of participants reported ever having a CBE and 78.4% (*n*=497) reported obtaining a CBE within the past year. As a screening test associated with access to a PHCP, CBE is significantly associated with having health care insurance *(X^2 [1, N=572], = 6.972, p = .031)* (Table 14). Additionally, women who had higher levels of education *(X^2 [6, N=574], = 15.923, p = .014)* and income *(X^2 [10, N=570], = 23.731, p = .008)* were also significantly more likely to have ever had a CBE than women with less income and education. Naturally, as women age they are more likely to have ever had a CBE. Therefore, CBE was also significantly associated with age with 100% of women age 60 years and older reporting *ever* having a CBE compared with only 75.8% of women 20-39 years of age *(X^2 [8, N=582], = 53.660, p = .000)*.

Having a CBE within the past year was positively associated with all of the demographic variables (Table 15). Participants with health insurance (87.9%), for example, were seven times more likely to have had a CBE within the past year than those without insurance (12.1%) *(X^2 [1, N=615] = 40.69, p = .000)*. Education was positively associated with CBE compliance *(X^2 [6, N=629], = 15.923, p = .014)*. Between college and graduate school, the higher the education level achieved, the more likely participants were to have had a CBE within the past year. Additionally, a significant difference existed between CBE compliance and income level; participants with the lowest income level were least likely to have had a CBE within the past year compared with those with higher incomes *(X^2 [10, N=625], = 23.731, p = .008)*. Lastly, statistically significant differences in compliance with CBE were seen as women age. All women who were 60

years of age and older had a CBE within the past year compared with 75.8% of women

under 30 years of age $(X^2 [8, N=637], = 53.660, p = .000])$.

Table 14

Bivariate Association Between Ever Had Clinical Breast Examination and Sociodemographic Variables

Independent Variable	Dependent Variable n (%)	X^2	p value
Insurance	**Ever had CBE**	6.972	**.031**
No	93 (86.9)		
Yes	479 (92.3)		
Education	**Ever had CBE**	15.923	**.014**
Less than college	28 (93.3)		
Some college	151 (85.3)		
College degree	216 (91.1)		
Graduate school	179 (96.8)		
Income	**Ever had CBE**	23.731	**.008**
<$15K	50 (80.6)		
$15K – $29.9K	93 (86.1)		
$30K – $49.9K	169 (91.8)		
$50K – $69.9K	127 (96.9)		
$70K – $99.9K	74 (91.4)		
≥$100K	57 (96.6)		
Age	**Ever had CBE**	53.660	**.000**
20 – 29	100 (75.8)		
30 – 39	212 (94.2)		
40 – 49	173 (95.1)		
50 – 59	76 (98.7)		
60+	21 (100)		

Table 15

Bivariate Association Between Clinical Breast Examination Screening and Sociodemographic Variables

Independent Variable	Dependent Variable n (%)	X^2	p value
Insurance	**CBE Compliance**	40.694	**.000**
No	58 (12.1)		
Yes	422 (87.9)		
Education	**CBE Compliance**	2.955	.086
Less than college	25 (5.2)		
Some college	129 (26.7)		
College degree	177 (36.6)		
Graduate school	153 (31.6)		
Income	**CBE Compliance**	25.667	**.000**
<$15K	36 (7.5)		
$15K – $29.9K	77 (16.1)		
$30K – $49.9K	137 (76.5)		
$50K – $69.9K	112 (23.4)		
$70K – $99.9K	64 (13.4)		
≥$100K	52 (10.9)		
Age	**CBE Compliance**	36.979	**.000**
20 – 29	77 (59.2)		
30 – 39	183 (81.7)		
40 – 49	131 (63.3)		
50 – 59	59 (28.5)		
60+	17 (8.2)		

Mammogram

Ever having a mammogram and compliance with mammography guidelines for women 40 years of age and older was significantly associated with having health care insurance $(X^2$ [1, N=266], = 8.149, p = .004), $(X^2$ [1, N=240], = 9.43, p = .002 respectively) (Table 16 and Table 17). Women who have less than a college degree were the least likely to be guideline compliant for mammography screening (35%). Mammography screening compliance decreased with age for study participants. In fact, 71.5% of women 50 - 59 years and 91.8% of women over the age of 60 years were *not* compliant with mammography screening guidelines. This is particularly concerning in light of the higher incidence of breast cancer in older women and that the new screening guidelines recommend screening initiation at age 50 years.

Table 16

Bivariate Association Between Ever Had Mammogram and Sociodemographic Variables

Independent Variable	Dependent Variable n (%)	X^2	p value
Insurance	**Ever had Mammogram**	8.149	**.004**
No	32 (13.3)		
Yes	208 (86.7)		
Education	**Ever Had Mammogram**	1.296	.730
Less than college	9 (3.7)		
Some college	66 (26.9)		
College degree	87 (35.5)		
Graduate school	83 (33.9)		
Income	**Ever Had Mammogram**	2.903	.715
<$15K	17 (7.1)		
$15K –$29.9K	34 (14.1)		
$30K – $49.9K	70 (29.0)		
$50K – $69.9K	52 (21.6)		
$70K – $99.9K	36 (14.9)		
≥$100K	32 (13.3)		
Age	**Ever Had Mammogram**	1.876	.392
40 – 49	159 (63.6)		
50 – 59	72 (28.8)		
60+	19 (7.6)		

Table 17

Bivariate Association Between Mammography Screening and Sociodemographic Variables

Independent Variable	Dependent Variable n (%)	X^2	p value
Insurance	**Mammography Compliance**	9.43	**.002**
No	21 (10.6)		
Yes	177 (89.4)		
Education	**Mammography Compliance**	3.321	.345
Less than college	7 (3.5)		
Some college	60 (29.7)		
College degree	68 (33.7)		
Graduate school	67 (33.2)		
Income	**Mammography Compliance**	4.149	.528
<$15K	12 (6.1)		
$15K – $29.9K	29 (14.6)		
$30K – $49.9K	57 (28.8)		
$50K – $69.9K	43 (21.7)		
$70K – $99.9K	28 (14.1)		
≥$100K	29 (14.6)		
Age	**Mammography Compliance**	.650	.723
40 – 49	131 (63.3)		
50 – 59	59 (28.5)		
60+	17 (8.2)		

A composite screening score including BSE, CBE, and mammography screening for women 40 years of age and older was calculated to assess overall screening adherence. The composite score was tested against the demographic independent variables to examine associations. Across all demographic variables, study participants were more likely to score a two – corresponding to having two of the three screening tests on time (Table 18). Of the four independent variables included in the bivariate analysis, only insurance was positively associated with screening compliance. Women with insurance were more likely to have had two of the three tests (56.7%) $(X^2 [2, N=246], = 6.541, p = .038)$.

Table 18

Bivariate Association Between Breast Screening Compliance and Sociodemographic Variables

Independent Variable	Dependent Variable *n* (%)			X^2	*p* value
Insurance	**1 Test**	**2 Tests**	**3 (all) Tests**	6.541	**.038**
No	9 (29.0)	10 (32.2)	12 (38.7)		
Yes	39 (18.1)	122 (56.7)	54 (25.1)		
Education	**1 Test**	**2 Tests**	**3 (all) Tests**	1.758	.941
Less than college	1 (12.5)	4 (50.0)	3 (37.5)		
Some college	12 (16.7)	40 (55.6)	20 (27.8)		
College degree	20 (23.0)	44 (50.6)	23 (26.4)		
Graduate school	15 (18.1)	46 (55.4)	22 (26.5)		
Income	**1 Test**	**2 Tests**	**3 (all) Tests**	4.994	.892
<$15K	5 (29.4)	10 (58.8)	2 (11.8)		
$15K – $29.9K	7 (20.0)	19 (54.3)	9 (25.7)		
$30K – $49.9K	12 (17.1)	37 (52.9)	21 (30.0)		
$50K – $69.9K	10 (18.5)	27 (50.0)	17 (31.5)		
$70K – $99.9K	9 (25.7)	16 (45.7)	10 (28.6)		
≥$100K	5 (14.7)	20 (58.8)	9 (26.5)		
Age	**1 Test**	**2 Tests**	**3 (all) Tests**	3.584	.465
40 – 49	38 (76.0)	90 (65.7)	43 (61.4)		
50 – 59	10 (20.0)	35 (25.5)	22 (31.4)		
60+	2 (4.0)	12 (8.8)	5 (7.1)		

Regression Analysis - Sociodemographic Characteristics

Logistic regression analysis was used to test the predictive value of sociodemographic characteristics on breast cancer screening compliance. In the bivariate analysis, only age was significantly associated with BSE and CBE compliance. Insurance status and income were also significantly associated with CBE compliance. Insurance status was the only variable significantly associated with mammography and overall screening compliance (Table 19).

Table 19

Summary of Independent and Dependent Variable Associations

Model Number	Independent Variable	Dependent Variable n (%)	X^2	p value
1	Age	BSE Compliance	21.083	**.000**
2	Insurance	CBE Compliance	40.694	**.000**
	Income	CBE Compliance	25.667	**.000**
	Age	CBE Compliance	36.979	**.000**
3	Insurance	Mammography Compliance	9.43	**.002**
A	Insurance	Screening Compliance Score	6.541	**.038**

Independent variables found to be significantly associated with the dependent variables of BSE, CBE, and mammography compliance were entered into a forward logistic regression analysis to determine the added value of each variable individually. Independent variables were entered into the regression as forced to test whether the variables held together as a model.

Models 1 – 3 assessed the predictive value of sociodemographic characteristics on individual screening test compliance. Since age and income represent categorical variables with more than two categories, dummy variables were created by the SPSS logistic regression procedure for age and income and coded as 0 = no, 1 = yes for each variable. All dummy age variables were entered into the logistic regression Model 1, to test their ability to predict BSE compliance (Table 20). Although none of the variables individually were significantly associated with BSE compliance, the model as a whole reached significance $(X^2$ [4, N=622], = 23.107, p =.000). Study participants who were 50 – 59 years of age were 1.493 times more likely to report being BSE compliant compared with other women. Model 2 describes the predictive value of the sociodemographic characteristics that reached significance during the bivariate analysis on CBE compliance (Table 21). Dummy variables for age and income were created by SPSS and entered into this model as was insurance. Overall, the model was significantly associated with CBE compliance $(X^2$ [10, N=594], = 74.977, p =.000). Women who made between $50,000 and $69,000 were 1.174 times more likely to be CBE compliant than women in other income ranges. Additionally, women who were in the 40-49 year age group were .902 times more likely to be compliant. Of the variables entered into the model, only insurance was significantly associated with CBE compliance. Model 3 examined the impact of insurance on mammography screening (Table 22). Insurance was statistically significant in the predictive model $(X^2$ [1, N=240], = 8.010, p = .003).

Table 20

Model 1: Summary of Logistic Regression Statistics for BSE Compliance and Sociodemographic Characteristics

Independent Variables	B	*SE*	*Wald*	*P*	Odds Ratio	C.I. For EXP (B) Lower/Upper
Age (20-29 years)	-.922	.550	2.810	.094	.398	.135/1.169
Age (30-39 years)	.194	.513	.143	.706	1.214	.444/3.319
Age (40-49 years)	.147	.518	.080	.777	1.158	.420/3.196
Age (50-59 years)	.401	.546	.538	.463	1.493	.512/4.352

Table 21

Model 2: Summary of Logistic Regression Statistics for Clinical Breast Examination Compliance and Sociodemographic Characteristics

Independent Variables	B	*SE*	*Wald*	*P*	Odds Ratio	C.I. For EXP (B) Lower/Upper
Age (20-29 years)	-1.415	.793	3.189	.074	.243	.051/1.148
Age (30-39 years)	-.370	.793	.217	.641	.691	.146/3.269
Age (40-49 years)	-.103	.805	.016	.898	.902	.186/4.369
Age (50-59 years)	-.753	.831	.822	.364	.471	.092/2.399
Income (<$15,00)	-.878	.516	2.894	.089	.416	.151/1.143
Income ($15K-29K)	-.463	.489	.896	.344	.629	.241/1.642
Income ($30K-49K)	-.532	.461	1.333	.248	.587	.238/1.450
Income ($50K-69K)	.161	.505	.101	.750	1.174	.436/3.160
Income ($70K over)	-.503	.509	.975	.324	.605	.223/1.641
Insurance	-1.311	.252	26.972	**.000**	.270	.164/.442

Table 22

Model 3: Summary of Logistic Regression Statistics for Mammography Compliance and Sociodemographic Characteristics

Independent Variables	B	*SE*	*Wald*	*P*	Odds Ratio	C.I. For EXP (B) Lower/Upper
Insurance	-1.215	.412	8.692	**.003**	.297	.132/.665

Since only insurance was found to be significantly associated with overall

screening compliance, it was the only variable used in Model A (Table 23). A

multinomial logistic regression was used because the compliance variable had more than

two categories. Only women 40 years of age and older were included in the overall

compliance score to control for differences in age of screening initiation across the three

tests. Participation in all three screening tests served as the reference category for the

regression. In the logistic regression, two tests were significantly associated with

insurance status (X^2 [2, *N*=281], = 6.601, *p* = .037).

Table 23

Model A: Summary of Logistic Regression Statistics for Overall Compliance and Sociodemographic Characteristics

Independent Variables	B	*SE*	*Wald*	*p value*	Odds Ratio	C.I. For EXP (B) Lower/Upper
1 test	.038	.488	.066	.938	1.038	.399/2.705
2 tests	-.997	.458	4.736	**.030**	.369	150/.906

The four models (1 – 3, A) used to predict BSE, CBE, mammography and overall compliance based on sociodemographic characteristics failed to reject the null hypothesis.

The following sections describe the analysis of the independent variables associated with wellness and breast cancer screening. These analyses specifically addressed Null Hypothesis #2: Breast cancer screening adherence is not predicted by utilization of healthy lifestyle behaviors such as maintaining a normal weight, engaging in physical activity, refraining from smoking, and being out to one's health care provider.

Breast Self-Examination

Wellness variables (smoking, BMI, physical activity, nutrition, and being out to one's health care provider), were all associated with one or more of the dependent screening variables. BMI was associated with ever BSE $(X^2$ [4, N=602], = 10.816, p = .029) (Table 24). Nutrition was positively associated with BSE compliance $(X^2$ [1, N=442], = 4.247, p = .039), with more women who consumed five or more fruits and vegetables being more likely to be BSE compliant (Table 25).

