



## Recipes Run in Our Families Not Illnesses: Older Black Women on Race, Health Disparities and the Health Care System

Item type	text; Electronic Dissertation
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RECIPES RUN IN OUR FAMILIES NOT ILLNESSES:  
OLDER BLACK WOMEN ON RACE, HEALTH DISPARITIES AND THE HEALTH  
CARE SYSTEM

By

Colette Marie Sims

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A Dissertation Submitted to the Faculty of the

DEPARTMENT OF ANTHROPOLOGY

In Partial Fulfillment of the Requirements for the Degree of

DOCTOR OF PHILOSOPHY

In the Graduate College

THE UNIVERSITY OF ARIZONA

2006

**THE UNIVERSITY OF ARIZONA  
GRADUATE COLLEGE**

As members of the Dissertation Committee, we certify that we have read the dissertation

prepared by Colette Marie Sims

entitled **Recipes run in Families not Illnesses: Older Black Women on Race, Health Disparities and the Health Care System**

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### **STATEMENT BY THE AUTHOR**

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SIGNED: Colette Marie Sims

## ACKNOWLEDGEMENTS

This dissertation was made possible through the love, prayers and hands of many extraordinary individuals and organizations that have been extended during this most challenging time in my life. I would like to acknowledge those people who have greatly impacted my academic development and who have shared some wonderful life lessons over the past ten years. Next to God I am indebted to these individuals who gave me unconditional and unwavering support.

First I would like to thank the Black women in Tucson, Arizona for trusting me with their insights and for the rich data that they provided with honesty and integrity. I would like to acknowledge the existence of their agency in this community. I want all of my sistah-friends (Fran, Kathy, Edria, Christie, Donna, and Deborah) to know that your support meant a lot to me. Ladies, together we created a tradition in love and sisterhood.

I would like to acknowledge and thank Dr. Mimi Nichter for her invaluable guidance, instruction, reflexive criticism and friendship. As my advisor and mentor you have continually offered your expertise, and foresight by pushing me to "strut my stuff" at conferences and in research opportunities. As the chair of my committee you freely gave enormous amounts of time to reading/editing/re-reading, reorganizing and finalizing this dissertation. Were it not for your due diligence and faith along with the weekly guidance of my friend, Dr. Victoria Stefani of the Writing Skills Improvement Program over the years the writing of this dissertation would not have been possible.

Especial thanks are extended to the other phenomenal members of my dissertation committee: Dr. Sheila H. Parker, from the College of Public Health, for her support, guidance, wisdom and friendship. Most importantly I thank you for taking a chance on an undergraduate so many years ago by asking me to join a research team on body image as part the Teen Life Style Project. To Dr. Mark Nichter, who recommended me to Sheila in the first place and who has been consistent in his mentoring, encouragement and support throughout my tenure at the University of Arizona. To Dr. Mamadou Baro for his guidance and willing instruction in the areas of research application. Many thanks are extended to all of you. I brought you together with no reservations and yet, you managed to exceed my expectations of what it would be like to work together. I appreciate each of your contributions.

I would like to acknowledge Dr. Maria T. Velez of the Graduate College and Norma Maynard of the Department of Anthropology for their time, love, prayers and unrelenting quests to assist with funding. I would also like to acknowledge the Africana Studies Program for giving me so many opportunities to grow and learn more about the Black experience and myself and aid in developing my skills in teaching and curriculum development.

## DEDICATION

First, I want to pay homage to my ancestors and acknowledge my grandmother, Gladys Mae Foster, who after graduating from a Black Teachers College was denied the right to teach because of de jure and de facto segregation. She taught me that a peaceful spirit is hard to come by so fight for it, fight hard!

My dissertation is dedicated to my father, Earl V. Pollard, a change agent who tirelessly molded and shaped our minds and characters for excelling in a world that would not necessarily appreciate our Black experience. Daddy you departed during the home stretch but I know your spirit was ever present. To my mothers Alveria M. Pollard and Mary Aloyse for giving me lived examples of grace, resiliency, resistance and the strength of Black womanhood. To my children Al, Macie and Adrienne Sims for choosing me as a parent and supporting my quest for this degree. I would most especially like to acknowledge my planet child who at twelve years of age, was the last one at home and had to use her skills of independent thought, and responsible action probably way before she wanted to because that's when I went back to school. To my sister, Edali for always foregrounded my accomplishments and to my little brother, Phil who built my computer and kept it updated and running all these many years. You all should know that I am proud of you too. This endeavor was blessed and guided by the collective spirit of my loved ones.

Next I want to pay tribute to my adopted community here in Tucson, Arizona as part of my extended family. I want all of my sistah-friends and those special men who are handling their business to know that I could not have reached this place without all of your words of encouragement, support and invaluable guidance that gave me opportunities to grow and learn. I praise God for you all. I am truly grateful for the roles you all have played in this chapter of my life.

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## ABSTRACT

Reducing racial and ethnic disparities in healthcare are ongoing concerns. A paucity of data on healthcare seeking behavior among older Black women has hampered efforts to make culturally responsive healthcare services available to this population. Little is known about how older Black women's expectations and perceptions of care affect their patterns of health behavior.

This study explored sociocultural contexts of health behavior with fifty Black women, aged 40 and older, in Tucson, Arizona by examining what prompts these women to seek services, identifying key factors affecting their access to and utilization of healthcare, documenting their experiences in healthcare settings and how these interactions influence their healthcare-seeking behavior. If effective healthcare service access and utilization are to be encouraged among older Black women, an informed understanding of the role cultural difference plays is essential.

This research has three purposes: to provide a forum for discussion of culturally relevant strategies and models for prevention of disease and promotion of wellness in Black communities; to provide perspectives on older Black women's health issues for policymakers and administrators in public health sciences; and to gain insight and document reasons for selected health behaviors among this population. Research funding from the NIH/ NIA has helped to establish this small multi-disciplinary data set on a specific race, gender and age sub-population group for future research and development of community resource partnerships; including public health education and effective

healthcare service delivery with intervention / promotion efforts targeting older Black women.

Findings: Older Black women's poorer health status reflects the cumulative effects of inadequate health care due to various discriminatory experiences and their mistrust of the health care system. Mistrust, expectations of racial bias, perceived cultural insensitivity, and lack of effective communication within healthcare settings were found to be barriers to their healthcare-seeking behavior. Neither healthcare providers nor older Black women can address these issues alone. Working towards more trusting relationships within healthcare settings is critical in beginning to address avoidable inequities in health status experienced by older Black women. This research is applicable to such disciplines as Sociocultural/Medical Anthropology, Health Education, Public Health, and Africana/Ethnic Studies.

## I. INTRODUCTION

“For above all, on behalf of the ailing world which surely needs our defiance, may we as Negroes [ Blacks] or women, never accept the notion of our place.” ( Lorraine Hansberry, *A Raisin in the Sun*, 1959, p. 25)

In this study I explore patterns of health behavior among older Black<sup>i</sup> women (defined as aged 40 and above) with respect to their access and utilization of preventive screening exams such as mammograms and pap exams. Morbidity and mortality data on Black women indicates that diseases such as breast and cervical cancer, as well as hypertension, diabetes, and cardiovascular problems have a greater impact among African American women--an impact that begins 7-10 years earlier than on non-Black populations.

Importantly, Black women die from breast cancer at a rate that is 12 to 20 percent higher than that of White women. Although White women are more likely to develop breast cancer, Black women are more likely to be diagnosed later and to die of this disease. For example, the five-year survival rate for a Black woman with breast cancer is 43 percent as compared to the survival rate for White women, which is over 90 percent (Moormeir, 1996). Differences in mortality rates between Black and White women are also apparent for women with cervical cancer; the death rate from cervical cancer is more than twice as high for Black women than it is for White women (Office of Analysis and Epidemiology, [NCHS], Center for Disease Control and Prevention. CDC Wonder Compressed Mortality File, 1999; Bach et al., 2002; Office of Minority Health, Health Issues Index, U.S. DHHS, 2003; Urban Institute and Kaiser Commission on Medicaid and the Uninsured, State Health Facts 2003).

Beyond exploring the individual health behaviors of older Black women, attention is also paid throughout this study to the overarching systems of oppression that operate within the multiple ecologies<sup>ii</sup> of social, cultural, economic, systemic and structural environments in which these women live. It is within these "ecosociocultural" contexts<sup>iii</sup> that "being" Black has become part of a racial identity, which is a complex, and multifaceted category that has been experientially, perceptually and historically produced, and sustained (Berkman & Kawachi, 2000; Krieger, 2002). In this study I explore multiple intersecting factors of "race," ethnicity, and gender that impact women's lives as they move through the health care system.

Through close attention to women's voices, I explore the significance of "race" and the meaning of "being" Black in their everyday lives as well as clinical encounters with healthcare providers and when obtaining mammograms and pap exams. Why do these factors matter? They matter because breast cancer is the leading cause of cancer deaths among Black women over 40 years of age and recent data has indicated that Black women may be more likely to develop breast cancer even earlier than age 40. Listening to women's narratives, on their experiences in the health care system, it becomes clear that mammograms and pap exam are often contested sites for the management of the older Black woman's body.

Many of the deaths among Black women from these diseases ( i.e., breast and cervical cancer) are noted as "racial/ethnic" disparities, although it is also noted in sociocultural epidemiology literature that this disparity is an "avoidable inequity" in the health and well-being of Black women (Swanson, 1999; IOM 2002; LaVeist, 2002).

Thus, one of the major discussions that flow throughout these following chapters examines inequitable and unequal treatment and access to preventive health care.

Through an analysis of fifty interviews with older Black women, I examine experiences of receiving less than optimal care due to "race," perceptions of the cultural knowledge held by doctors and nurses, and, more broadly the women's ideas about healthcare services.

My overall goal is to illuminate women's perceptions of disparities and inequities in healthcare. This is accomplished by examining an important defining issue that impacted Black women's health and well being over the lifecourse, i.e., having an identity by "race" and "being" Black. I use the term "being" Black<sup>iv</sup> as a signifier and a sign because either has significance or meaning based on the cache value of the beliefs of racial and implied biological difference. By that I mean that we as a society believe that we can perceive another human being as a separate species of human, e.g., a "race," because we continue to use established systems of racial classifications extracted from perceived racial characteristics, such as skin color. Consequently, racial claims, truths, beliefs, and stereotypes have been developed, established and sustained, e.g., "race was made into a difference and simultaneously into a rationale for racial inequality" (Frankenburg, 1997, p.139). It is reasonable to assume that Whites and Blacks have gone through very different socialization processes within our "racial democracy"<sup>v</sup> (Goldberg, 1997; Hutchinson, 1997; Cornell & Hartmann, 1998).



### Study Overview

Over a twenty-four month period, I interviewed fifty older Black women defined as those aged 40 and older. Interviews focused on the trajectory of their individual health seeking behavior, and specifically how past personal experiences or the experiences of others in what I have termed their networks of support<sup>vi</sup> have influenced their attitudes toward and utilization of the health care system. Emphasis was placed on a discussion of whether and when older Black women choose to utilize preventive screening exams for breast and cervical cancer, as these have been identified as critically important for women's health.

There are four main objectives of this study (1) to examine what prompts older Black women to seek, access/utilize preventive healthcare services, (2) to identify key factors affecting their access and utilization of screening programs, (3) to explore and document the unmet expectations that older Black women have regarding preventive and curative healthcare services, (4) to identify how preventive healthcare education, and service delivery could be improved so they will be more readily accessible and acceptable to African American women.

It is at the site of their Black body where these women experience and actively apprehend the world (Rosaldo, 1984). A number of questions are explored in this dissertation including: what type of care did women expect to receive when they entered a healthcare provider's office? How do they perceive their interactions with healthcare providers? To what extent do they advocate for themselves in these interactions? Are their experiences in healthcare settings shared with other Black women?

What emerges from a close reading of their narratives is the extent to which gendered racial bias is encountered in healthcare settings and encounters with healthcare providers. As an underserved group, the unique disadvantages of older Black women are the result of having membership in three devalued status groups: older age, being female, and "being" Black. As a generational group of women, they have lived through a period of collective re-telling and re-memory<sup>vii</sup>, upheaval and change in the status of women and the status of Blacks in the United States (Landrine, 1996; Williams et al., 1997, 2003).

I believe that our ability to understand the patterns of health behavior among older Black women must first begin with an appreciation of their membership in a "racial" group which impacts all their experiences. My analysis reveals how older Black women have developed and maintained a deep mistrust of the U.S. health care system. And how this affects their interactions with doctors.