Table 24

Bivariate Association Between Ever Performed Breast Self-Examination and Wellness Variables

Independent Variable	Dependent Variable n (%)	X^2	p value
Current Smoking	**Ever Performed BSE**	.632	.427
No	463 (93.7)		
Yes	123 (91.8)		
BMI	**Ever Performed BSE**	10.816	**.029**
Underweight	3 (60.0)		
Ideal weight	131 (93.6)		
Overweight	154 (95.1)		
Obese	179 (94.2)		
Morbidly obese	96 (91.4)		
Physical Activity	**Ever Performed BSE**	3.783	.151
Light to medium	212 (92.2)		
Strenuous to very strenuous	247 (93.9)		
No physical activity	13 (81.3)		
Daily Fruit and Vegetable Intake	**Ever Performed BSE**	.207	.679
0-4	293 (94.5)		
5 or more	129 (95.6)		
Out to Primary Health Care Provider (PHCP)	**Ever Performed BSE**	2.586	.274
No PHCP	91 (90.1)		
Not out to PHCP	193 (93.7)		
Out PHCP	298 (94.6)		

Table 25

Bivariate Association between Breast Self-Examination Compliance and Wellness
Variable

Independent Variable	Dependent Variable n (%)	X^2	p value
Current Smoking	**BSE Compliance**	.092	.762
No	152 (31.0)		
Yes	43 (32.3)		
BMI	**BSE Compliance**	5.259	.262
Underweight	2 (40.0)		
Ideal weight	48 (34.5)		
Overweight	56 (35.0)		
Obese	61 (32.1)		
Morbidly obese	24 (22.9)		
Physical Activity	**BSE Compliance**	4.355	.113
Light to medium	65 (28.3)		
Strenuous to very strenuous	93 (35.6)		
No physical activity	3 (18.8)		
Daily Fruit and Vegetable Intake	**BSE Compliance**	4.257	**.039**
0-4	91 (29.5)		
5 or more	53 (39.6)		
Out to Primary Health Care Provider (PHCP)	**BSE Compliance**	.169	.919
No PHCP	30 (30.0)		
Not out to PHCP	64 (31.4)		
Out PHCP	101 (32.2)		

Clinical Breast Examination

Associations between ever had CBE, compliance with CBE guidelines and the four wellness- related independent variables were tested as part of this analysis. Two of the four independent variables tested, physical activity $(X^2$ [4, N=518], = 14.445, p = .006) and out to health care provider $(X^2$ [4, N=633], = 16.079, p = .003) were significantly associated with ever having a CBE (Table 26). Of participants who were out to their PHCP, 95.3% reported ever having a CBE compared with 89.3% of participants who were not out. Non-smokers were also more likely to have ever had a CBE (92.1%) when compared with current smokers (89.1%).

The analysis of CBE compliance showed a high level of sensitivity to wellness activities (Table 27). Statistically significant associations were observed for smoking $(X^2$ [1, N=629], = 8.784, p = .003), BMI $(X^2$ [4, N=604], = 12.410, p = .015), and outness to providers $(X^2$ [2, N=622], = 88.610, p = .000). Non-smokers were more likely to be CBE compliant (80.8%) compared with smokers (68.9%). Eighty-eight percent (88.0%) of participants who were out to their primary care providers reported compliance with CBE screening guidelines compared with 81% of women who were not out to their provider. Outness with health care providers was significantly associated with the two dependent variables: ever used CBE $(X^2$ [4, N=633], = 16.079, p = .003) and CBE compliance $(X^2$ [2, N=622], = 88.610, p = .000).

Table 26

Bivariate Association Between Ever Had Clinical Breast Examination Screening and Wellness Variables

Independent Variable	Dependent Variable *n* (%)	X^2	*p* value
Current Smoking	**Ever had CBE**	1.246	.536
No	464 (92.1)		
Yes	122 (89.1)		
BMI	**Ever had CBE**	9.289	.319
Underweight	4 (80.0)		
Ideal weight	124 (87.9)		
Overweight	156 (95.1)		
Obese	181 (92.8)		
Morbidly obese	99 (90.8)		
Physical Activity	**Ever had CBE**	14.445	**.006**
Light to medium	217 (92.3)		
Strenuous to very strenuous	243 (91.0)		
Daily Fruit and Vegetable Intake	**Ever had CBE**	2.275	.321
0-4	299 (93.4)		
5 or more	129 (94.2)		
Out to Primary Health Care Provider (PHCP)	**Ever had CBE**	16.079	**.003**
No PHCP	85 (83.3)		
Not out to PHCP	188 (89.5)		
Out PHCP	306 (95.3)		

Table 27

Bivariate Association Between Clinical Breast Examination Compliance and Wellness Variables

Independent Variable	Dependent Variable n (%)	X^2	p value
Current Smoking	**CBE Compliance**	8.784	**.003**
No	399 (80.8)		
Yes	93 (68.9)		
BMI	**CBE Compliance**	12.410	**.015**
Underweight	1 (20.0)		
Ideal weight	108 (78.3)		
Overweight	134 (83.2)		
Obese	151 (78.2)		
Morbidly obese	84 (78.5)		
Physical Activity	**CBE Compliance**	.767	.681
Light to medium	182 (79.5)		
Strenuous to very strenuous	201 (76.4)		
No physical activity	13 (81.3)		
Daily Fruit and Vegetable Intake	**CBE Compliance**	.028	.868
0-4	257 (81.6)		
5 or more	106 (80.9)		
Out to Primary Health Care Provider (PHCP)	**CBE Compliance**	88.610	**.000**
No PHCP	44 (44.0)		
Not out to PHCP	166 (81.0)		
Out PHCP	279 (88.0)		

Mammography

Overall, mammography screening was less sensitive to the impact of wellness activities, perhaps because of the high levels of mammography utilization in general. Only one of the independent variables was significantly associated with ever having a mammogram. Slightly more than ninety percent (92.1%) of non-smokers 40 years of age and older reported ever having a mammogram (Table 28). A higher proportion of women who were morbidly obese reported ever having a mammogram (95.2%) and being mammogram compliant (90.0%). A significant association was also observed between being out to PHCP and mammography compliance $(X^2 [2, N=244], = 22.663, p = .000)$ and not being out to one's PHCP (Table 29).

Table 28

Bivariate Association Between Ever Had Mammogram and Wellness Variables

Independent Variable	Dependent Variable *n* (%)	X^2	*p* value
Current Smoking	**Ever Had Mammogram**	2.910	.088
No	9 (92.1)		
Yes	50 (84.7)		
BMI	**Ever Had Mammogram**	2.021	.732
Underweight	1 (100)		
Ideal weight	40 (88.9)		
Overweight	70 (93.3)		
Obese	86 (89.6)		
Morbidly obese	40 (95.2)		
Physical Activity	**Ever Had Mammogram**	.107	.948
Light to medium	95 (89.6)		
Strenuous to very strenuous	91 (89.2)		
No physical activity	6 (85.7)		
Daily Fruit and Vegetable Intake	**Ever Had Mammogram**	.261	.609
0-4	130 (92.9)		
5 or more	70 (90.9)		
Out to Primary Health Care Provider (PHCP)	**Ever Had Mammogram**	3.067	.216
No PHCP	30 (83.3)		
Not out to PHCP	90 (91.8)		
Out PHCP	124 (92.5)		

Table 29

Bivariate Association Between Mammogram Compliance and Wellness Variables

Independent Variable	Dependent Variable n (%)	X^2	p value
Current Smoking	**Mammogram Compliance**	1.939	.164
No	167 (84.3)		
Yes	38 (76.0)		
BMI	**Mammogram Compliance**	6.408	.171
Underweight	0		
Ideal weight	33 (82.5)		
Overweight	57 (82.6)		
Obese	73 (83.0)		
Morbidly Obese	36 (90.0)		
Physical Activity	**Mammogram Compliance**	1.081	.582
Light to medium	80 (83.3)		
Strenuous to very strenuous	75 (82.4)		
No physical activity	4 (66.7)		
Daily Fruit and Vegetable Intake	**Mammogram Compliance**	2.112	.146
0-4	107 (82.3)		
5 or more	63 (90.0)		
Out to Primary Health Care Provider (PHCP)	**Mammogram Compliance**	22.663	**.000**
No PHCP	16 (53.3)		
Not out to PHCP	82 (90.1)		
Out PHCP	105 (85.4)		

Screening Compliance

Analysis of four of the five wellness independent variables revealed that individuals who were guideline compliant to BSE, CBE, and mammograms were more likely to have also engaged in the desired wellness activities (Table 30). For example, 28% of non-smokers were compliant with all three screening guidelines compared with 20.4% of smokers. Additionally, 30.2% of participants who had a BMI calculated as ideal were compliant with guidelines for all three tests compared with 25% of participants who were morbidly obese. Sixty percent of participants who were morbidly obese were compliant with only two of the screening tests. None of the associations with overall screening compliance rose to the level of significance.

Table 30

Bivariate Association Between Breast Screening Compliance and Overall Screening Compliance Wellness Variable

Independent Variable	Dependent Variable n (%)			X^2	p value
Current Smoking	**1 Test**	**2 Tests**	**3 (all) Tests**	2.413	.299
No	36 (17.9)	108 (53.7)	57 (28.4)		
Yes	14 (25.9)	29 (53.7)	11 (20.4)		
BMI				7.244	.511
Underweight	1 (100)	0 (0)	0 (0)		
Ideal weight	10 (23.3)	20 (46.5)	13 (30.2)		
Overweight	16 (21.9)	35 (47.9)	22 (30.1)		
Obese	15 (16.9)	51 (57.3)	23 (25.8)		
Morbidly obese	6 (15.0)	24 (60.0)	10 (25.0)		
Physical Activity				3.656	.455
Light to medium	15 (15.8)	54 (56.8)	26 (27.4)		
Strenuous to very strenuous	19 (20.2)	47 (50.0)	28 (29.8)		
No physical activity	2 (33.3)	4 (66.7)	0 (0)		
Daily Fruit and Vegetable Intake				2.912	.233
0-4	26 (19.4)	74 (55.2)	34 (25.4)		
5 or more	14 (19.4)	32 (44.4)	26 (36.1)		
Out to Primary Health Care Provider (PHCP)				3.580	.466
No PHCP	7 (29.2)	10 (41.7)	21 (16.3)		
Not out to PHCP	19 (19.6)	50 (51.5)	76 (58.9)		
Out PHCP	21 (16.3)	28 (28.9)	32 (24.8)		

Regression Analysis - Wellness Activity

Regression analysis was used to test the predictive value of wellness activities on breast cancer screening compliance. Only those independent variables that were significantly associated with the dependent variables were entered into the logistic regression models (Table 31). In the bivariate analysis, only intake of fruits and vegetables was positively associated with BSE compliance (*p=.039*). CBE compliance, however, was associated with smoking status (*p* = .003), BMI (*p* = .015), and being out to one's primary care provider (*p* = .000). Compliance with mammography screening for women 40 years of age and older was only significantly associated with being out to one's primary care provider.

Table 31

Summary of Bivariate Analysis for Significantly Associated Independent Variables for Wellness Variables

Independent Variable	Dependent Variable	X^2	*p value*
Daily fruit and vegetable intake	BSE Compliance	4.257	**.039**
Current smoking	CBE Compliance	8.784	**.003**
BMI	CBE Compliance	12.410	**.015**
Out to PHCP	CBE Compliance	88.610	**.000**
Out to PHCP	Mammogram Compliance	22.663	**.000**

Due to a high number of missing cases in the fruits and vegetable variable, a missing variable mean (MVM) was calculated in SPSS 12.0. Therefore, the MVM was used in the regression analysis. Regression analysis revealed significant associations between intake

of fewer fruits and vegetables and BSE compliance (Table 32); however, the *chi square*

for Model 4 did not reach significance.

Table 32

Model 4: Summary of Logistic Regression Statistics for BSE Compliance and Wellness Activity

Independent Variables	B	*SE*	*Wald*	*p*	Odds Ratio	C.I. For EXP (B) Lower/Upper
Fruits/Vegetables 1 (0-4)	-.445	.216	4.228	**.040**	.641	.419/.979
Fruits/Vegetables 2 (5+)	-426	-238	3.196	.074	.653	.410/1.042

Model 5 assessed the predictive value of wellness activities on CBE compliance

(Table 33). Three of the six variables included in Model 5 (out to PHCP, *p =.000;*

smoking status, *p =*.011; being underweight, *p =*.041) reached significance. Smokers

were 1.8 times more likely to be CBE compliant (*p = .*011*).* Overall, Model 5 predicted

compliance to CBE compliance *(X^2 [6, N=589], = 45.237, p =.000)*; however, the

relatively small odds ratios of the individual variables suggest that the individual

variables do not contribute much to the model. Women who were overweight were 1.346

times more likely to be CBE compliant (*p =*.382).

Table 33

Model 5: Summary of Logistic Regression Statistics for Clinical Breast Examination Compliance and Wellness Activity

Independent Variables	B	*SE*	*Wald*	*p*	Odds Ratio	C.I. For EXP (B) Lower/Upper
Out to PHCP	-1.151	.224	26.496	**.000**	.316	.204/.490
Smoking status	.610	.240	6.446	**.011**	1.840	1.149/2.946
BMI - underweight	-2.443	1.194	4.188	**.041**	.087	.008/.902
BMI - ideal weight	-.090	.336	.072	.789	.914	.474/1.764
BMI - overweight	.297	.341	.763	.382	1.346	.691/2.625
BMI obese	.054	.317	.029	.864	1.056	.567/1.966

Only being out to one's health care provider was entered into Model 6 to predict mammography compliance (Table 34). Women who were 40 years of age and older and out to their health care provider were .730 times more likely to be mammography compliant ($p = .362$). Overall, the model did not reach statistical significance $(X^2 [1, N=244], = .836, p =.360)$.

Table 34

Model 6: Summary of Logistic Regression Statistics for Mammography Compliance and Wellness Activity						
Independent Variables	B	*SE*	*Wald*	*p*	Odds Ratio	C.I. For EXP (B) Lower/Upper
Out to PHCP	-.314	.345	.831	.362	.730	.372/1.435

Participation in wellness activities inconsistently predicted screening. Therefore, the data from this analysis allow for the rejection of the null hypothesis in predicting BSE and CBE compliance but not mammography compliance.

Sexual Orientation

This section includes the analysis of Null Hypothesis #3: Breast cancer screening compliance is not predicted by gender identity (butch, androgynous, femme) and sexual orientation (lesbian, bisexual). Hypothesis 3 will be examined in relation to the four screening variables, BSE, CBE, mammogram and the composite screening score and include both ever had examination and guideline compliance with screening.

The literature demonstrates barriers to accessing care for lesbians that may inhibit their utilization of preventive screening (Solarz, 1999). However, when compared with bisexual women, there were no significant differences in BSE, CBE, or mammography ever use or compliance (Tables 35 – 37). Ever had BSE, CBE, and mammograms ranged from 88.9% - 93.4% for both lesbian and bisexual women. Although, BSE compliance was the lowest in both groups (31.6% among lesbians and 29.5% among bisexual women), compliance with other tests were considerably higher. Additionally, no significant differences were found in overall screening compliance (Table 38).