"Being Black," having a "race," and issues of power are critical factors in understanding the patterns of health behavior across the life-course. Encounters between Black women and healthcare providers across the life course contributes to the cultural archives that are shared among women, through their networks of support and are often referenced as "what we all know."<sup>viii</sup> I have framed some of the narratives of the participants using the term "ethnic notions" as aspects of "what we all know." This concept represents and speaks to an ethos of Black culture that has been constructed in response to "being" Black. Ethnic notions have served as a wellspring of continuity and resistance in communities long subjected to racial bias and exclusion (Turner, 1993). Hill (1998) noted in her research on patterns of health behavior among southern Black

women that "the threads of the past are linked to ever changing present experience" as collective social memory among Black women of similar age and culture (p.46). Women in my study are not speaking of some distant past or about theoretical abstractions. Rather, these women offer dynamic and reflective accounts of their everyday lives, of living as Blacks and as women across and through time, and of facing the reality of not having secured full citizenship and full dignity as Americans. These women give testimony, witness, and voice to the longevity of what W.E. B DuBois ([1903], 1963) wrote over a century ago, "that the problem of the 20<sup>th</sup> century is the problem of the color line," which still solidly resonates as a central problem of the 21<sup>st</sup> century.

In Chapter two I provide an overview of the literature relevant to this dissertation with a particular focus on and "race," socioeconomic position and culture including the current health status of African Americans and older Black women, the "avoidable" disparities in breast and cervical cancer, and influences on healthcare seeking. In Chapter three, I detail the methodology and introduce the women whom I interviewed. Chapter four identifies and examines "being" Black and the development and maintenance of mistrust among older Black women. Chapter five goes into greater detail on the nature of the Black experience as an underlying cause of negative healthcare experiences specifically focusing on disrespect, women's experiences in the health care system, racial and sexual stereotypes that they encounter as perceived by the older Black women. In, Chapter six, I explore the significance of faith and spirituality as part of the mind-body-spirit continuum and detail how agency is framed with Black culture through hyper-vigilance, "earned" mistrust and healthy paranoia. Specifically where women

authoritatively express their needs--often with negative consequences. I conclude with a summary of findings and a discussion of future policy implications.

## II. LITERATURE REVIEW

### OVERVIEW

This literature review is comprised of two parts. In, section one, I provide background data on the health status of African Americans in the U.S., and locally in the Southwest. I then move to a discussion of cervical cancer and breast cancer highlighting key differences between older Black women and White women. Reasons for these differences are discussed including cultural perceptions (such as, mistrust and skepticism) which impede healthcare seeking. In, section two, I provide a historical review of racial bias in the U. S., with a specific focus on the Black experience. Finally, I explore how racial bias effects healthcare access and utilization including patient-provider communication.

Nationally, an examination of age-adjusted mortality rates for all causes by race/ethnicity for women reveals that despite declining death rates over time, African American women have consistently had higher mortality rates than White women ( Krieger, 2002). In recent years, life expectancy and overall health status have improved for a majority of older women, due in part to advances in medical technology and an increased focus on preventive healthcare screening programs such as mammograms, annual physicals and pap exams. Yet according to the literature, racial/ethnic sub-populations in the U.S., such as older African American women, continue to suffer more by comparison than older White American women on essentially every indicator of morbidity, mortality, and access to healthcare ( Krieger, 2002 ).

Much research suggests that preventive health behavior may go beyond the mere availability of healthcare service. This stream of the literature (reviewed below) considers local knowledge gleaned from experiences, perceptions, and historical events that have influenced the lives and attitudes of older African American women and contribute to their patterns of healthcare access and utilization. Researchers have also suggested that because of various discriminatory experiences, many African Americans are suspicious of preventive and curative healthcare systems in the United States. I outline their findings in the following discussion (Leigh,1995; Miller et al.,1996; Williams,1998, 1999, 2002; Haynes & Smedley, 1999; Kinsella, 2000; Link & Phelan, 2000; Mills & Combs, 2001; Blake, 2002; Krieger, 2002).

#### African Americans: National Health Status Indicators

The Black<sup>ix</sup> population of the United States has until recently primarily consisted of African Americans. Blacks of African descent have resided in the United States for more than 400 years. To summarize events over such a span of time inevitably leads to oversimplification. The African ancestors of the group known today as African Americans were brought to what is now known as the United States as indentured servants and later as slaves by Europeans, beginning in the early 1600's. In 2000, African Americans numbered 35.5 million, or roughly 13 percent of the nation, reflecting a 57 percent increase over 30 years (US Census Bureau, 2000). African Americans are a largely urban population with the majority living in the South (54 percent). Only 8 percent live in the West. These regional proportions have stayed virtually the same over the last three decades (US Census Bureau, 2000).

Individuals of all ethnic backgrounds who are poor, lack health insurance, or otherwise have inadequate access to quality care experience high incidence and mortality rates. For example, according to the National Institutes of Health, (2002) many low-income White populations have cancer diagnosis rates as high as or higher than those for ethnic minority groups most affected by the disease. However, this being said, the excess mortality of Blacks compared with Whites is still staggering. It is also true that even though there has been a decline in mortality among Blacks, many of the disparities between rates for Blacks and Whites regardless of [SES] have increased over the past decade. When looking at mortality to incidence ratios, many ratios have worsened for Black Americans. This may be the result of inequities in healthcare due to racial stereotyping or bias within the healthcare system.

"Being" Black in the United States has a lot to do with varying levels of access to quality healthcare and optimal treatment, material wealth, social standing and subsequent relations of power. In the U.S. "race" is a sociopolitical way of categorizing a population. It is not a biological categorization. Numerous studies have shown that there is not equal treatment among Black and White patients in the United States. Thus I argue that if poor Whites and poor Blacks were to receive equal treatment then the literature would show equal outcomes among individuals with equal disease. When there is equal treatment, "race" is not a factor in outcomes (Miller et al., 1996; Haynes & Smedley, 1999; Freeman & Payne, 2000).

As a "vulnerable" racial "sub-population group" (National Institutes of Health, [NIH], 2002), African Americans generally experience higher rates of illness and death

than Whites from virtually every health condition. In 1990, life expectancy at birth was 7 years longer for Whites than for Blacks (National Center for Health Statistics [NCHS], 2003; Freeman & Payne, 2000; Haynes & Smedley, 1999; Miller et al., 1996).

According to Cooper et al. (1997, 1998), the largest volume of epidemiological data on health inequalities among "racial" groups can be found in relation to the Black and White populations in United States.

Nationally, African Americans only represent around 13 percent of the U.S. population but have an overall mortality rate that exceeds that of Whites by 31 percent. Age-adjusted death rates for the Black population exceeded those for the White population for specific diseases by 40 percent for stroke, 29 percent for heart disease, 25 percent for cancer, and nearly 800 percent for HIV/AIDS (Arias, 2002; CDC, NCHS Vital Statistics System, 2001; U.S. Census, 2000; Cooper et al., 1997, 1998).