Table 35

Bivariate Association Between Breast Self-Examination Screening and Gender Identity

Independent Variable	Dependent Variable *n* (%)	X^2	*p* value
Sexual Orientation	**Ever Performed BSE**	.083	.773
Lesbian	498 (93.4)		
Bisexual	88 (92.6)		
Sexual Orientation	**BSE Compliance**	.165	.685
Lesbian	167 (31.6)		
Bisexual	28 (29.5)		

Table 36

Bivariate Association Between Clinical Breast Examination Screening and Sexual Orientation

Independent Variable	Dependent Variable *n* (%)	X^2	*p* value
Sexual Orientation	**Ever Had CBE**	.104	.950
Lesbian	497 (91.5)		
Bisexual	88 (90.7)		
Sexual Orientation	**CBE Compliance**	.272	.602
Lesbian	414 (77.8)		
Bisexual	77 (80.2)		

Table 37

Bivariate Association Between Mammogram Screening and Sexual Orientation

Independent Variable	Dependent Variable *n* (%)	X^2	*p* value
Sexual Orientation	**Ever Had Mammogram**	.143	.706
Lesbian	225 (91.1)		
Bisexual	24 (88.9)		
Sexual Orientation	**Mammogram Compliance**	.145	.703
Lesbian	186 (83.0)		
Bisexual	20 (80.0)		

Table 38

Bivariate Association Between Breast Screening Compliance and Sexual Orientation

Independent Variable	Dependent Variable *n* (%)			X^2	*p* value
Sexual Orientation	**1 Test**	**2 Tests**	**3 (all) Tests**	.893	.640
Lesbian	45 (19.7)	124 (54.1)	60 (26.2)		
Bisexual	5 (19.2)	12 (46.2)	9 (37.6)		

Gender Identity

Previous research has shown that butch identified women have diminished utilization of cancer screening services due to homophobia in the health care system (Hiestand et al., 2007). According to qualitative data collected by this researcher, butch identified women reported discomfort with gynecologic screening and were afraid of accessing care due to homophobic attitudes of care provider (Pearson-Fields & Scout, submitted for publication). Of the independent variables associated with sexual orientation and gender identity, only the latter was positively associated with any of the dependent variables (Table 39, Table 40). Women who considered themselves to be femme were significantly more likely to have ever performed a BSE (p=.049), and to be CBE compliant (p =.03). Although similar relationships existed for ever having a mammogram and mammography compliance, they did not reach significance (Table 41, Table 42).

Table 39

Bivariate Association Between Breast Self-Examination Screening and Gender Identity

Independent Variable	Dependent Variable n (%)	X^2	p value
Gender Identity	**Ever Performed BSE**	6.014	**.049**
Butch	104 (88.9)		
Neither	236 (93.3)		
Femme	243 (95.7)		
Gender Identity	**BSE Compliance**	.702	.704
Butch	35 (29.9)		
Neither	76 (30.3)		
Femme	84 (33.3)		

Table 40

Bivariate Association Between Clinical Breast Examination Screening and Gender Identity

Independent Variable	Dependent Variable n (%)	X^2	p value
Gender Identity	**Ever CBE**	4.941	.293
Butch	112 (91.5)		
Neither	213 (90.2)		
Femme	238 (92.2)		
Gender Identity	**CBE Compliance**	6.55	**.038**
Butch	89 (74.2)		
Neither	189 (75.0)		
Femme	210 (83.3)		

Table 41

Bivariate Association Between Mammogram Screening and Gender Identity

Independent Variable	Dependent Variable n (%)	X^2	*p* value
Gender Identity	**Ever Had Mammogram**	3.61	.164
Butch	54 (90.0)		
Neither	97 (87.4)		
Femme	94 (94.4)		
Gender Identity	**Mammogram Compliance**	2.816	.245
Butch	41 (77.4)		
Neither/Androgynous	78 (80.4)		
Femme	83 (87.4)		

Table 42

Bivariate Association Between Breast Screening Compliance and Gender Identity

Independent Variable	Dependent Variable n (%)			X^2	*p* value
Gender Identity	**1 Test**	**2 Tests**	**3 (all) Tests**	6.658	.155
Butch	10 (19.6)	27 (52.9)	14 (27.5)		
Neither/Androgynous	28 (26.7)	54 (51.4)	23 (21.9)		
Femme	12 (12.6)	54 (56.8)	29 (30.5)		

Regression Analysis - Sexual Orientation/Gender Identity Activity

Statistically significant associations were not uncovered between sexual orientation and any of the screening variables. Additionally, BSE and mammography screening were not impacted by gender identity. However, CBE compliance was positively associated with gender identity. As the only independent variable in this model to achieve significance, gender identity was used in the logistic regression. To facilitate analysis, several dummy variables were created to describe butch, neither butch nor femme, and femme gender identities.

Overall, Model 7 was predictive of CBE compliance *(X^2 [2, N=624], = 6.712, p =.035)* (Table 43). Of the three gender identity dummy variables entered into the model,

only butch identity and neither butch/femme identity were included in the analysis and

androgynous was the constant. Women who identified as neither butch nor femme were

significantly more likely to be compliant with CBE guidelines (OR, .600, $p = .022$, CI

.388/.929). Due to the limited number of variables in the bivariate analysis that reached

significance at the $p=<.05$ and the limited scope of their impact, only gender identity was

used in the logistic regression. These data support acceptance of the null hypothesis that

sexual orientation and gender identity are not predictive of breast cancer screening

compliance.

Table 43

Model 7: Summary of Logistic Regression Statistics for a Clinical Breast Examination Compliance and Sexual Orientation/Gender Identity

Independent Variables	B	*SE*	*Wald*	*p*	Odds Ratio	C.I. For EXP (B) Lower/Upper
Butch gender identity	.044	.254	.030	.863	1.045	.635/1.720
Neither butch or femme	-.511	.223	5.247	**.022**	.600	.388/.929

This section includes both bivariate and regression analyses of Null Hypothesis

#4 which states: There is no difference in breast cancer screening adherence based on

experiences with health care providers including having a PHCP, being out to one's

provider, previous negative experiences, anticipated negative experiences. This

hypothesis will be examined for each of the screening tests, BSE, CBE, mammography,

and the composite screening score. Each bivariate analysis will include ever had and

guideline compliance for each test. The logistic regression will include those independent variables that were significantly associated with the dependent variables.

Physician recommendation for breast cancer screening remains an important predictor of adherence. However, one must have a primary care provider and presumably a relationship with that provider that is not based on fear of being treated badly. Four independent variables, having a primary health care provider, being out to one's primary care provider, being afraid or worried about being treated badly or discriminated against by a PHCP, and actually being treated badly or discriminated against by a PHCP with one's health care provider were examined for their association with breast cancer screening adherence.

Breast Self-Examination

As previously stated, performing a BSE is the one screening test that can be done without a relationship with a health care provider. However, a bivariate analysis of ever performed a BSE and provider experience showed a significant relationship to having a health care provider $(X^2$ [1, N=624], = 5.119, p = .024) (Table 44). Participants with a provider were significantly more likely to have ever performed a BSE than those without a PHCP. No significant associations were identified in the bivariate analysis of BSE compliance and provider experience (Table 45).

Table 44

Bivariate Association Between Ever Performed Breast Self-Examination and Provider Exposure

Independent Variable	Dependent Variable n (%)	X^2	p value
Have a Primary Health Care Provider	**Ever Performed BSE**	5.119	**.024**
No	27 (5.5)		
Yes	461 (94.5)		
Out to Primary Care Health Provider	**Ever Performed BSE**	2.586	.274
No	17 (5.4)		
Yes	298 (94.6)		
Anticipated negative experiences	**Ever Performed BSE**	.240	.651
No	16 (7.4)		
Yes	201 (82.6)		
Previous Negative Experiences	**Ever Performed BSE**	.606	.436
No	9 (8.4)		
Yes	98 (91.6)		

Table 45

Bivariate Association Between Breast Self-Examination Compliance and Provider Experience

Independent Variable	Dependent Variable n(%)	X^2	p value
Have a Primary Health Care Provider	**BSE Compliance**	.257	.693
No	41 (30.4)		
Yes	256 (32.2)		
			.919
Out to Primary Health Care Provider	**BSE Compliance**	.169	
No	64 (31.4)		
Yes	101 (32.2)		
Anticipated Negative experiences	**BSE Compliance**	2.306	.125
No	157 (72.4)		
Yes	60 (27.6)		
Previous Negative Experiences	**BSE Compliance**	.702	.402
No	77 (73.0)		
Yes	30 (28.0)		

Clinical Breast Examination

Experiences with providers were strongly linked to whether participants ever had a CBE and whether participants were compliant to CBE guidelines. Women who had a PCHP $(X^2$ [2, N=637], = 12.033, p = .002) and who were out to their provider $(X^2$ [4, N=633], = 16.079, p = .003) were significantly more likely to have ever had a CBE (Table 46). Previous experiences, be they anticipated or actual, were less likely to result in significantly different ever CBE. Eighty eight percent (88.7%) of participants who reported anticipating a negative experience with their PHCP had a CBE, compared with 92.8% of participants who did not anticipate a negative experience. Conversely, 93.5.0% of women who had a previous negative experience reported ever having a CBE compared with 91% of participants who reported no previous negative experiences with providers.

CBE compliance was significantly associated with each of the provider experience independent variables (Table 47). For several of the provider experience variables, this is a natural association given that CBE compliance is provider dependent; however, at least one of the provider variables speaks to the provider patient relationship directly. Of women who had a PHCP, 85.7% reported being CBE compliant compared with 50.4% who did not have a PHCP $(X^2$ [2, N=626], = 77.500, p = .000). Eighty eight percent (88.0%) of respondents who reported being out to their PHCP were also CBE compliant $(X^2$ [2, N=622], = 88.601, p = .000). Additionally, women who did not anticipate negative experiences or did not report having actual negative experiences were more likely to be CBE compliant that those who reported anticipated or actual negative experiences $(X^2$ [1, N=626], = 10.647, p = .001) and $(X^2$ [1, N=628], = 4.329, p = .037) respectively.

Table 46

Bivariate Association Between Ever Clinical Breast Examination and Provider Experience

Independent Variable	Dependent Variable n (%)	X^2	p value
Have a Primary Health Care Provider	**Ever CBE**	12.033	**.002**
No	116 (84.1)		
Yes	466 (93.4)		
Out to Primary Care Provider	**Ever CBE**	16.079	**.003**
No	188 (89.5)		
Yes	306 (95.3)		
Anticipated negative experiences	**Ever CBE**	3.512	.173
No	384 (92.8)		
Yes	196 (88.7)		
Previous Negative Experiences	**Ever CBE**	.876	.645
No	483 (91.0)		
Yes	101 (93.5)		

Table 47

Bivariate Association Between Clinical Breast Examination Compliance and Provider Experience

Independent Variable	Dependent Variable n (%)	X^2	p value
Have a Primary Health Care Provider	**CBE Compliance**	77.500	**.000**
No	68 (50.4)		
Yes	421 (85.7)		
Out to Primary Health Care Provider	**CBE Compliance**	88.601	**.000**
No PCP	44 (44.0)		
No	166 (81.0)		
Yes	279 (88.0)		
Anticipated negative experiences	**CBE Compliance**	10.647	**.001**
No	336 (82.0)		
Yes	151 (70.8)		
Previous Negative Experiences	**CBE Compliance**	4.329	**.037**
No	417 (79.9)		
Yes	75 (70.8)		

Mammogram

Mammography, as a function of provider relationships, yielded mixed results. None of the provider experiences represented in this analysis was significantly associated with ever having a mammogram (Table 48). However, 91.9% of women who reported having a PHCP reported ever having a mammogram compared with 86.3% of women without a PHCP. Although not statistically significant, the impact of actual and anticipated negative experiences was in the anticipated direction, i.e., women who lacked these experiences were more likely to have ever had a mammogram. Additionally, slightly more women who were out to their primary care provider (92.5%) reported ever having a mammogram compared with women who were not out (91.8%); however, this did not reach the level of significance.

Two of the four independent variables in the provider experience model were significantly associated with mammography compliance for women 40 years of age and older (Table 49). Both having a PHCP (X^2 [2, N=248], = 16.929, p = .000) and being out to one's PHCP (X^2 [2, N=244], = 22.663, p = .000) were significantly associated with compliance. Eighty-four percent (84.4%) of participants who were not worried about being discriminated against or treated badly by their PHCP were mammogram compliant compared with 79.3% of participants who were worried about being discriminated against or treated badly by their PHCP.

Table 48

Bivariate Association Between Ever Had Mammogram and Provider Experience

Independent Variable	Dependent Variable n (%)	X^2	p value
Have a Primary Health Care Provider	**Ever Had Mammogram**	1.573	.210
No	44 86.3		
Yes	204 91.9		
Out to Primary Health Care Provider	**Ever Had Mammogram**	3.067	.216
No	90 91.8		
Yes	124 92.5		
Anticipated negative experiences	**Ever Had Mammogram**	.034	.605
No	161 (91.5)		
Yes	86 (89.6)		
Previous Negative Experiences	**Ever Had Mammogram**	.960	.327
No	205 91.9		
Yes	42 87.5		

Table 49

Bivariate Association Between Mammogram Compliance and Provider Experience

Independent Variable	Dependent Variable n (%)	X^2	p value
	Mammogram Compliance		
Have a Primary Health Care Provider		16.929	**.000**
No	27 (61.4)		
Yes	178 (87.3)		
Out to Primary Health Care Provider	**Mammogram Compliance**	22.663	**.000**
No	82 (90.1)		
Yes	105 (85.4)		
	Mammogram Compliance		
Anticipated negative experiences		1.005	.316
No	135 (84.4)		
Yes	69 (79.3)		
	Mammogram Compliance		
Previous Negative Experiences		.004	.949
No	170 (82.9)		
Yes	35 (83.3)		

Regression Analysis – Provider Experience

In the bivariate analysis, all four independent variables - having a PHCP, out to PHCP, anticipated and actual negative experiences with a health care provider were positively associated with CBE compliance (Table 50). Additionally, both having a PHCP and being out to PHCP were also significantly associated with mammography compliance. Therefore, these variables were entered into the logistic regression Models 8 and 9.

Table 50

Summary of Significant Associations Between Provider Experience and Screening

Independent Variable	Dependent Variable n (%)	X^2	*p* value
Have a PHCP	CBE Compliance	77.500	**.000**
Out to PHCP	CBE Compliance	88.601	**.000**
Anticipated negative experiences	CBE Compliance	10.647	**.001**
Previous negative experiences	CBE Compliance	4.329	**.037**
Have a PHCP	Mammogram Compliance	16.929	**.000**
Out to PHCP	Mammogram Compliance	22.663	**.000**

Models 8 and 9 represent an analysis of the predictive value of provider experience on CBE and mammography compliance, respectively. In Model 8, having a PHCP and being out to one's PHCP were significant at the $p \leq .05$ level (Table 51). Participants who anticipated a negative experience with their PHCP were 1.5 times more likely to be CBE compliant, whereas participants who had actual negative experiences with health care providers were 1.3 times more likely to be compliant. Neither reached

significance. An examination of the inverse of being out to one's PHCP revealed women who were *not* out were 1.92 times more likely to be CBE compliant. Overall, the model was predictive of CBE compliance *(X^2 [4, N=609], = 83.142, p =.000)*.

Only two variables were included in Model 9 which analyzed the predictive value of provider experience on mammography compliance (Table 52). Only being out to one's PHCP was significant at *p* = .001. Participants 40 years and older who had a health care provider were 1.2 times more likely to be compliant with mammography screening guidelines. Although participants who were out to their PHCP were significantly more likely to be compliant with mammography screening (OR .243, *p* = .001, CI .103/.575), participants who were *not* out were 4.1 times more likely to be compliant with mammography screening guidelines. As stated, the null hypothesis must be rejected because provider experience is statistically associated with the screening compliance dependent variables that were analyzed.