Cancer among African Americans has been found to be more prevalent and more likely to be fatal due to late diagnosis and inadequate therapeutic care when compared to Whites. In fact, Blacks have a 10 percent higher incidence rate and a 30 percent higher death rate from all of the cancers combined when compared to Whites. In addition, African Americans have less likelihood of surviving cancer 5 years after diagnosis than Whites, for all cancers and at all stages of diagnosis (Haynes & Smedley, 1999; Ghafoor, et al., 2002; Ries, et al., 2002; NCHS, 2003; CDC, 1999, 2001, 2003; American Cancer Society [ACS], 2003; Office of Minority Health [OMH], 2003; Urban Institute and Kaiser Commission, 2003).



### Health Status of African Americans in Arizona

In Arizona, African Americans comprise only about 3% of the total population (Arizona Department of Health Services [ADHS], 2001), yet a review of mortality-morbidity data at the state level, shows that African Americans suffer from higher incidences of disease, higher mortality due to disease, and poorer survival rates from disease than all Whites in Arizona (Office of Analysis and Epidemiology, NCHS, CDC, 1999, 2001; ADHS, 2001; Urban Institute and Kaiser Commission, 2003).

A recent study using 2001 population-level data for the State of Arizona, which investigated racial differences in the relative health status among the five minority ethnic groups in Arizona [White non-Hispanic; Hispanics; Blacks (or African American); Asians (Asian or Pacific Islanders including Hawaiians) and American Indians] ranked the health status of African Americans "worse than average" across at least 70 indicators or measures of health status, such as cardiovascular disease, cancer, and diseases of the heart (ADHS, 2001, Chart Data).

Clearly, this evidence suggests that the burden of death and illness experienced by Blacks in Arizona is not only disproportionate to their population numbers in the state, as compared to Whites, but is also disproportionately expressed when compared to the other (much larger) racial/ethnic sub-population groups, such as, Hispanics and American Indians.

## INEQUITABLE & AVOIDABLE HEALTH DISPARITIES

### African American Women

According to census and gerontology data race/ethnicity, age, and gender can be perceived as fundamental measures of exposure to health risks. Nationally, slightly more than 18 million or 12.7 % of all females living in the United States were African American. This population also has more proportionally older female adults than many of the other racial/ethnic sub-population groupings. It is estimated that by the year 2050, three of every 10 African Americans in the United States will be female and over 80 years of age (U. S. Census, 2000; National Institute on Aging [NIA], 2006). In general, older African American women outnumber older Black men; these women are more likely to be widowed and the longer that they live the more likely they are to be affected by chronic illness, disability, and dependency (US Census Bureau, 2000; NIA, 2006).

African American women experience many of the same health problems as White women, yet as a group Black women seem to be in much poorer health, use fewer health services, and continue to suffer disproportionately from premature death, disease, and disabilities. Mortality data in 2001 showed that the average life expectancy at birth for an African American woman is 74.7 years, with White women exceeding this life expectancy estimate by almost 6 years ( U. S. Vital Statistics,2001). Many or all of these differences are believed to be due to disparities in treatment, poverty, and reduced access to medical care or diagnosis at a later stage when the disease has spread ( Bradley et al., 2001; Shavers et al., 2002).

Of concern in this dissertation are the reasons behind these major discrepancies in the overall health status of older Black women with particular emphasis on the context of "race" and the sociocultural environment of screening exam access, referral, and utilization and older age as distinguishing factors associated with early detection and treatment and are addressed throughout this literature review and discussed further in later chapters.

One of the factors implicated in high cancer rates among African American women may be diet and weight-related. Research also indicates that a high-fat diet is linked to certain types of cancer, including cancer of the breast, colon, rectum, and ovaries. Thus, obesity is another significant cause of mortality and morbidity among African American women over 40 years of age and has been linked to increased cancer death rates. According to a recent Health Issues Index from the Office of Minority Health (2003) more than 75% of African American women between the ages of 20 and 74 were classified as overweight or obese in 1999-2000, with many among them having elevated blood pressure. Obesity in Black women has been linked with later tumor stage at the time of diagnosis which could be related to differences in estrogen metabolism such that Black women may have greater stores or production of estrogen due to obesity (Taoli et al., 1995, 1996; Chen et al., 1994; Coates, 1990). African American women who are overweight are also at an increased risk for hypertension, stroke and diabetes (ACS 2003; Professional Guide to Diseases, 2002; NCHS, 2002, 2003).

### Gynecological Cancers

The literature notes that for all cancers (gynecologic, lung, and colo-rectal ) combined, African American women have the highest death rate overall when compared to White women (NCHS, 2002, 2003). Gynecologic cancers can be cancers of the breast, cervix, uterus, or of the ovaries. Screening exams are designed to identify the presence of these cancers. The most commonly administered screening exams for gynecologic cancer are the mammography and the pap exam (ACS, 2003). Whereas mammography is an early detection screening measure, a pap exam is considered a truly preventive exam as it can detect pre-cancerous cells before the disease is present (Bryon, 2004).

### Preventive Screening Measures

Cancer of the cervix is probably one of the most preventable cancers because a precancerous condition can be identified early through the Papanicolaou (Pap) screening test (NIH, 1996). Regular pap exams detect changes in the cervix and precancerous changes in the cervix can be treated before they become cancerous.

Screening programs for cervical cancer recommend that a Pap smear be done for all women by age 18 or who are sexually active, regardless of age. Women who have multiple sexual partners should be screened annually, but those in long-term, stable relationships who have had negative Pap smears three years in a row may be screened less often (ACS, 2003; OMH, 2003; Womens' Cancer Center, 2005).

Screening programs for cancer of the uterus are not as satisfactory as screening for cancer of the cervix because of the inaccessibility of the uterine cavity. In addition,

pap smears detect only a small percentage of endometrial cancers. There have been studies of other screening methods that can be performed in the doctor's office, with several showing the benefit of using endometrial biopsies to screen high-risk women who have no symptoms (Office of Research on Womens Health, 2002; ACS, 2003; Womens' Cancer Center, 2005). Unfortunately, there are no diagnostic methods accurate enough to be used for routine screening of women without symptoms of ovarian cancer. A Pap smear will detect ovarian cancer in only 10 percent of women with the disease (Office of Research on Womens Health, 2002; ACS, 2003; Womens' Cancer Center, 2005). Nonetheless, it is recommended that all women have an annual pelvic and rectal examination since an ovarian mass can occasionally be detected.

Screening programs for breast cancer range from self-breast exam [ SBE ]to a clinical breast exam [CBE] by a healthcare provider to annual mammography (Womens' Cancer Center, 2005; ACS, 2003;Office of Research on Womens Health, 2002). In cancer of the breast, malignant cells are found in the breast tissues. Breast cancer is the most common cancer in women, the second leading cause of cancer death for all women (after lung cancer), and the leading cause of death in women between the ages of 40 and 55. If detected early, breast cancer can be treated effectively and mortality rates are substantially decreased when breast cancer is detected and treated at an early stage (Womens' Cancer Center, 2005; ACS, 2003;Office of Research on Womens Health, 2002).

### Cervical Cancer

Older women generally accounted for 41% of cervical cancer deaths in the United States (NIH, 1996). Among older African American women, cervical cancer incidence and mortality continue to increase steadily up to age 80 and older. A higher incidence rate of cervical cancer was noted among older Black women (26.6%), almost twice that of older White women (13.8%), indicating that older White women may have cervical cancer detected through optimal care while the disease is still localized (Ries et al., 1999). The factors associated with poorer cervical cancer survival for Black women include "race" and older age and later stage at diagnosis, with African-American women.

Data collected from Surveillance, Epidemiology and End Results [SEER]<sup>x</sup> indicated that from 1990-1994, Black women aged 65 and older were twice as likely to experience higher incidences of and higher mortality from cervical cancer than White women of the same age group do. Per 100,000 women, Black women age 65 had a 34.4% cervical cancer incidence rate and a 23.3% mortality rate, respectively, compared to White women who were over 65 years of age and had a 14.7% cervical cancer incidence rate and an 8.0% mortality rate ([SEER], 1994).

Five-year survival rates among African American women have also historically been lower than among White women for all stages of the disease, even for those African American women who were diagnosed at stage I of cervical cancer. According to the literature, between 1986 and 1991, more than 71% of the White women diagnosed with cervical cancer survived five years or longer, but only 56 percent of the Black women survived five years after a diagnosis of cervical cancer (Miller et al., 1996). Furthermore,

SEER (2000 ) data also reported that between 1989 and 1994 the five-year survival rate actually decreased for African American women. In the span of three years , five-year survival rate had dropped to that of 54% from 56% for Black women as compared to an increase of to 87% from an earlier rate of 71% five-year survival rate for White women (Ries et al., 2000).

Cervical cancer also occurs almost twice as often in younger African American women as in age-matched White women. According to Hewitt et al., (1999) even though younger (aged 15 – 44) African American women were screened more frequently for cervical cancer than any other racial/ethnic sub-population group of females, younger Black women were twice as likely to be diagnosed with an advanced stage of the disease, with only about 40% of the cervical cancers among this population being detected while the disease was still localized, compared to about a 54% detection rate among White women while the disease is still localized.

The literature review on incidence, morbidity and mortality in relation to cervical cancer indicates that a Black woman's encounter with preventive and curative health care services, as well as the trajectories of her healthcare-seeking behavior across the life-course, needs to be explored further. It is interesting to note that although the pap screening exam is supposed to act as a preventive measure against the escalation of this disease due to earlier detection and treatment, even those young Black women who are screened more frequently than their White counterparts still have lower survival rates.

I suspect that the reasons for these low numbers may be due to a constellation of factors, such as late detection, diagnosis and ecosociocultural factors that impact the

access and delivery of preventive healthcare service given to Black women and similar issues may be operating with younger women as well. These issues will be discussed in the narrative data from the older Black women who share their experiences and expectations in healthcare settings.

### Breast Cancer

Recently the gap has widened in mortality disparity from breast cancer between Black and White women, paradoxically during a period of unprecedented advances in the detection and treatment of breast cancer. While improvements in health interventions and early detection are responsible for much of the decreasing mortality in White women. African American women appear to have benefited far less from these factors ( Krieger, 1998, 2002; Krieger, et al., 1999; NCHC 2002, 2003; ACS 2003).

Disparities in the overall health status and specifically from breast cancer have been indicated in the literature for Black women over the age of 40 as compared to White women of similar age. For example, Black women over 40 years of age have a higher mortality rate from breast cancer than their White counterparts, which is most likely the a reflection of lower rates of early detection as well as treatment disparities (IOM, 2002). According to the literature, Black women are often younger at the time of diagnosis for breast cancer and older Black women are diagnosed more frequently with later stages of breast cancer than older White women are. Therefore, older Black women have a significantly higher risk of dying from this disease than their White counterparts (Krieger et al., 1999; Krieger, 1997, 2002; ACS, 2003; NCHS, 2002, 2003).



As noted in the literature, if one were to combine the relatively high incidence and the relatively high mortality rates for African American women, according to Krieger (2002), "the result is that Black women [in the United States] ...have among the highest breast cancer mortality in the world" (p.3). Adequately explaining the true reasons for this inequality continues to be difficult and has resulted in the development of several bodies of literature on breast cancer risks, outcomes, and racial difference from a variety of disciplines, including medical anthropology, public health surveillance, pathology, epidemiology, and medicine.

As I began a review of the data collected on incidence and survival rates for breast cancer among African American and White women over the past 20 years, I was puzzled that the literature indicated that "no disparity existed in incidence and mortality from breast cancer between Black and White women" prior to 1980 (Heimann et al., 1997; Bach et al., 2002; Bradley et al., 2002; Brawley, 2002). However, upon further investigation, I discovered that much of the data on breast cancer incidence and mortality prior to this date did not include any significant data on African American women. Thus, it is not possible to report on disparities in incidence and survival from breast cancer among African American women prior to 1980 not because no disparity exists, but rather that there is no data to utilize for comparison (Heimann et al., 1997; Bach et al., 2002; Bradley et al., 2002; Brawley, 2002). Thus, it appears that there is a "racializing" component present to explain the absence of Black women as a research population. One is led to question why data on Black women are absent in early literature on incidence and mortality from breast cancer. Of particular concern is the fact that this omission may

have impeded the delivery of preventive care to this population, a topic I will return to throughout the dissertation.

Why is data not available prior to 1980? Several possibilities exist: (1) that because access to screening and diagnosis may not have been available or utilized by Black women so systematic collection of data to assess a five-year survival rate was not possible and / or (2) mistrust of the health system among African American women may have hindered the recruitment and participation of these women in clinical studies.