Table 51

Model 8: Summary of Logistic Regression Statistics for Clinical breast Examination Compliance and Provider Experience

Independent Variables	B	*SE*	*Wald*	*p*	Odds Ratio	C.I. For EXP (B) Lower/Upper
Have PHCP	-1.496	.239	39.169	**.000**	.224	.140/.358
Out to PHCP	-.654	.239	7.497	**.006**	.520	.326/.830
Anticipated Negative Experience	.439	.234	3.530	.060	1.552	.981/2.454
Actual Negative Experience	.308	.284	1.170	.279	1.360	.779/2.375

Table 52

Model 9: Summary of Logistic Regression Statistics for Mammogram Compliance and Provider Experience

Independent Variables	B	*SE*	*Wald*	*p*	Odds Ratio	C.I. For EXP (B) Lower/Upper
Have PHCP	.197	.403	.240	.624	1.218	.553/2.684
Out to PHCP	-1.414	.439	10.365	**.000**	.243	.103/.575

Summary of Findings

This chapter examined the relationship between the four dependent screening variables and fourteen independent risk factors for diminished breast cancer screening utilization. Dependent variables consisted of BSE, CBE, and mammogram compliance based on accepted guidelines at the time the data were collected. An additional screening score was calculated from the three screening methodologies to assess overall compliance with accepted guidelines. Independent variables were categorized into four theoretical models to test the association and predictive value on the dependent screening variables listed above. The theoretical models of sociodemographic risk factors, participation in wellness activities, sexual orientation/gender identity, and provider experience were developed based on existing literature on barriers to screening utilization for lesbians and bisexual women. The theoretical models formed the basis of the research questions for this study.

The analysis methodology used for this study consisted of several progressive steps including univariate analysis using frequencies for categorical data and means for continuous variables. As a first step, several variables were recoded to facilitate analysis. For example, continuous variables were recoded as categorical variables and categories

for several categorical variables were collapsed to mitigate the impact of outliers and missing data. Data were screened to examine distribution, multicollinearity, and the impact of missing data on the analysis. An acceptable level of missing data was determined and in cases where missing data exceeded that threshold, missing values were replaced with estimated means using SPSS Version 12.0. Bivariate analysis using *chi-square* was performed to uncover statistically significant relationships between the dependent variables and independent variables. Independent variables that were significantly associated with the dependent variables within each theoretical model were then entered into a logistic regression. Forced logistic regression was selected due to its ability to assess theoretical models as opposed to stepwise logistic regression which is used as a means of developing theoretical models.

Nine models were developed and analyzed (Table 53). Models 1 – 3 assessed the sociodemographic risk factors on breast cancer screening compliance. Models 4 – 6 analyzed the impact of participation in wellness activities on compliance. Sexual orientation and gender identity comprised Model 7 and was only analyzed in relation to CBE compliance. Since sexual orientation was not significantly associated with any of the compliance dependent variables it was excluded from the logistic regression analysis altogether. Provider experience was only statistically associated with CBE and mammography compliance, therefore it was only included in Models 8 – 9.

Sociodemographic risk factors were positively associated with each of the breast cancer screening compliance variables analyzed in Models 1-3, thereby allowing for the rejection of the null hypothesis. The theoretical models that included participation in wellness activities were more complex to assess. Two of the three screening compliance

variables could be predicted by participation in wellness activities. Since mammography screening was not impacted by participation in wellness activities, we are not able to reject the null hypothesis. Sexual orientation and gender identity also proved complex in their association with breast cancer screening compliance. Since significant variance in any of the screening compliance variables was not seen based on sexual orientation, it was dropped from the theoretical models tested through logistic regression. Additionally, gender identity was the only independent variable in this model to be associated with screening and it was only associated with CBE compliance. However, Model 7 showed a significant relationship between gender identity and CBE compliance, therefore allowing for the rejection null hypothesis. Lastly, the theoretical models which included provider experience, although only assessed for CBE and mammography compliance, were significantly associated.

Table 53

Summary of Logistic Regression (Forced) Models and Chi-square Equations

Model	Model Description	Dependent Variable	Chi-square
1	Sociodemographic characteristics	BSE Compliance	X^2 [4, N=622], = 23.107, p = **.000**
2	Sociodemographic characteristics	CBE Compliance	X^2 [10, N=594], = 74.977, p = **.000**
3	Sociodemographic characteristics *	Mammography Compliance	X^2 [1, N=240], = 8.010, p = **.003**
A	Sociodemographic characteristics	Overall Compliance Score	X^2[2, N=281], = 6.601, p = **.037**
4	Wellness activity	BSE Compliance	X^2 [1, N=422], = 4.185, p = **.041**
5	Wellness activity	CBE Compliance	X^2 [6, N=589], = 45.237, p =**.000**
6	Wellness activity*	Mammography Compliance	X^2 [1, N=244], = .836, p = *.360*
7	Sexual orientation/ gender identity	CBE Compliance	X^2 [2, N=624], = 6.712, p = **.035**
8	Provider experience	CBE Compliance	X^2 [4, N=609], = 83.142, p = **.000**
9	Provider experience*	Mammography Compliance	X^2 [2, N=242], = 11.144, p = **.004**

Note. Women 40 years and older

Chapter 5: Summary, Conclusion, and Recommendations

Introduction

The purpose of this chapter is to explore the analysis of data collected through the Black Women 2 Women Spirit Health Study. The original study, funded by the Komen for the Cure, was conducted by this researcher in the early 2000s. The goal of the original study was to address the literature gap on African American health beliefs, access to health care, utilization of health care services, social support, community connectedness, risk behaviors, and personal and family medical history. This analysis examined the predictive power of specific independent variables on compliance with BSE, CBE and mammography guidelines. Participant characteristics were divided into four predictive models based on associations found in the literature. The predictive models formed the basis of the research questions and included: sociodemographic characteristics; participation in wellness activities; sexual orientation and gender identity; and provider experience. Associations were explored between the models listed above and the following dependent variables: ever performed BSE; ever received CBE, ever received mammogram; compliance with BSE; CBE; and mammography guidelines. An overall screening compliance score was also computed and analyzed.

Presented herein are the interpretation of the study findings as they relate to breast cancer screening compliance for African American lesbian and bisexual women as well as a discussion of the four research questions posed in this study. Additionally, limitations uncovered during the data analysis will be examined in this chapter. Lastly, the potential implications for social change and recommendations for action as well as future study will be described.

Interpretation of Findings

Breast Cancer Screening

Breast Self-Examination

As mentioned in Chapter 2, the benefit of BSE has been questioned by the United States Preventive Services Task Force on more than one occasion (USPSTF, 2002; USPSTF, 2009). Many women perform BSE sporadically and have reduced self-efficacy in the performance of the screening test (Champion & Menon, 1997). Previous studies have differed on the prevalence of BSE among lesbians. Roberts and Sorenson (1999) found that lesbians had similar rates of preventive cancer screening as women in the general population with 43% of lesbians reporting occasional use of BSE. Zaritsky and Dibble (2010), on the other hand found that lesbian sisters did significantly fewer BSEs than their heterosexual sisters. Almost all the women who participated in the Spirit Health Study reported ever using BSE (96.4%). However, less than a third were compliant with monthly BSE. In the bivariate analysis, only sociodemograhic characteristics and wellness activities were assciated with BSE. These two theoretical models revealed that age (Model 1) and fruits and vegetable intake (Model 4) were positively associated with BSE compliance.When age was entered into the logistic regerssion, none of the age categories rose to the level of significant assoction. Conversly, when fruit and vegetable intake was entered into the logistical regression, consuming an average of 0-4 fruits and vegetables per day was found to be significant. As mentioned earlier, this variable contained a high percentage of missing cases resulting in the use of a missing variable mean (MVM) being entered into the analysis. Therefore,

participation in BSE could not be predicted by participation in wellness activities and the null hypothesis is accepted. Given that BSE is the only screening methodology that is driven by the individual and not impacted by barriers to accessing health care, it seems likely that it would be associated with other wellness activities. However, this was not the case. Participants' lack of regular practice with BSE may be related to women's overall lack of confidence in performing the procedure correctly, knowing what to look for, and the frequency with which one needs to perform BSE to be compliant.

Clinical Breast Examination

Recommendations regarding clinical breast examinations (CBE) have varied throughout the past decade. Although the ACS recommends three year intervals for CBE beginning at age 20 years for otherwise healthy women (Smith et al., 2003), variations in the amount of time spent per examination has led many to question the impact of the examination. The USPSTF's 2009 recommendations cite insufficient evidence to support or recommend against CBE for women 40 years and over (U.S. Preventive Services Task Force, 2009). However, obtaining a CBE provides patients with an opportunity for provider interaction that may yield benefits beyond early cancer detection such as the delivery of preventive health messages and the like. Like mammography, CBE is typically a function of access to care. Additionally, women who participate in CBE are more likely to also have a mammogram (Jelinski, Maxwell, Onysko, & Bancey, 2005). Therefore, individuals who experience barriers to healthcare are likely to miss these opportunities.

In this study, the majority of African American lesbians and bisexual women reported ever having a CBE and slightly more than three quarters of participants reported

having a CBE within the past year. When analyzed in relationship to sociodemographic characteristics (Model 3), CBE compliance was significantly associated with insurance status, income, and age. When entered into the logistic regression model, only health insurance was predictive of CBE compliance; however, the model overall was significantly associated with compliance. Therefore, these findings supported the rejection of the null hypothesis for this model.

Compliance to CBE was also measured in association with participation in wellness activities. A bivariate analysis revealed significant associations between smoking status, BMI, and disclosure of sexual orientation to PHCP. Model 5 assessed the predictive value of wellness activities on CBE compliance. Three of the six variables included in this model including: out to primary health care provider, smoking status, and being underweight were significant. Smokers were almost twice as likely to be CBE compliant and women who were overweight were almost one and a half times more likely to be CBE compliant. Although the model overall was predictive of CBE compliance, the individual variable associations proved interesting. The logistic regression used to assess the null hypothesis revealed that women who were overweight or obese were more likely to be CBE compliant than other women. However, previous research has suggested a lack of sensitivity in CBE among overweight women (Wee et al., 2000). Therefore, it is unclear what positive impact this association may have for overweight women. In other words, although overweight women may be more likely to be CBE compliant, the CBEs that they have may be less likely to be effective. Additionally, it is unclear why current smoking status would be significantly associated

with CBE compliance. Nonetheless, wellness was predictive of CBE compliance thereby allowing for the rejection of the null hypothesis for this model.

Lastly, CBE compliance was tested in association with sexual orientation, gender identity, and provider experience. The logistic regression analysis of the predictive value of gender identity (Model 7) found that a femme gender identity was significantly associated with CBE compliance with femme women being more than one and a half times more likely to be CBE compliant than other women in the model. While previous literature has not examined differences in CBE compliance based on gender identity, these findings suggest that butch-identified women may have decreased levels of compliance. Although, the reasons for this are unclear, one could speculate that this variance may be due to discomfort on either the patient or provider side. Further research is needed to determine if this is an avenue for intervention. Rejection of the null hypothesis for this model is supported by the study data.

Mammography

Studies of lesbians and bisexual women have shown varying levels of utilization of mammography screening. Statistics have ranged from 69% in one study to 79% in another study (Valanis et al., 1999). However, few studies have examined screening utilization among African American lesbians and bisexual women. In this study, almost all the age eligible participants reported ever receiving a mammogram, and the vast majority of study participants were guideline compliant. It should be noted that the way compliance to guidelines was measured in other studies varies from one to two years. Therefore, although the percentages appear much high for this sample, a direct comparison to other studies may not be possible. Given the high proportion of

participants who were mammography guideline compliant, it was dificult to see

statisitically significant variations based on the models studied.Of the independent

variables tested using bivariate analysis only insurance, having a primary care provider,

and being out to one's primary care provider were significantly associated with

mammography compliance. Although participation in wellness activities had no

signifcant impact on mammography compliance, non-smokers were slightly more likely

to be mammogram compliant. Provider recomemendation remains a critical driver of

mammography screening (Schueler et al., 2008; Crump et al., 2000). Therefore, it is

reasonable to expect that having a provider would be significantly associated with

mammography compliance as was the case in this study.

Few studies have addressed the process of coming out for African American

lesbians and bisexual women. Previous studies have shown a reluctance of African

American lesbians to disclose their sexual orientation in health care settings (Mays et al.,

1993. A study by Cochran & Mays (1988) showed about a third of African American

lesbians were out to their PHCP. In a more recent study 42% of African American

lesbians reported being out to their PHCP and talking about issues relevent to their sexual

orientation (Bowleg, Burkholder, Teti, & Craig, 2008). Almost half of participants in this

study reported being out to their PHCP. The differences in outness among African

American lesbians may be related to cultrual shifts in acceptance of gays and lesbians

over the past fifteen years which have lead to increased lesbian visibility in health care

settings. The prevailing wisdom in lesbian health is that being out to one's PHCP

improves patient-provider communication, and by extension, utilization and/or

compliance with screening recommendations. However, outness with one's PHCP was not significantly associated with mammography compliance in this study.

The fear of and actual experiences with discrimination plays an interesting role in mammography compliance. Data from this study support the assertion that the decision to disclose sexual orientation may be related to fear of being treated badly or discriminated against. Although no significant differences were seen, slightly more than half of the women who were afriaid to visit their PHCP because they thought they would be treated badly or discriminated against chose not to come out. The data further show that being unafaid of discrminiation increased the liklihood of mammography compliance. This suggests that women who feel more comfortable with providers, or at least are not worried about being treated badly, may enjoy a better relationship which in turn impacts their screening compliance. This may be because lesbians who do not fear being treated badly by their provider do not delay seeking care and therefore are more likely to receive screening recommendations and follow through on those recommendations. Further study of the lesbian – provider relationship, the drivers of this fear and the role fear has on compliace is needed. Nevertheless, the lesbians in this study showed a certain level of resilience to experiences of descrimination. Despite actually being treated badly by their PHCP in the past, African American lesbians in this study were still likely to be compliant with mammography guidelines. Neither anticipation of discrimination nor actual expereinces of discrimination from the PHCP were significantly associated with mammography compliance. These data lead us to accept the null hypothesis on the predictive value of provider experience on mammogrpahy compliance.

Based on the design of the original study, sexual orientation was defined as lesbian or bisexual only. Therefore, women who had a heterosexual orientation were not eligible to participate in the study. This sampling design prevents analysis of differences between lesbian and their heterosexual counterparts and limits comparisons to lesbian and bisexual women. Upon bivariate analysis, differences in mammography compliance based on sexual orientation did not reach statistical signifcance. A similar proprotion of lesbians and bisexual women reported compliance with guidelines. This finding is comparable to other studies of lesbian and bisexual women that found similar one year screening rates (Valanis et al., 2000). Additionally, although differences in gender identity were not statistically associated with mammography compliance, more femme-identied women reported being compliant than butch-identified women and women who identified as neither butch or femme.