Although data on African American women are now included in breast cancer incidence and mortality statistics, such data has largely focused on "racial" disparities in breast cancer. However, in reporting health disparities in the current literature the focus seems to be solely on the predictive nature of "race" and seems to adopt a victim blaming perspective. In some studies, "race" seems to be used as a proxy variable implying genetic difference in Black/White differences in breast cancer (Chen et al., 1994; Joslyn et al., 1996; Brown, 1999; Joslyn & West, 2000; Poola et al., 2002). For example, such studies infer an association of aggressive tumor growth as "predisposed" in the bodies of Black women implying a sort of deficiency of the Black female body to fight off disease.

As a woman ages, her chances of being diagnosed with breast cancer, increases almost two-fold every 10 years. Among African American women, approximately 75% of those women diagnosed with breast cancer are over the age of 50 (ACS, 2003; NCHS, 2003, 2002). Breast cancer incidence rates reflect the number of new cases in a given year per 100,000 persons. According to the National Center for Health Statistics, in 2002 and 2003 older White women reported the highest incidence (114 cases per 100,000

women) with older Black women reporting 100 cases per 100,000 women. Yet, despite these lower incidence rates, older Black women continue to have a significantly higher mortality rate from this disease, with rapid increases in mortality since 1990. For example, in 1990, breast cancer mortality for older Black women was 16% higher than that for older White women, and by 1995 the rate for older Black women had increased to 29% when compared to older White women. In 2000, the breast cancer mortality rate for older Black women was 31% higher than that for older White women, and in 2001, the mortality rate had climbed to over 34% higher for older Black women than for older White women (Chen et al., 1994; Krieger et al., 1999; Hunter, 2000; Bach et al., 2002; Krieger, 2002; NCHS, 2002, 2003).

Over the last several years' mortality rates for breast cancer have decreased significantly for White women. While women in other racial/ethnic groups have also experienced recent decreases in breast cancer mortality (perhaps due to health promotion activities or better screening detection measures) yet despite that fact; serious gaps remain in mortality rates among African American women. Based on the most recent data, African American women of any age are less likely to survive five years with breast cancer (National Breast Cancer Screening Consortium, 1990; Wingo et al., 1998; Ries et al., 2000; Breen et al., 2001; Earp et al., 2002; Legler et al., 2002; Lukwago et al., 2003; SEER, 2003).

### Breast Cancer and Obesity

Earlier I indicated that obesity was considered a factor among older Black women and the detection of breast cancer. Forshee et al., (2003) and others noted that African-American women of all ages had a poorer diet and a higher BMI than White women and they were less active physically, putting them at a much greater risk for obesity. Furthermore, Black women with breast cancer are less likely than White women to be diagnosed while their disease is still at a localized stage (stage I) because of their nutritional status and a prevalence of obesity (Forshee et al., 2003). Jones et al. (1997) conducted a population based, retrospective study of reproductive age Black and White women with diagnosed breast cancer. This study was to determine the extent to which obesity, specifically severe obesity, could explain racial differences in late stage diagnosis. Researchers found that Black women were more likely than White women to be severely obese (26% vs. 7%) and to have problems seeing or feeling breast lumps during clinical or self breast exams due to being overweight, and were significantly more likely to be diagnosed with stage II or later breast cancer than White women (Jones et al., 1997).

In addition, the body weight of the woman, as reported at the time of diagnosis has been a strong predictor of a five-year survival rate with breast cancer. A statistically significant lower survival ratio has been noted in the literature (Greenberg et al., 1985) with increasing weight gain among all women. Much of the literature has also indicated that in combination a high fat diet, body mass index [BMI] and a lack of physical activity have been positively associated with increased risk and mortality from breast cancer in

both pre-and postmenopausal African American women (Ragland et al., 1991; Jones et al., 1997). According to a recent American Cancer Society (2003) study, overweight women are 60% more likely to die from breast cancer than normal weight women are. Therefore, breast cancer survival also appears to relate particularly to body weight and poor diet and by extension a lack of physical activity (Trentham-Dietz et al, 1997; Huang et al, 1999; Morimoto et al, 2002; ACS, 2003; Calle et al., 1993, 2003).

#### RACE PERSPECTIVES ON BREAST CANCER MORBIDITY & MORTALITY

In this section I will review a body of literature that focuses on exploring the source of disparities in breast cancer and mortality and morbidity from that disease among older Black women. The first perspective employs a genetic perspective: that is, the "racial" difference in breast cancer among Black and White women is a predictive variable using a genetic model<sup>xi</sup> as the template (Williams, 2002). The focus of this body of research is on the biologic expressions of "racial" differences in breast cancer and tumor etiology. The findings from this body of research suggest that disparities in breast cancer incidence and survival between Black and White women exist due to biological "racial" differences that are evidenced by a more "aggressive" growth of breast cancer tumors in Black women's bodies (Blake et al., 2002; Williams, 2002).

The second perspective is a review of the research literature that employs an ecosociocultural model as a template to explore "racial" difference, breast cancer, and "race" as a prognostic variable in breast cancer incidence and survival. In this model "race" is seen as a complex, multidimensional sociocultural phenomena and functions as

a prognostic rather than a predictive variable in pre-disposing African American women to disease. This body of literature suggests that the much poorer health status of older Black women while related to individual diet, nutrition, and patterns of health behavior, is also clearly associated with lack of early diagnosis/detection as a result of systemic problems of accessibility. More importantly this body of work notes that the health status of older Black women is related to their access and utilization of a health care system that is unresponsive to particular segments of the population, particularly the poor and "racial" sub-population groups (Krieger et al., 1993; Williams & Collins 1995; Lillie-Blanton et al., 1996; Bailey, 2000; Williams & Jackson, 2000; Williams, 2002; Krieger, 1998, 2002).

#### "Race" as a Predictive Factor in Breast Cancer

The literature suggests that breast cancer actually "behaves" differently in the bodies of Black women than in the bodies of White women. Some researchers have even gone so far as to suggest that breast cancer may actually be a different disease in Black women than in White women (Brown, 1999). Still other researchers suggest that the drugs used to treat breast cancer have not been tested as adequately in Black women as they have in White women (Freedman, 1995, 1998), which probably has some validity given the reluctance historically of these women to willingly participate in clinical trials.

In a study that reviewed "racial" difference from symptom recognition to medical consultation, Coates et al. (1992) found that Black women with breast cancer were two

times more likely to have stage IV breast cancer and one and one-half times more likely to have stage III breast cancer than White women. Similarly, at diagnosis, Black women were almost twice as likely as White women were to have tumors larger than 5 cm or tumors that had extensions to the chest wall or skin. Several studies conducted in the U.S. and South Africa, after adjusting for age and stage at diagnosis have established that the nature of tumors in breast cancer and the distribution of tumor type differ substantially between Black and White women. In these studies, Black women were more likely to be diagnosed with more estrogen positive tumors resulting in more aggressive tumor growth.

Recent research has indicated that the normal breast tissue of African American women has one less protective isoform<sup>xii</sup>, and more copies of the two other isoforms than in normal breast tissue of White women, which may contribute to the aggressive growth and rapid spread of cancer cells in African American women (Chen et al., 1994; Elledge et al., 1994; Moormeir et al., 1996; Lyman, 1997; Chang et al., 1998; Joslyn & West, 2000; Poola et al., 2002). The National Cancer Institute [NCI] Black/ White Cancer Survival Study by Chen et al., (1994 ) collected data from participating hospitals in three metropolitan areas, reviewing slides of tumors and evaluating nine tumor characteristics for Black and White patients. Results indicate that tumor pathology varied substantially between White and Black women, with Black women typically having more aggressive cancer cell types. After adjusting for age, stage at diagnosis, and metropolitan area, Black women were significantly “more likely to have grade 3 tumors, and more necrosis and significantly less likely to have well-defined tubular formation and more positive

estrogen receptor status than White women” (Chen, p.127). These results have subsequently been interpreted as evidence that Black women have more aggressive tumors than White women do (Chen et al., 1994; Moormeir et al., 1996; Joslyn & West, 1999; Poola et al., 2002).

In another study of breast cancer survival among women diagnosed with primary breast cancer using data collected by the SEER program which tabulated the number of women with breast cancer from 1988 to 1995, researchers Joslyn and West (1999), compared the effect of "race" and breast cancer survival with patient age, tumor stage at time of diagnosis, hormone receptor status, tumor histology, and menopausal status. In this study, African American women were found to be significantly more likely to present with advanced stages of breast cancer at younger ages and within each stage category, the "racial" differences in breast cancer survival may be due in part to tumor biology and a more aggressive cancer cell type, which results in the growth of tumors that are less responsive to therapy and treatment (Joslyn & West, 1999). This study further concurs with other studies of this ilk that suggest that "race" could be seen as an independent predictor of survival from breast cancer because Black women have significantly poorer survival ratios when compared to White women. (Chen et al., 1994; Elledge et al., 1994; Moormeir et al., 1996; Lyman 1997).



### "Race" as a Prognostic Factor in Breast Cancer

This body of health research focuses on prognostic variables, late stage at diagnosis presenting with advanced stages of breast cancer, differences in screening practices, and limited access to screening exams which have an impact on breast cancer incidence and survival among Black women. These factors reflect a combination of biological, genetic, environmental, and lifestyle differences that are more likely to account for variations in stage and mortality of breast cancer, particularly in older African American women. In these studies "race" was not seen to be an independent predictor/ risk factor for a particular hormone receptor status and histology (Hunter et al., 1993; Eley et al., 1994; ; Heimann et al., 1997; Chu et al., 1999; Lannin et al., 1998; Li et al., 2002).

Eley et al. (1994), in a examination of the ability of recognized prognostic factors to account for the observed poorer survival in Black women with breast cancer compared to White women utilized data from the NCI Black/White Cancer Survival Study and acknowledged that there does appear to be a greater susceptibility to breast cancer in Black women under 40 years of age. However, when they incorporated tumor disease characteristics and variables of stage, with treatment, comorbidities, and other sociodemographic factors into a model using breast cancer deaths ( instead of reviewing slides of tumors) as the outcome measure, researchers found that "racial" differences for survival between Black and White women were no longer statistically significant. Similarly, Howard et al.(1998) conducted a study to examine differences in breast cancer survival between African American and White women to determine whether there is a

racial difference in survival. This study, after accounting for stage of cancer, health status, health behavior, utilization patterns, access to care, quality of care, and doctor patient relationships found that the effect of [race] was marginal after adjusting for these factors.

Lannin et al., (1998), suggest that socioeconomic variables in conjunction with cultural beliefs and attitudes could largely account for the reported dramatic effect of "race" on breast cancer stage, tumor size, and "racial" differences in survival from this disease. Therefore, despite evidence that differences exist in the distribution of breast cancer tumor characteristics at diagnosis, there is just as compelling a body of evidence that, after adjustment for tumor characteristics and other prognostic variables, "racial" differences in survival are not significant and "race" is not such a clear independent predictor, but should be considered along with other prognostic factors, such as co-variables that reflect treatment, access, utilization, socioeconomic positions, cultural beliefs, biases, and other demographics (Kaufman et al., 1997; Krieger et al., 1993, 1997; LaVeist et al., 2002).

The relationship between "race", breast and cervical cancer, preventive care, tumor growth, and stage specific-survival differentials is certainly complex. Importantly, tumors in Black women do not seem to follow a more aggressive course simply due to biological [race] difference once breast cancer is diagnosed and if *optimal* treatment occurs. Additionally, even though their contribution is most likely minimal, genetics and biological factors should not be ruled out. And while all research shows that Black women disproportionately present with later-stage disease, have a higher breast cancer

mortality rate and larger tumors than White women, the literature also notes that Black women have poorer access to care and are diagnosed at a later date than White women (Chu et al., 1999; Brawley, 2002; Clegg et al, 2002). Taken as a whole, this body of literature leads us to question the perceived "racial" difference in incidence and survival rates of Black and White women.

#### ECONOMIC AND SOCIOCULTURAL INFLUENCES ON HEALTHCARE SEEKING

In this section I provide a brief overview from anthropological and public health literature that underscores some of the systemic, structural and sociocultural barriers that may influence the patterns of health behavior among older Black women. Health disparities occur as a result of many variables, including "race" and /or ethnicity, biological factors, later diagnosis, treatment differences, gender, age, income, insurance status, less access to healthcare, rural or urban geographic location, and individual patterns of health behavior (Dressler, 1991; Good, 1994; Leigh, 1995; Miller et al., 1996; Keesing & Strathern, 1997; Kawachi, 2000; Mayberry et al., 2000; Coreil et al., 2001). Other barriers to preventive healthcare for older Black women noted include not having a regular physician, physician reluctance to provide information regarding screening, and fear of radiation (Stein et al., 1991; Mickey et al., 1995; McCarthy et al., 1998).