Independent variables that reached significance in the bivariate analysis were entered into several theoretical frameworks to address the four research questions. The purpose of the research questions was to determine if screening compliance could be predicted based on sociodemographic characteristics, participation in wellness activity, sexual orientation/gender identity, and finally, provider experience. Since mammography compliance was only significantly associated with three independent variables, it was only analyzed in three of the four research questions. A logistic regression examining the impact of Model 3 sociodemographic characteristics and Model 9 provider experience showed a postive predictive value of the model on mammography compliance. Therefore these data do not allow for the rejection of the null hypothesis as stated for

mammography compliance in research question1 and research question 4. However, the null hypothesis for Research Question 3 is rejected.

Combined Screening

The decision to compute a breast cancer screening composite score was made to facilitate analysis of overall screening compliance although it can be argued that assigning equal weight to each screening test may over inflate or under represent the relative importance of each screening methodology. However, the assignment of a weighted score to screening would have been little more than capricious given the controversy and dissention expressed by national organizations and community based organizations about screening recommendations. For example, although no official body recommends BSE, it continues to be taught by community public health educators as a way of helping women become comfortable with their bodies and improve the likelihood that breast changes are caught and reported early. While many of these changes may not be indicative of cancer and the practice of BSE does not decrease breast cancer mortality, it remains a constant in the women's health community. Additionally, recommendations for the inclusion of CBE in the breast cancer screening triumvirate are lacking or lukewarm. Even the recommendations for mammography screening have been controversial of late. By creating a composite score that gives equal weight to all three tests, we are able to ascertain if women are fully engaged in breast cancer screening without ascribing a judgment to that engagement.

Overall, the majority of study participants 40 years of age and older were compliant with one to two tests (76.6%). Given the relatively low compliance with BSE screening, it seems reasonable to assume that mammography and CBE compliance

contributed the most to the overall compliance score. Therefore, issues of access to care such as health insurance should have been positively associated with overall compliance. In fact, bivariate analysis revealed that insurance was the only sociodemographic characteristic positively associated with overall compliance. Insured women were significantly more likely to have had two of the three tests than women without insurance. Although none of the wellness activities were significantly associated with overall screening compliance, 60% of women who were morbidly obese scored a two on the overall composite score. Two thirds of women who engaged in no physical activity reported a composite score of 2. Additionally, half of current smokers had a screening composite score of two as well. Similar results were found among the different gender identity groups – with 2 being the most common composite score. Participants with a lesbian identity were more likely to report two tests than bisexual women. Based on these findings, sexual orientation/gender identity, wellness activities, and provider experience were not predictive of overall screening compliance, allowing us to accept the null hypothesis in these questions.

Limitations

As mentioned in Chapter 1, there are three main limitations associated with this study. First and foremost, this study was conducted using a convenience based sampling methodology that relied on recruitment of African American lesbians who were connected to the lesbian community at large and therefore already enjoyed a certain level of outness. While one consequence of this sampling methodology is that the data are not generalizable to the population of African American lesbians, it may have also greatly shaped the experiences reported by the women who completed this survey. For example,

it could be argued that women who subscribed to an African American lesbian magazine may have a very different experience of the world than someone who does not. This level of functioning within the community may indeed suggest a certain availability and utilization of resources both internal and external and a certain level of resilience that may mitigate barriers and fear about accessing health care services. As a result, study participants reported extremely high levels of breast cancer screening – higher even than that reported on national studies of American women. Additionally, almost all the women who participated in this study were insured, another factor known to significantly impact access to care.

Additionally, although the survey was anonymously completed by women across the country, reporting information on stigmatized activities such as smoking, obesity, and non-utilization of appropriate breast cancer screening may have impacted social desirability biases. This may be especially acute in light of the awareness some participants may have had about the increased risk that lesbians faced through the national effort to increase services for lesbians with cancer. In other words, it may be possible that the work of such groups as the Mautner Project in raising awareness about cancer among lesbians may have contributed to women being more likely to inaccurately report that they had participated in cancer screening. Although, a certain amount of social desirability bias may be at play in these findings, they are similar to other studies that have seen increased utilization of breast cancer screening among lesbians. However, the comparison to the general population of African American women's screening rates shows glaring dissimilarities. According to the ACS Cancer Facts and Figures for African Americans, 2009-2010, only 64.9% African American women reported use of

mammography within the last 2 years, compared with 82.8% of African American

lesbian participants in this study (ACS, 2009).

An additional limitation that was uncovered during the data analysis was the lack

of a comparison group in the original study design. As such, this study yielded no insight

into whether African American lesbians were different from non-African American

lesbians, African American heterosexual women, or other groups. Comparisons with

published statistics are imprecise at best due to differences in how samples were derived

and issues of compliance are operationalized. This limitation may lead to inaccurate

conclusions that African American lesbians are better off when it comes to screening

compliance than other groups. Further studies are needed to confirm these findings.

Implications for Social Change

Although data collected on lesbians have shown disparities in access and

utilization of cancer screening services (Solarz, 1999), cancer screening utilization among

African American lesbian and bisexual women is infrequently studied. The data collected

and analyzed for this study addresses this shortcoming by providing a large sample of

African American lesbians and bisexual women that allow for a deeper understanding of

the cancer screening behaviors in this group. Additionally, by adding to the literature, this

study may spur additional researchers to engage this community in research activities.

Past studies on lesbian health have lead to increased understanding of lesbian health

behavior and the development of culturally relevant interventions and policy changes that

have greatly reduced discriminatory and heterosexist practices throughout the U.S. Data

from this study can lead to increased awareness of the screening behaviors of African

American lesbians and will help to inform program developers and providers as they seek

to improve or support breast cancer screening utilization in this population. Although adherence to screening guidelines was generally high, behavioral risk factors such as obesity were also high. Additionally, women who were not out to their primary care provider were more likely to be mammography guideline compliant than women who were out to their providers. Much work is necessary to improve comfort levels with lesbian identity among providers and translate those improvements to patients in ways that enhance the patient provider relationship.

Recommendations for Action

One of the results of the original study was the development by this researcher of the Spirit Health Education (SHE) Circles, a holistic wellness program aimed at providing support to African American lesbians as they embark upon a journey to wellness. This eight week program focuses on increasing utilization of cancer screening (breast, cervical, and colorectal), and increasing support for health lifestyle behaviors such as smoking cessation, healthy eating, increased physical activity, and increased intake of fruits and vegetables. Given the risk behaviors exhibited by study participants such as smoking, overweight and obesity, the low levels of strenuous physical activity, and low intake of five or more fruits and vegetables per day, it is safe to assume that, despite the lack of access barriers, these women may still be at increased risk for breast cancer. Therefore, the replication of programs such as the SHE Circle may be important vehicles for reduction of behavioral risk factors for cancer while supporting utilization of multiple cancer screening modalities. Findings from the Black Women 2 Women Spirit Health Survey can be used to support the implementation of the SHE Circle and similar programs. Additionally, study findings have been disseminated to public health

practitioners through presentations at numerous national conferences including the American Public Health Association, the Black Lesbian Conference, the Gay and Lesbian Medical Association Women in Medicine Conference, and the Fenway Lesbian Health Research Forum. Data presented herein will be submitted for publication in relevant public health journals to further add to the body of literature on African American lesbian health.

<div align="center">**Recommendations for Further Study**</div>

The study of lesbian health research has grown over the past two decades; from the seminal study of lesbian health conducted in the 1980's by Bradford et al., to the auspicious IOM taking up the issue of lesbian health in 1999 (Solarz, 1999), the issues affecting lesbian health have received increased attention. However, as the field of research has grown to include both convenience and population based sampling methodologies as well as quantitative and contextual qualitative research, relatively little attention has been paid to lesbians that are outside of the mainstream. Research into the health behaviors and impediments to health access experienced by African American, Latina, Asian Pacific Islander, butch-identified, and lesbians of low socioeconomic status remains limited. The data collected in this study describe a very specific subgroup within a population. As such, some questions are answered but many others are raised. For example, are the experiences of access and utilization quite different for uninsured African American lesbians, or African American lesbians living at lower SES, or without adequate education and resources? What role does community connectedness and outness in other areas of one's life have on health care self efficacy? Further exploration is

needed to uncover and describe the nuances impacting care that may exist for these communities.

Another interesting question pertains to whether African American lesbians are behaviorally more similar to African American heterosexual women or non-African American lesbians. For example, the lesbians in this study have low rates of tobacco use, similar to those of African American women in the general population. Insurance rates for the study participants are comparatively higher than those of African American women in the general population. Lastly, participation in breast cancer screening was more similar to that of lesbians in other studies as opposed to those of African American heterosexual women. Therefore, more research is needed to further delineate the uniqueness of the behavioral and sociodemographic characteristics of this subgroup as a means of creating culturally appropriate interventions to support access and utilization of preventive health services.

As more states begin to include sexual orientation on the BRFSS and other population based surveys, we are developing an increased understanding of lesbian health in general and screening behavior in particular. However, little remains known about the rate of breast cancer among lesbians. Prevailing wisdom maintains that lesbians may be at increased risk for breast cancer and late diagnosis of disease based on risk factors and diminished access to care. However, this can only be borne out by the reporting of sexual orientation in the nation's cancer registry data. Of course the challenges to collecting this data element are great, particularly given the fact that many hospitals struggle with accurately reporting innocuous characteristics such as race. However, until this type of

data is collected, we continue to design policies and develop programs based on only half the story.

Summary

As Audre Lorde wrote many years ago

"I write for those women who do not speak, for those who do not have a voice because they were so terrified, because we are taught to respect fear more than ourselves. We've been taught that silence would save us, but it won't."
(Audre Lorde, as cited in Tate, 1983).

For many lesbians throughout the United States, fear and silence have been central themes in their interactions with the health care system. Patients fear that the intake forms used by providers to gather pertinent health and risk factor information will reveal that they are sexually active but not using birth control. This often leads to uncomfortable questions based on provider heterosexist assumptions that discount lesbian identity. For self-empowered lesbians living in large urban centers, possessing health care insurance, education, and income – such as the participants of this study - these fears may have a diminished impact on access to healthcare. However, these fears are still real for many. This research speaks for those women who are unable to speak for themselves. By dispelling the myth of ethnoheterosexuality and raising the level of awareness of an often neglected group, we expand the discussion that will ultimately benefit all.

The role of lesbian health research over the past decade has had a profound impact. As I write this concluding paragraph at the end of National LGBT Health Awareness week, the IOM has just released The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding on March 31, 2011(Institute of Medicine, 2011). On April 1, 2011, the USDHHS released a set of

recommendations for LGBT health that among other things stated that the LGBT community has received less than the compassionate delivery of health care services than they deserve, (USDHHS, 2011). These recommendations mark the one year anniversary of President Obama's Presidential Memorandum on Hospital Visitation issued in April 2010 that guaranteed visitation rights to same sex family members. While there is still a long way to go to achieve full parity and non-discriminative care, the stage is truly set for a healthier tomorrow for the LGBT community.

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Appendix A

Women to Women

Spirit Health Study

The Mautner Project
1707 L Street, Suite 230
Washington, DC 20036
1-866-W2W-SPIRIT
or
1-866-929-7747

This questionnaire will ask about your health behaviors and your thoughts about your healthcare. The answers you give throughout this questionnaire are very important in helping us understand the health of black lesbian and bisexual women. Your answers will be added to the responses of women across the country. The responses you give us will be completely confidential and never linked to you as an individual. No names or other identifying information will be kept. Thank you for agreeing to participate in this important study.

SECTION A – GENERAL INFORMATION

A1. Do you consider yourself black or African American
- O_1 Yes
- O_2 No → STOP

A2. Where did you get this questionnaire *(Mark all that apply)?*
- O_1 Requested copy through toll free number
- O_2 Venus subscription
- O_3 Church
- O_4 A friend
- O_5 Healthcare worker / Doctor's Office / Clinic
- O_6 Therapist's Office
- O_7 School
- O_8 Organization
- O_9 Public gathering
- O_{10} Bookstore
- O_{11} Newsletter
- O_{12} Bar
- O_{13} Signed up for study
- O_{14} Other, specify _____

A3. How did you fill it out?
- O_1 By yourself
- O_2 In a group
- O_3 Other, specify _____

SECTION B - WOMEN'S HEALTH

The first section of this questionnaire asks about your reproductive history.

B1. How old were you when you had your first menstrual period? _____ # of years *(Please give your best guess if you are not sure)*

B2.   What is your current menstrual status? *(Mark one circle only.)*
      O_1 Periods have temporarily stopped
           why _____
      O_2 Still having periods like I've always had
      O_3 Still having periods, but not like I've always had
      O_4 Going through menopause or the change of life
      O_5 Periods have permanently stopped
      O_6 None of the above

      > a. If your periods have permanently stopped, why have your periods stopped? *(Mark one circle only.)*
      > O_1 I had a hysterectomy and/or removal of both ovaries
      > O_2 Due to chemotherapy or radiation therapy for illness
      > O_3 Natural menopause not due to surgery, chemotherapy, or radiation
      > O_4 Other _____

B3.   Are you currently taking female replacement hormones (like estrogen) for menopause (including pills, injections, or patches)?
      O_1 No ⟶ **(GO TO B5)**
      O_2 Yes

      > a. What type of prescribed hormones are you taking *(Mark all that apply)*?
      > O_1 Premarin or other Estrogen pills alone
      > O_2 Progesterone (Provera, etc., pills alone
      > O_3 Estrogen and progesterone together
      > O_4 Patch estrogen alone
      > O_5 Patch estrogen and progesterone
      > O_6 Estrogen vaginal creme
      > O_7 Other, specify _____

B4.   Have you ever used birth control pills?
      O_1 No ⟶ **(GO TO B4)**
      O_2 Yes

      > a. If you used birth control pills, what is the total length of time that you used them? *(Mark one circle only)*
      > O_1 less than 6 months
      > O_2 6-11 months
      > O_3 1-2 years
      > O_4 3-4 years
      > O_5 5 years or more
      >
      > b. Why did you take birth control pills? *(Mark all that apply)*
      > O_1 Birth Control
      > O_2 Make periods regular
      > O_3 Reduce menstrual cramps
      > O_4 Other, specify _____

B5.   Have you ever used either Norplant or Depo-Provera?
      O_1 No
      O_2 Norplant (birth control implants)
      O_3 Depo-Provera (birth control shots)
      O_4 Don't know

B6. Have you ever been pregnant?
       O_1 No   →   **(GO TO B7)**
       O_2 Yes

> a. How many times have you been pregnant, include still births, live births, miscarriages and terminations?   _____ # of pregnancies
>
> b. How many children have you had?   _____ # of children
>
> c. How old were you when you had your first child?   _____ age
>
> d. How did you become pregnant? *(Mark method and number of pregnancies by that method)*
> O_1 Sex with a man   _____ # of pregnancies
> O_2 Artificial insemination Known donor   _____ # of pregnancies
> O_3 Artificial insemination Unknown donor   _____ # of pregnancies
> O_4 In vitro fertilization   _____ # of pregnancies

B7. How many children are currently living with you (include partner's children, biological, adopted, foster or other children)?   _____# of children

SECTION C - ACCESS TO HEALTH CARE

In this section you will be asked questions about your access to and use of various health care services. We are also interested in any difficulties that you may have experienced in receiving health care and situations where you felt you were treated badly by a healthcare provider?

C1. What type of insurance do you have? *(Mark one circle only)*
    O_1 I don't have any insurance
    O_2 Medicare
    O_3 Medicaid
    O_4 Champus/Tricare/Champ-VA
    O_5 HMO through job (like Kaiser Permanente)
    O_6 HMO self-paid
    O_7 HMO partner's policy
    O_8 Private health insurance (like Blue Cross) through job
    O_9 Private health insurance, self-paid
    O_{10} Private health insurance, partner's policy

C2. Do you currently have a primary health care provider?

    O_1 No

    O_2 Yes

> **a. (IF NO) Why not?** *(Mark all that apply)*
> - O_1 No insurance
> - O_2 Have not chosen one
> - O_3 Go to clinic and see different doctors
> - O_4 Other, specify _____

> **b. (IF YES) What type of provider is it?** *(Mark one circle only for <u>primary</u> provider)*
> - O_1 Medical Doctor
> - O_2 Naturopathic doctor
> - O_3 Chiropractor
> - O_4 Nurse practitioner
> - O_5 Physician's assistant
> - O_6 Herbalist
> - O_7 Spiritual Healer
> - O_8 Midwife
> - O_9 Other_____

C3. Please tell me how important the following health care provider characteristics are to you.	Not at all important (1)	Somewhat unimportant (2)	Somewhat important (3)	Very important (4)
a. How important is it to you to have a **lesbian** primary health care provider?	O	O	O	O
b. How important is it to you to have a **female** primary health care provider?	O	O	O	O
c. How important is it to you to have a primary health care provider that is **lesbian** sensitive?	O	O	O	O
d. How important is it for you to have a primary health care provider that is knowledgeable about **lesbian** healthcare needs?	O	O	O	O
e. How important is it for you to have a primary health care provider who is **African American**?	O	O	O	O
f. How important is it for you to have a primary health care provider that is knowledgeable about **African American** health care needs.	O	O	O	O
g. How important is it to you to have a **lesbian** gynecologist?	O	O	O	O
h. How important is it to you to have a **female** gynecologist?	O	O	O	O
i. How important is it to you to have a gynecologist who is **lesbian** sensitive?	O	O	O	O
j. How important is it for you to have a gynecologist that is knowledgeable about **lesbian** healthcare needs?	O	O	O	O
k. How important is it for you to have a gynecologist who is **African American**?	O	O	O	O
l. How important is it for you to have a gynecologist that is knowledgeable of **African American** health care needs?	O	O	O	O

C4. Have you ever been **worried or afraid to visit a primary care provider** because you thought you would be discriminated against or treated badly?

    O_1 No ⟶ **(GO TO C6)**

    O_2 Yes

4

C5. Why did you think you would be discriminated against or treated badly? *(Mark all that apply)*
   O_1 Racism
   O_2 Homophobia or Heterosexism
   O_3 Insurance status
   O_4 Literacy level
   O_5 Income
   O_6 Education level
   O_7 Gender
   O_8 Overweight
   O_9 Ageism
   O_{10} Sexism
   O_{11} How butch you look
   O_{12} Don't know
   O_{13} Other, specify _____

C6. Have you ever **delayed seeking healthcare** because you thought you would be discriminated against or treated badly?
   O_1 No ⟶ **(GO TO C8)**
   O_2 Yes

C7. Why did you think you would be discriminated against or treated badly? *(Mark all that apply)*
   O_1 Racism
   O_2 Homophobia or Heterosexism
   O_3 Insurance status
   O_4 Literacy level
   O_5 Income
   O_6 Education level
   O_7 Gender
   O_8 Overweight
   O_9 Ageism
   O_{10} Sexism
   O_{11} How butch you look
   O_{12} Don't know
   O_{13} Other, specify _____

C8. Were you ever **afraid to get healthcare in the emergency department** because you thought you would be discriminated against or treated badly?
   O_1 No ⟶ **(GO TO C10)**
   O_2 Yes

C9. Why did you think you were discriminated against or treated badly? *(Mark all that apply)*
   O_1 Racism
   O_2 Homophobia or Heterosexism
   O_3 Insurance status
   O_4 Literacy level
   O_5 Income
   O_6 Education level
   O_7 Gender
   O_8 Overweight
   O_9 Ageism
   O_{10} Sexism
   O_{11} How butch you look
   O_{12} Don't know
   O_{13} Other, specify _____

C10. Have you ever been discriminated against or treated badly by **your primary care provider**?
O_1 No $\longrightarrow$ **(GO TO C13)**
O_2 Yes

C11. Why did you think you were discriminated against or treated badly? *(Mark all that apply)*
O_1 Racism
O_2 Homophobia or Heterosexism
O_3 Insurance status
O_4 Literacy level
O_5 Income
O_6 Education level
O_7 Gender
O_8 Overweight
O_9 Ageism
O_{10} Sexism
O_{11} How butch you look
O_{12} Don't know
O_{13} Other, specify _____

C12. If you have had any negative experiences, briefly explain what happened. Please use additional space if necessary.
_____
_____
_____

C13. Do you have any friends or acquaintances who have been discriminated against or treated badly by their primary health care provider?
O_1 No $\longrightarrow$ **(GO TO C15)**
O_2 Yes

C14. Why did they think they were discriminated against or treated badly? *(Mark all that apply)*
O_1 Racism
O_2 Homophobia or Heterosexism
O_3 Insurance status
O_4 Literacy level
O_5 Income
O_6 Education level
O_7 Gender
O_8 Over weight
O_9 Ageism
O_{10} Sexism
O_{11} How butch they look
O_{12} Don't know
O_{13} Other, specify _____

C15. Are you "out" to your primary care provider? (By "out", we mean have you told them about your sexual orientation)

O_1 Do not have a primary care provider (PCP) ⟶ **(GO TO C16)**

O_2 No **(GO TO a)**

O_3 Yes **(GO TO b)**

a. **If you have not** "come out", what impact do you think coming out would have on the quality of your health care?

O_1 Negatively impact

O_2 No impact

O_3 Positive impact

O_4 Don't know

b. **If you have** "come out" to your primary care provider, what impact has that coming out had on the quality of your health care?

O_1 Negative impact

O_2 No impact

O_3 Positive impact

O_4 Don't know

C16. Where do you go when you needed routine health care? *(Mark all that apply)*

O_1 Private doctor's or practitioner's office

O_2 HMO Clinic (such as Kaiser, etc)

O_3 Community Health Center

O_4 Public Health Department

O_5 Emergency Room

O_6 Health services at school

O_7 Health services at work

O_8 Urgent care center

O_9 Veterans Administration (VA Hospital)

O_{10} Other, specify _____

C17. When was your last complete physical exam or check up? This is just a routine visit to the provider and not for any specific illness or injury. *(Mark one circle only)*

O_1 In the last year

O_2 More than 1 year but less than 2 years ago

O_3 More than 2 years but less than 3 years ago

O_4 More than 3 years but less than 4 years ago

O_5 More than 4 years ago

SECTION D - HEALTH SCREENINGS

This section asks questions about screening for health conditions as well as cancer screening. Please think about all the screening tests or procedures you have done in your life to answer these questions.

D1. Have you ever had a mammogram? A mammogram is an x-ray of the breast.

O_1 No
O_2 Yes ⟶ **(GO TO D2)**

a. (IF NO) Why not? *(Mark all that apply)* ⟶ **(GO TO D6)**
  O_1 Too young to have a mammogram
  O_2 Lack of health insurance
  O_3 No one recommended it
  O_4 Lack of time
  O_5 Forgot to schedule appointment
  O_6 Afraid of the results
  O_7 Afraid the mammogram will be painful
  O_8 Afraid staff won't be gay friendly
  O_9 Afraid of radiation
  O_{10} Don't think that I am at risk
  O_{11} Procrastination/ put it off
  O_{12} Couldn't get appointment
  O_{13} Other, specify _____

D2. How old were you when you had your first mammogram? _____ age

D3. How many *mammograms* have you had in your lifetime? _____ # of mammograms.

D4. How often have you had *mammograms* in the past? *(Mark one circle only.)*
  O_1 Twice a year
  O_2 Once a year
  O_3 Once every 2 years
  O_4 Once every 3 years
  O_5 Once every 4 or 5 years
  O_6 I don't have mammograms on a regular schedule

D5. When was your **LAST mammogram?** *(Mark one circle only.)*
  O_1 Within the past 12 months (I have had a mammogram since this time last year) ⟶ **(GO TO D6)**
  O_2 Between 1 and 2 years ago ⟶ **(GO TO D6)**
  O_3 Between 2 and 3 years ago
  O_4 Between 3 and 4 years ago
  O_5 More than 4 years ago

a. If more than 2 years ago, why? *(Mark all that apply)*
  O_1 Lack of health insurance
  O_2 Lack of time
  O_3 Forgot to schedule appointment
  O_4 Afraid of the results
  O_5 Afraid the mammogram will be painful
  O_6 Waiting time for an appointment
  O_7 Don't think that I am at risk
  O_8 Other, Specify _____

This next group of questions are about Breast Self Examiniations (BSE). A breast self examination (BSE) is when you examine your own breasts (or have a friend examine your breasts) for lumps, discharge or other changes.

D6. Have you ever received instruction from another person on how to perform **breast self-examination**? *(Mark one circle only.)*
    O_1 No
    O_2 Yes

D7. Have you **ever** performed a **breast self-examination (BSE)?**
    O_1 No   ⟶   **(GO TO D15)**
    O_2 Yes

D8. How often have you performed **breast self-examinations** *in the past 12 months? (Mark one circle only.)*
    O_1 Weekly
    O_2 Every month
    O_3 Every 2 months
    O_4 Every 3 or 4 months
    O_5 Every 6 months
    O_6 Once a year
    O_7 I don't perform breast self-examinations on a regular schedule

D9. When did you **LAST** do a **breast self-examination** (Mark one circle only)
    O_1 Within the past 30 days (I have done a breast self-exam since this time last month)
    O_2 Between 1 and 2 months ago
    O_3 Between 2 and 3 months ago
    O_4 Between 3 and 4 months ago
    O_5 4 or more months ago

D10. How do you remember to perform **breast self-examinations**? *(Mark all that apply)*
    O_1 I don't remember
    O_2 Do before/after each menstrual period
    O_3 Use a shower card reminder
    O_4 Use a "buddy program" or circle of friends to remind me
    O_5 Partner reminds me
    O_6 Other, specify _____

The following questions ask about how you examine your breasts.

When you perform breast self-examinations, do you....	Rarely or never (1)	Sometimes (2)	Usually (3)	Always (4)
D11. examine your breast in front of a mirror to look for dimpling, puckering, changes in skin texture, etc.?	O	O	O	O
D12. feel for lumps while lying down?	O	O	O	O
D13. feel for lumps while standing up?	O	O	O	O
D14. check your nipples for an unusual discharge?	O	O	O	O

This next section asks about *clinical breast exam.* **This is where your doctor or health care provider checks your breasts for lumps or discharge. It is usually done in a doctor's office as part of a routine physical examination.**

D15. Have you **ever** had a **clinical breast exam**?
    O_1 No   ⟶   **(GO TO D18)**
    O_2 Yes
    O_3 Don't Know   ⟶   **(GO TO D18)**

9

D16. How often have you had **clinical breast examinations** in the past? *(Mark one circle only)*
  - O_1 Twice a year
  - O_2 Once a year
  - O_3 Once every 2 years
  - O_4 Once every 3 years
  - O_5 Once every 4 or 5 years
  - O_6 I don't have clinical breast exams on a regular schedule

D17. When was your **LAST clinical breast exam?** *(Mark one circle only)*
  - O_1 Within the past 12 months (I have been examined since this time last year)
  - O_2 Between 1 and 2 years ago
  - O_3 Between 2 and 3 years ago
  - O_4 Between 3 and 4 years ago
  - O_5 More than 4 years ago

D18. Have you ever had genetic testing for the gene related to breast cancer (BRCA I/BRCA II)?
  - O_1 No
  - O_2 Yes

Now we will ask questions about a Pap Test - also called a Pap smear. During this test a doctor or other health care provider checks your cervix for infections, inflammation, abnormal cells or cancer.

D19. Have you **ever** had a **pap smear**?
  - O_1 No ⟶ **(GO TO D24)**
  - O_2 Yes
  - O_3 Don't Know ⟶ **(GO TO D24)**

D20. How often do you have **pap smears?** *(Mark one circle only.)*
  - O_1 Twice a year or more
  - O_2 Once a year
  - O_3 Once every 2 years
  - O_4 Once every 3 years
  - O_5 Once every 4 or 5 years
  - O_6 I don't get pap smears on a regular schedule

D21. When did you **LAST** have a **pap smear**? *(Mark one circle only)*
  - O_1 Within the past 12 months (I have had a pap smear since this time last year)
  - O_2 Between 1 and 2 years ago
  - O_3 Between 2 and 3 years ago
  - O_4 Between 3 and 4 years ago
  - O_5 More than 4 years ago

> a. If more than 2 or more years ago, why? *(Mark all that apply)*
>   - O_1 Didn't have health insurance
>   - O_2 Didn't have time
>   - O_3 Forgot to schedule appointment
>   - O_4 Afraid of the results
>   - O_5 Afraid the test will be painful
>   - O_6 Don't think that I am at risk
>   - O_7 Other, specify _____

D22. Have you ever had an "abnormal" pap smear?
    O_1 No   ⟶   **(GO TO D24)**
    O_2 Yes

D23. Was cancer considered a possible reason for your abnormal pap smear result?
    O_1 No
    O_2 Yes

D24. Has your health care provider ever told you that you don't need a ***pap smear***?
    O_1 No
    O_2 Yes, why _____

The next questions ask about other health screening tests that you may have had.

D25. Have you ever had any of the following tests?	No (1)	Yes (2)	Don't Know (3)
CA-125/CA-125 II test. This test is used to find high levels of antibodies commonly found in ovarian cancer.	O	O	O
Diabetes (often called 'sugar')?	O	O	O
Glaucoma?	O	O	O
Cholesterol?	O	O	O
High/Low blood pressure?	O	O	O

We are interested in your future health care plans. This last question asks about screenings you are planning to have in the future?

D26. Do you plan to have any of the following screening tests in the next five years? *(Mark all that apply)*
    O_1 Genetic testing for breast cancer
    O_2 Breast Self Exam
    O_3 Clinical Breast Exam
    O_4 Mammogram
    O_5 Colorectal cancer screening
    O_6 Pap Smear
    O_7 Diabetes (Sugar) screening
    O_8 Bone Density Screening
    O_9 Glaucoma
    O_{10} High/Low blood pressure
    O_{11} Other, specify _____
    O_{12} No

SECTION E - PERSONAL MEDICAL HISTORY

The chart below asks about your personal medical history.

E1. Has a doctor ever told you that you have any of the following conditions? **If yes**, mark the condition and the age it was *first* diagnosed.

Condition	APROXIMATE AGE AT DIAGNOSIS					
	No (1)	Yes (2)	29 and under (3)	30-39 (4)	40-49 (5)	50 or more (6)
a. Angina (chest pain)	O	O	O	O	O	O
b. Asthma	O	O	O	O	O	O
c. Arthritis	O	O	O	O	O	O
d. Blood clots in the lungs or legs	O	O	O	O	O	O
e. Breast Cancer	O	O	O	O	O	O
f. Cervical cancer	O	O	O	O	O	O
g. Colon or rectal cancer	O	O	O	O	O	O
h. Congestive Heart Failure	O	O	O	O	O	O
i. Cysts in breast	O	O	O	O	O	O
Was it confirmed by biopsy?	O	O	O	O	O	O
j. Diabetes (not during pregnancy)	O	O	O	O	O	O
k. Endometriosis	O	O	O	O	O	O
l. Fibroids	O	O	O	O	O	O
m. Heart attack	O	O	O	O	O	O
n. Hepatitis B	O	O	O	O	O	O
o. Hepatitis C	O	O	O	O	O	O
p. High blood pressure (not during pregnancy)	O	O	O	O	O	O
q. High cholesterol	O	O	O	O	O	O
r. HIV	O	O	O	O	O	O
AIDS	O	O	O	O	O	O
s. Human Papaloma Virus (HPV)	O	O	O	O	O	O
t. Lung Cancer	O	O	O	O	O	O
u. Lupus	O	O	O	O	O	O
v. Multiple Sclerosis	O	O	O	O	O	O
q. Ovarian Cancer	O	O	O	O	O	O
x. Sickle cell anemia	O	O	O	O	O	O
y. Sexually Transmitted Disease	O	O	O	O	O	O
z. Stroke (CVA)	O	O	O	O	O	O
aa. Tuberculosis	O	O	O	O	O	O
bb. Other Cancer	O	O	O	O	O	O
cc Other serious illness						
Type_____	O	O	O	O	O	O
Type _____	O	O	O	O	O	O

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(Please be sure that you have filled in the approximate age of diagnosis in the previous question).

E2.   Have you ever had breast surgery or any of the following procedures? *(Mark all that apply)*

O_1 No, I have never had any breast surgery ⟶ **(GO TO E3)**
O_2 Cyst aspiration, (a needle to remove fluid from a fluid filled sac in the breast).
O_3 Breast biopsy, (tissue is removed from the breast for study)
O_4 Breast reduction
O_5 Breast augmentation (enlargement)

a. If you had a biopsy, how many breast biopsies have you had? _____# of biopsies

b. **If you have had a cyst aspiration** or breast biopsy, what were the results of your most recent biopsy?
   O_1 Benign **(GO TO E3)**
   O_2 Malignant

c. If you were diagnosed with breast cancer, at what stage was your cancer diagnosed?
   O_1 Stage 0
   O_2 Stage I
   O_3 Stage II
   O_4 Stage III

d. What treatment did you receive for your breast cancer? *(Mark all that apply)*
   O_1 Mastectomy
   O_2 Lumpectomy
   O_3 Chemotherapy
   O_4 Radiation
   O_5 Complementary or Alternative Medicine
   O_6 Other, specify _____
   O_7 None

E3.   Have you ever taken Tamoxifen to prevent breast cancer?
   O_1 No
   O_2 Yes

E4.   Have you ever participated in a clinical trial for the treatment or prevention of breast cancer?
   O_1 No
   O_2 Yes,
      Name of Study _____
      Length of Participation _____months

E5. The following questions are about breast cancer screening. To what extent do you disagree or agree with each statement?	Strongly Disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly Agree (5)
a. More lesbians get breast cancer than straight women.	O	O	O	O	O
b. Whenever I hear of a friend or relative getting breast cancer, it makes me realize that I could also get it.	O	O	O	O	O
c. The older I get, the more I think about the possibility of getting breast cancer some day.	O	O	O	O	O
d. My chances of getting breast cancer as an African American woman are higher than other non-African American women.	O	O	O	O	O
e. If more African American lesbians got mammograms regularly there would be fewer deaths from breast cancer.	O	O	O	O	O

E5. The following questions are about breast cancer screening. To what extent do you disagree or agree with each statement?	Strongly Disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly Agree (5)
f. If I examined my own breasts regularly, I might find a lump sooner than if I just went to the doctor for a check-up. *Benefit*	O	O	O	O	O
g. It does not really matter if I find a lump in my breast myself, because by then it will be too late anyway. *Seriousn*	O	O	O	O	O
h. The technicians at the mammography center are not lesbian friendly. *Barriers*	O	O	O	O	O
i. Examining my breasts often makes me worry unnecessarily about breast cancer. *Bar*	O	O	O	O	O
j. Even though BSE is a good idea, I don't know what I am supposed to feel. *Barriers*	O	O	O	O	O
k. My doctor examines my breasts so I don't have to. *Barriers*	O	O	O	O	O

E6. The following questions ask how you feel about your health in general. To what extent do you disagree or agree with each statement?	Strongly Disagree (1)	Moderately Disagree (2)	Moderately Agree (3)	Strongly Agree (4)
a. If I get sick, it is my own behavior that determines how soon I get well again.	O	O	O	O
b. No matter what I do, if I am going to get sick, I will get sick.	O	O	O	O
c. Having regular contact with my physician is the best way for me to avoid illness.	O	O	O	O
d. Most things that affect my health happen to me by accident.	O	O	O	O
e. Whenever I don't feel well, I should consult a medically trained professional.	O	O	O	O
f. I am in control of my health.	O	O	O	O
g. My family has a lot to do with my becoming sick or staying healthy.	O	O	O	O
h. When I get sick, I am to blame.	O	O	O	O
i. Luck plays a big part in determining how soon I will recover from an illness.	O	O	O	O
j. Health professionals control my health.	O	O	O	O
k. My good health is largely a matter of good fortune.	O	O	O	O
l. The main thing that affects my health is what I myself do.	O	O	O	O
m. If I take care of myself, I can avoid illness.	O	O	O	O
n. Whenever I recover from an illness, it's usually because other people (for example, doctors, nurses, family, and friends) have been taking good care of me.	O	O	O	O
o. No matter what I do, I'm likely to get sick.	O	O	O	O
p. If it's meant to be, I will stay healthy.	O	O	O	O
q. If I take the right actions, I can stay healthy.	O	O	O	O
r. Regarding my health, I can only do what my doctor tells me to do.	O	O	O	O

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SECTION F - FAMILY MEDICAL HISTORY

Now I would like you to think about your family medical history. These next questions ask about conditions that members of your family may have had. By family we mean mother, father, siblings, aunt, cousins, grandparents or other blood relatives.

F1.   Has anyone in your family been diagnosed with any of the following conditions? *(Mark all that apply)*
   O_1 Lupus
   O_2 High Blood Pressure
   O_3 Heart Disease
   O_4 High Cholesterol
   O_5 "Sugar" Diabetes
   O_6 Sickle Cell Anemia
   O_7 None of these conditions
   O_8 Don't know

F2.   Has anyone in your family ever been diagnosed with cancer?
   O_1 No   ⟶ **(GO TO SECTION G)**
   O_2 Yes
   O_3 Don't Know ⟶ **(GO TO SECTION G)**

F3.   If yes, what is their relationship to you, type of cancer and approximate age at diagnosis?

RELATIVE	TYPE OF CANCER	APPROXIMATE AGE AT DIAGNOSIS			
		(1) 29 and Under	**(2)** 30-49	**(3)** 50-69	**(4)** 70-89
Mother O_1		O	O	O	O
Father O_2		O	O	O	O
Siblings					
Female O_3		O	O	O	O
Male O_4		O	O	O	O
Children					
Female O_5		O	O	O	O
Male O_6		O	O	O	O
Grandchildren					
Female O_7		O	O	O	O
Male O_8		O	O	O	O
Mother's Mother O_9		O	O	O	O
Mother's Father O_{10}		O	O	O	O
Father's Mother O_{11}		O	O	O	O
Father's Father O_{12}		O	O	O	O

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RELATIVE	TYPE OF CANCER	APPROXIMATE AGE AT DIAGNOSIS			
		(1) 29 and Under	(2) 30-49	(3) 50-69	(4) 70-89
Mother's siblings					
Female O_{13}	_____	O	O	O	O
Male O_{14}	_____	O	O	O	O
Father's siblings					
Female O_{15}	_____	O	O	O	O
Male O_{16}	_____	O	O	O	O

(Please be sure that you have filled in the approximate age of diagnosis in the previous question).

SECTION G - HIV/STDs

This next section asks about HIV/AIDS and sexually transmitted diseases. Please remember that this questionnaire will never be linked to your name or any other identifying information. Any information you provide us is totally anonymous. Please answer these questions honestly.

G1. Have you ever been tested for HIV?
    O_1 No   ⟶   **(GO TO G3)**
    O_2 Yes
    O_3 Don't Know   ⟶ **(GO TO G3)**

G2. How many times have you been tested for HIV? _____ #times

G3. How do you currently protect yourself from HIV or sexually transmitted diseases/infections *(Mark all that apply)*?
    O_1 No protection used
    O_2 Abstinence
    O_3 Condoms (with men)
    O_4 Female Condom
    O_5 Washing sex toys before sharing them
    O_6 Dental Dam or other barrier for oral sex
    O_7 Non-oxynol 9
    O_8 Condom on sex toys
    O_9 Other, specify _____

G4. Have you ever been diagnosed with an STD?
    O_1 No   ⟶   **(GO TO SECTION H)**
    O_2 Yes

G5. What STD were you diagnosed with? *(Mark all that apply)*
    O_1 Syphilis
    O_2 Gonorrhea
    O_3 Herpes
    O_4 Chlamydia
    O_5 Human Papillomavirus/Genital Warts

SECTION H - VIOLENCE

The next questions are about violence you may have experienced.

	No	Yes	If yes, were you ...?					
			Slapped (1)	Punched (2)	Kicked (3)	Spit at (4)	Called Names (5)	Other (6)
H1. Have you ever experienced violence because of your sexual orientation/identity?	O	O	O	O	O	O	O	O
H2. Have you ever experienced violence based on your gender presentation (i.e., how gay or how butch you look)?	O	O	O	O	O	O	O	O
H3. Have you ever experienced violence in a same sex relationship?	O	O	O	O	O	O	O	O

SECTION I - EXERCISE/NUTRITION

I1.   On average, during the past week, how many hours each day did you spend...

Activity	None (1)	Less than 1 hour (2)	1 hour (3)	2 hours (4)	3-4 hours (5)	5-6 hours (6)	7-9 hours (7)	10 or more (8)
a. Light activity (cleaning house, playing softball, golf)	O	O	O	O	O	O	O	O
b. Moderate Activity (such as walking briskly, cycling, dancing)	O	O	O	O	O	O	O	O
c. Strenuous Activity (such as jogging, playing football, swimming)	O	O	O	O	O	O	O	O
d. Very Strenuous Activity (such as running, racquetball, skiing)	O	O	O	O	O	O	O	O

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The next questions are about the foods you usually eat or drink.

I2.　Please tell me how often you eat or drink each one, for example, twice a week, three times a month, etc. Include foods you eat, both at home and away from home.

	Per Day (1)	Per Week (2)	Per Month (3)	N e v e r (4)	Don't know (5)
a. How often do you drink fruit juices such as orange, grapefruit, or tomato?	____	____	____	O	O
b. Not counting juice, how often do you eat fruit?	____	____	____	O	O
c. How often do you eat green salad?	____	____	____	O	O
d. How often do you eat potatoes not including french fries, fried potatoes, or potato chips?	____	____	____	O	O
e. How often do you eat carrots?	____	____	____	O	O
f. Not counting carrots, potatoes, or salad, how many servings of vegetables do you usually eat?	____	____	____	O	O
g. Has a health care provider ever told you that you needed a dietary supplement?	____	____	____	O	O

The next few questions are about your weight and body image.

I3.　What is your current weight?_____ # pounds

I4.　How tall are you? ____ feet _____ inches

I5.　Do you consider yourself now to be...?
　　　O₁ Overweight
　　　O₂ Underweight
　　　O₃ About the right weight

I6.　During the past twelve months have you tried to lose weight?
　　　O₁ No
　　　O₂ Yes, how _____

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SECTION J - OUTNESS/SOCIAL SUPPORT

J1. Use the following rating scale to indicate how open you are about your sexual orientation to the people listed below. Try to respond to all of the items, but leave items blank if they do not apply to you. You can make more than one mark for a group. For example, if one brother definitely knows and another brother definitely does not know, you can mark both options in the brother column.

	Mother	Father	Brothers	Sisters	Extended family/relatives	My new straight friends	My work peers	Members of my religious community	Leaders of my religious community	Strangers, new acquaintances	My work supervisors
Person definitely does not know about your sexual orientation status	O 1	O 2	O 3	O 4	O 5	O 6	O 7	O 8	O 9	O 10	O 11
Person probably knows about your sexual orientation status, but it is never talked about.	O 1	O 2	O 3	O 4	O 5	O 6	O 7	O 8	O 9	O 10	O 11
Person probably knows about your sexual orientation status, but it is rarely talked about	O 1	O 2	O 3	O 4	O 5	O 6	O 7	O 8	O 9	O 10	O 11
Person definitely knows about your sexual orientation status, and it is never talked about.	O 1	O 2	O 3	O 4	O 5	O 6	O 7	O 8	O 9	O 10	O 11
Person definitely knows about your sexual orientation status, but it is rarely talked about.	O 1	O 2	O 3	O 4	O 5	O 6	O 7	O 8	O 9	O 10	O 11
person definitely knows about your sexual orientation status, and it is openly talked about	O 1	O 2	O 3	O 4	O 5	O 6	O 7	O 8	O 9	O 10	O 11

J2. How important is being "out" to you?
- O1 Very important
- O2 Somewhat important
- O3 Somewhat unimportant
- O4 Not important

J3. How important is it for you to keep your sexual orientation a secret?
- O1 Very important
- O2 Somewhat important
- O3 Somewhat unimportant
- O4 Not important

Now I would like to ask you a few questions about the support you receive from your friends and family.

J4.   Can you count on anyone to provide you with emotional support such as talking over problems or helping you make a difficult decision?
      O_1 No
      O_2 Yes
      O_3 Don't Know

J5.   In the last year, who was **most** helpful in providing you with emotional support? *(Mark one circle only)*
      O_1 No one
      O_2 Didn't need emotional support
      O_3 Spouse/partner/lover
      O_4 Daughter
      O_5 Son
      O_6 Sister/Brother
      O_7 Parent
      O_8 Other relative
      O_9 Neighbors
      O_{10} Co-workers
      O_{11} Church members
      O_{12} Club members
      O_{13} Professionals
      O_{14} Friends
      O_{15} Ex-lover/Ex-partner
      O_{16} Other, specify _____

J6.   In the last year could you have used more emotional support than you received?
      O_1 No   ⟶   **(GO TO J7)**
      O_2 Yes
      O_3 Don't Know

> a. If yes, would you say that you could have used...
> O_1 a lot more
> O_2 some more
> O_3 a little more emotional support

J7.   If you need some extra help financially, could you count on anyone to help you for example, by paying any bills, housing costs, hospital visits, or providing you with food or clothes?
      O_1 Yes
      O_2 No
      O_3 Offered help but wouldn't accept it

J8.   In general, how many close friends do you have? By close friends I mean relatives or non-relatives that you feel at ease with, can talk to about private matters and can call on for help?

      _____ # of close friends

J9. Which of the following events or organizations do you visit, use or belong to?

	N/A (1)	Predominately White LGBT (2)	Predominately Black LGBT (3)	Predominately White Straight (4)	Predominately Black Straight (5)
a. Bars	O	O	O	O	O
b. Bookstores	O	O	O	O	O
c. Churches	O	O	O	O	O
d College Groups	O	O	O	O	O
e. E-mail Lists	O	O	O	O	O
f. Political/Activist Organizations	O	O	O	O	O
g. Support Groups	O	O	O	O	O
h. Newspapers	O	O	O	O	O
i. Community Centers	O	O	O	O	O
j. Conferences	O	O	O	O	O
k. Film Festivals	O	O	O	O	O
l. Hot Lines	O	O	O	O	O
m. Pot Luck Dinners	O	O	O	O	O
n. Websites/Internet Services	O	O	O	O	O
o. Pride Events	O	O	O	O	O
p. Social Groups	O	O	O	O	O
Bingo	O	O	O	O	O
Magazines	O	O	O	O	O
s. Parties/Dances	O	O	O	O	O
t. Volunteer Groups	O	O	O	O	O
u. Other, Specify	O	O	O	O	O

SECTION K - SMOKING

The following section is about smoking cigarettes. Please answer for tobacco cigarettes only.

K1. Have you ever smoked a whole cigarette
- O_1 No ⟶ **(GO TO K9)**
- O_2 Yes
- O_3 Don't Know

K2. How old were you when you smoked a whole cigarette for the first time?   _____Age

K3. Do you currently smoke cigarettes?
- O_1 No ⟶ **(GO TO K9)**
- O_2 Yes

K4. Do you want to quit smoking cigarettes?
- O_1 Yes
- O_2 No

K5. During the past 30 days, on average, how many cigarettes did you smoke per day? _____ # Cigarettes

K6. Have you ever tried to quit smoking cigarettes?
    O_1 No ———▶ **(GO TO K9)**
    O_2 Yes

K7. How many times have you tried to quit smoking cigarettes? _____ # times

K8. During the past year what have you used to help you quit smoking? *(Mark all that apply)*
    O_1 None
    O_2 Therapy (Smoking Cessation clinics, Personal Therapy)
    O_3 Prescription (Zyban/Wellbutrine)
    O_4 Naturopathy (Accupressure, Hypnosis, Nutritional Support)
    O_5 Nicotine Replacement Therapy (Inhaler, nasal spray, gum, patch)
    O_6 Other

K9. Is there anyone, besides you, currently living in your house who smokes cigarettes?
    O_1 No ———▶ **(GO TO L1)**
    O_2 Yes

K10. Do they smoke inside or outside the house? *(Mark one only)*
    O_1 Inside
    O_2 Outside
    O_3 Both

SECTION L - ALCOHOL/DRUG USE

The next group of questions are about alcohol use. By drink we mean one 12oz can/bottle of beer, glass of wine, or an ounce of liquor, often called a shot, or a mixed drink with liquor in it.

L1. Did you ever drink alcoholic beverages (beer, wine, wine cooler, or liquor)?
    O_1 No ———▶ **(GO TO L2)**
    O_2 Yes, but I no longer drink
    O_3 Yes, I drink currently

---

a.   How old were you when you had your first drink of alcohol? Please do not include any time when you only had a sip or two from a drink.

      _____ age

b.   During the past 30 days, on how many days did you have a drink of alcohol?

      _____ # of Days. **(If answer is 00 GO TO L2)**

c.   On the days that you drank during the past 30 days, how many drinks did you usually have?

      _____ # of Drinks

d.   During the past 30 days, on how many days did you have 4 or more drinks on the same occasion? By that we mean at the same time or within a couple of hours of each other.

      _____ # of days

The following questions ask about drug use. Please remember that your answers are completely confidential. Your personal identity will never be associated with the answers you give. Please answer these questions honestly.

L2.   For each drug please tell me if you have ever used it, if you have used it in the past year, and if you have used it in the past 30 days.

Drug	Ever Used		Used in the Past Year		Used in the Past 30 days	
	Yes	No	Yes	No	Yes	No
a. Marijuana	①	②	①	②	①	②
b. Cocaine (including powder, crack or freebase)	①	②	①	②	①	②
c. Heroin	①	②	①	②	①	②
d Other, specify_____	①	②	①	②	①	②

SECTION M - DEMOGRAPHICS

This is the final section of the questionnaire. The next questions will allow us to compare your information with other participants of this survey.

M1.   How old are you?   _____ years

M2.   What is your date of birth?   ____/____/_____
                                      mo   day   year

M3.   What is your race and cultural sub group? *(Mark all that apply)*
   - O₁ Black / African Heritage
      - O₁ₐ African American
      - O₁ᵦ Afro-Caribbean
      - O₁𝒸 African Immigrant
      - O₁𝒹 Hispanic
   - O₂ White
      - O₂ₐ Hispanic
      - O₂ᵦ Non-Hispanic
   - O₃ Native American
   - O₄ Asian/Pacific Islander
   - O₅ Other,_____

M4.   Describe your living situation? *(Mark one circle only)*
   - O₁ Own
   - O₂ Rent
   - O₃ Live in parent's home
   - O₄ Live on campus
   - O₅ Military Base
   - O₆ Homeless
   - O₇ Shelter
   - O₈ Living in child's home
   - O₉ Other, specify_____

M5. What is your zip code? _____

M6. What is the highest level of school you have completed?
- O_1 Less than 6th grade
- O_2 6th–11th grade
- O_3 High school or GED equivalent
- O_4 Some college (no Degree)
- O_5 Associate Degree
- O_6 Bachelor's Degree
- O_7 Masters Degree
- O_8 Professional School
- O_9 Doctoral Degree

M7. Are you currently employed full-time or part-time?
- O_1 Yes

> a. If yes, would you say that you are...
> - O_1 Employed full time
> - O_2 Employed part time
> - O_3 Self Employed

- O_2 No

> a. What is your occupation when you **are** employed? _____
>
> b. If no, are you...
> - O_1 On Public Assistance
> - O_2 In the military
> - O_3 On disability
> - O_4 Retired
> - O_5 Homemaker
> - O_6 Other _____

M8. Are you currently or have you ever been in the military
- O_1 Yes
- O_2 No

M9. Are you currently a student?
- O_1 Yes, Full time
- O_2 Yes, Part time
- O_3 No

M9a. *If in school,* what diploma or degree are you working towards? _____

M10. Which range of figures comes closest to your household income before taxes for the past calendar year, including public assistance, alimony, child support, etc...? *(Mark one circle only.)*
- O_1 Less than $15,000
- O_2 $15,000 to $29,999
- O_3 $30,000 to $49,999
- O_4 $50,000 to $69,999
- O_5 $70,000 to $99,999
- O_6 $100,000 to $149,999
- O_7 $150,000 or more

M11. How many people, including you, are supported by this income? _____ #person/people

M12. What is your current relationship status? *(Mark only one)*
- O_1 Single
- O_2 Civil union/same sex marriage
- O_3 Married (male spouse)
- O_4 Living with a partner/girlfriend (not married)
- O_5 In a committed relationship but **not** living with a partner
- O_6 Widowed
- O_7 Separated
- O_8 Divorced
- O_9 Other

M13. In general, are you sexually attracted to...*(Mark one circle only)*
- O_1 Only women
- O_2 Mostly women
- O_3 Both women and men
- O_4 Mostly men
- O_5 Only men

M14. Have your sexual partners in the last year been... *(Mark one circle only)*
- O_1 Exclusively female
- O_2 Both female and male
- O_3 Exclusively male
- O_4 No partner

M15. Have your sexual partners in the last 5 years been... *(Mark one circle only)*
- O_1 Exclusively female
- O_2 Both female and male
- O_3 Exclusively male
- O_4 No partner

M16. What best describes the gender of the person/persons with whom you currently have sex? *(Mark all that apply)*
- O_1 Female
- O_2 Male
- O_3 Female to Male (transsexual, either pre- or post-operative)
- O_4 Male to Female (transsexual, either pre- or post-operative)
- O_5 Other Gendered
- O_6 Not currently having sex

M17. In general, what word best describes your previous/current female partner's gender identity? *(Mark one only)*
- O_1 Butch
- O_2 Femme
- O_3 Androgynous (Neither butch nor femme)
- O_4 Other, specify _____

M18. During the past 30 days, how many female sexual partners have you had?   _____ #female sex partners

M19. During the past 30 days, how many male sexual partners have you had?   _____ #male sex partners

M20. During the past 30 days, how many transgendered sexual partners have you had? _____ #trans sex partners

M21. What word best describes your sexual orientation/identity? *(Mark one circle only)*
- O_1 Lesbian
- O_2 Bisexual
- O_3 Heterosexual
- O_4 Other, specify _____

M22. Where would you place yourself on a scale that rates only your femme aspects (1 being not femme, 10 being the very femme)?

$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
1	2	3	4	5	6	7	8	9	10

Not Femme   Very Femme

M23. Where would you place yourself on a scale that rates only your butch aspects (1 being not butch, 10 being very butch)?

$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
1	2	3	4	5	6	7	8	9	10

Not Butch   Very Butch

M24. What word best describes your gender identity? *(Mark one circle only)*
   $\bigcirc_1$ Butch
   $\bigcirc_2$ Femme
   $\bigcirc_3$ Androgynous (Neither butch nor femme)
   $\bigcirc_4$ Other, specify _____

M25. Have you ever considered transitioning to male? (By transitioning we mean taking steps such as changing your dress, hair or name to be more male, or taking hormones or having surgery.)
   $\bigcirc_1$ Yes
   $\bigcirc_2$ No

M26. How do most people perceive your gender?
   $\bigcirc_1$ Female
   $\bigcirc_2$ Male
   $\bigcirc_3$ Both
   $\bigcirc_4$ Don't Know

M27. Have you ever intentionally tried to pass as male?
   $\bigcirc_1$ Yes
   $\bigcirc_2$ No

M28. Have you ever taken testosterone to alter your secondary sex characteristics? By secondary sex characteristics I mean muscle mass, facial hair, and voice. *(Mark one circle only)*
   $\bigcirc_1$ No, not considering
   $\bigcirc_2$ No, but I am considering
   $\bigcirc_3$ Yes, prescribed by doctor
   $\bigcirc_4$ Yes, **not** prescribed by doctor

Please feel free to share with us any information that you think we should know that we did not ask about.

_____

_____

_____

_____

Is there anything about your answers to this questionnaire that surprised you, or did you learn anything about resources that may be available to you?

_____

_____

_____

_____

Thank you for taking the time to fill out this questionnaire. Your answers will go a long way to help us learn more about our health, and develop interventions specifically aimed at Lesbians and bisexual women of African descent.

For Office Use ONLY:

	Staff Initial
Received Date	_____ _____
Editing Date	_____ _____
DE Date	_____ _____

Please complete this questionnaire and send it back in
the postage-paid envelope within one week.

Thank You!

Curriculum Vitae

NAME Cheryl "Amari Sokoya" Pearson-Fields	POSITION TITLE Program Director, Cancer Screening and Control Division, DC Department of Health		
INSTITUTION AND LOCATION	DEGREE (if applicable)	YEAR(s)	FIELD OF STUDY
Marquette University	BA	1985	Broadcast Communication
George Washington University	MPH	1996	Public Health
Walden University	PhD		Public Health

A. Positions and Honors.

Positions and Employment
1985-1990	Operations Manager, SRA Technologies, Inc.
1990-1995	Project Director, Macro International, Inc.
1996-1999	Project Coordinator, Children's National Medical Center
2001-2003	Health Education and Research Director, The Mautner Project
2003-2006	Deputy Director, The Mautner Project
2006-2008	Executive Director, Capital Breast Care Center
2008-2009	President, Sokoya Consulting Group, Inc.
2009-Present	Program Director, Cancer Screening and Control Division, DC Department of Health

Other Experience and Professional Memberships
1994	Office of Maternal and Child Health, Task Force on Women's Health
1995-1996	Board of Directors, Mautner Project for Lesbians with Cancer
1996-1998	Preceptor, The George Washington University School of Public Health
2000	Service Delivery and Access to Services Working Group, Scientific Workshop on Lesbian Health
2000	California Breast Cancer Research Program Grant Review Committee
2000-2001	Organizing Committee, National Coalition for Lesbian, Gay, Bisexual, and Transgender Health
2001	Conference Committee, Centers for Disease Control and Prevention Cancer Conference
2001-2003	Public Education Advisory Board, National Alliance for Ovarian Cancer
2002-2004	Experts Panel, Gay and Lesbian Medical Association
2002	Conference Committee, Lesbian, Gay, Bisexual, Transgender and Intersex Health Summit
2003	Steering Committee, National LGBT Tobacco Action Plan
2003-2004	Co-Chair, American Cancer Society Women's Work group
2005 –2006	Member, Latin American Research Consortium
2010-Present	Clinical Trials Advisory Committee
2010-Present	DC Screen for Life Colorectal Cancer Screening Advisory Committee
20011-Present	Advisory Committee, DC Cancer Consortium

Honors

2001   Ford Foundation Research Fellowship
2002   Community Service Award, Unity Fellowship Movement
2004   "Raising Star" Community Service Recognition Award, Women's Monthly Magazine
2004   Walter J. Lear, MD Outstanding Student Research Award

B. Selected peer-reviewed publications (in chronological order).

1. Pearson-Fields, A. S., & Scout. Constructing gender identity among butch identified lesbians: Implications for cancer screening. Submitted manuscript, December 2009
2. Johnson SB, Frattaroli S, Campbell J, Wright, J, Pearson-Fields, AS, Cheng, TL. "I know what love means." Gender-based violence in the lives of urban adolescents. J Women's Health 2005:14:172-179.
3. Cheng TL, Wright JL, Pearson-Fields CB, Brenner, RA. The spectrum of intoxication and poisonings among adolescents: Do ICD-9 E-codes underestimate the morbidity burden? (In revision).
4. Cheng TL, Schwarz D, Brenner RA, Wright JL, Fields CB, O'Donnell R, Rhee P, Scheidt PC. Adolescent Assault Injury: Risk and protective factors and locations of contact for intervention. Pediatrics 2003:112:931-938.
5. Fields C. Access for All. Health & Sexuality: 2001: Fall edition.
6. Fields CB, Scout. Addressing the needs of lesbian patients. Journal of Sex Education and Therapy. 2001: 26(3).
7. Scout, Bradford J, Fields CB. Creating health care access for lesbians and women who partner with women. J American Public Health Association. 2001:6:989-990.
8. Cheng TL, Wright JL, Fields CB, Brenner RA, O'Donnell R, Schwarz D, Scheidt PC. Violent injuries among adolescents: Declining morbidity and mortality in an urban population. Annals of Emergency Medicine 2001:37:292-300.
9. Cheng TL, Fields CB, Brenner RA, Wright JL, Lomax T, Scheidt PC. Sports injuries: An important cause of morbidity in urban youth. Pediatrics 2000: 105: E32.
10. Cheng TL Wright JL, Fields CB, Brenner RA, Schwarz D, O'Donnell R, Scheidt PC. A new paradigm of injury Prevention: 1999:59-61.