Reasons for health disparities may include sociocultural differences between the healthcare provider and the population served, Yabroff and Mandlbatt (1999) found that one of the most consistent reasons to have a mammogram/pap exam for both Black and White women was a physician's recommendation. However, they conclude that

"compliance with such a recommendation may be complicated by distrust of the medical profession" ( p.749). This is particularly true among African American women.

Other factors that affect utilization of preventive screening exams among Black women are ideas about risk for particular illnesses. Research on breast cancer, among minority populations have noted that many women feel that testing is unnecessary in the absence of symptoms or if no one in their networks of support have not had the illness (Freeman, 1991;Grady,1992; Kawaga-Singer, 1997; Yabroff & Mandlblatt, 1999)

Barriers to preventive healthcare suggests that for an older Black woman, getting a mammogram and/or a pap exam as a preventive measure against breast/cervical cancer may be associated to the socioeconomic position (SEP)<sup>xiii</sup>, including a woman's level of education, insurance and employment status, and sociocultural environment (Everson, et al., 2002).

#### Mistrust and Suspicion of the Health Care System

The literature indicates that "Blacks are more averse to using the health care system in general, perhaps reflecting previous negative experience with it" (Whittle et al., 1995, p.586). Many members of the African American community are "already alienated from the health care system and the government" (Thomas & Quinn, 1991, p. 1499). As a consequence, older African Americans who have experienced racism or discrimination may be less willing to be vulnerable and place trust in a system of unknowns, such as preventive healthcare. A history of racial bias may effect older Black women such that they may be more skeptical about whether they will receive accurate diagnosis and optimal treatment, and maybe more reluctant to got to the doctor if not absolutely

necessary (Bailey, 2000, 1987; Blendon et al., 1989; Jones et al., 1990; Feagin, 1991; Smelser et al., 2001; Smedley et al., 2002).

Importantly, it is not just a Black woman's own past experiences, but also the experiences of others in her networks of support that may operate as influences on her levels of trust in the health care system. Freedman, in a study of health concerns among African American women, documented her interviewees' lack of trust in their White healthcare providers, their beliefs that White doctors routinely overlook diseases prevalent in the African American community, and their concerns that they may be used as guinea pigs (Freedman, 1998). Similarly, findings of a large nationwide survey (n=500) conducted on patients' trust of the medical establishment in 1999 concluded that:

Almost 80% of African Americans believe they could be used as "guinea pigs" for medical research without their consent; approximately 63% of African Americans believed their physicians often prescribed medication as a means to experiment on people without their knowledge or consent and 25% of African Americans believed that their doctor had given them an experimental treatment without their consent (Corbie-Smith, 2002, p.5-8).

Not surprisingly, African Americans, generally have a greater unwillingness to participate in clinical trials than their White counterparts. This may place them at a disadvantage, as it may limit their knowledge about new diagnostic and treatment options, and also their ability to access newer technology stemming from clinical trials (Thomas et al., 1991; Moore et al., 1994; Carlisle et al., 1997; Gamble, 1997; Ayanian et al., 1999; Corbie-Smith, 1999; Epstein et al., 2000).

Many African Americans receive primary health care in emergency rooms and receive care from several physicians, "none of whom may be knowledgeable about the

available protocols nor interested enough in the patient to refer him/her for inclusion in a clinical trial" (Shavers-Hornaday, Lynch, Burmeister and Torner, 1997, p. 35).

Furthermore, much of this research takes place at university medical centers, and many African Americans may feel that the university medical facility "is available only to select segments of the population (e.g., White, middle class) and not to the minority populations," thus limiting their participation in studies (Welsh, Ballard, Nash, Raiford & Harrell, 1994, p. 40). Additionally, African Americans may seek care at neighborhood institutions, where little research is conducted ( El-Sadr & Capps, 1992).

Research has shown that Black patients have less access to healthcare services and often receive less empathy, attention, and information from their doctors than do Whites (IOM, 2002). For example, the recent Institute of Medicine Report (2002) *Unequal Treatment: Confronting Racial/Ethnic Disparities in Health Care* identified study after study documenting dramatic racial/ethnic disparities in treatment decisions and diagnosis. Even when analyses controlled for economic status, health insurance status, or condition upon presentation, "race" was found to influence the quality and intensity of care, disposition after treatment, and the receipt of screening exams and treatment among African Americans (Ayanian et al., 1999; McMahnnon et al., 1999; Einbinder & Schulman, 2000; IOM, 2002; Smelser et al., 2002) and many others.

### Access and Under-Utilization of Mammogram and Pap Exams as Barriers

Numerous patterns of care studies indicate that older African American women receive care that is less than adequate when compared with care that is provided to older White women, indicating serious health disparities in treatment. Additionally, African Americans generally are more likely to use public facilities, and to be crisis oriented in their healthcare-seeking behavior (Jackson 1981; Bailey 1991). With regards to screening, there are often a discontinuity in the language and interpretation of screening guidelines which are found to be confusing, not only to the older Black woman, but to the healthcare provider as well. As a consequence of poor healthcare, the likelihood decreases that older Black women will go independently for preventive screening exams; it is also unlikely that they will be recommended for these exams by providers with whom they have little continuity of care (Krieger et al., 1993; Williams & Collins, 1995; Kinsella, 2000; Mills et al., 2001).

Studies on the effects of "race" on the use of services among Medicare-insured women found that older Black women had lower mammography utilization rates than their White counterparts despite Medicare reimbursement. Furthermore, several studies concluded that while the number of primary care visits was a predictor of mammography, this factor alone still did not explain the observed Black-White differences in the access and utilization of mammography screening as (Burns et al., 1996; Gornick et al., 1996). So why is it that an older Black woman would under-utilize screening mammography, fail to seek treatment, not get clinical breast exams, and not do monthly self breast exams?

## RACE MATTERS: THE ENIGMA OF THE STIGMA

In my review of the literature that involved surveillance and epidemiological studies on breast cancer among Black women, I found discussions that suggested that Black women die sooner than White women because of observed "racial" differences in tumor biology. I have also found other studies from sociocultural and medical anthropology, and public health on prevention of this disease that demonstrate that Black women are less likely to receive timely screening exams, diagnosis and treatment options from healthcare providers and less than optimal care for cancer from the health care delivery system than White women (Bach et al., 2002; Smedley et al., 2002; CDC, 2003; NCHS, 2003).

Both of these perspectives are used in the literature to make clear references to "race," and perceptions of "racial" difference between Black and White women and/or (bio) sociocultural contexts with respect to breast cancer etiology. However, timely and early diagnostic examination, and utilization of screening exams are what results in the detection of breast cancer, and when obtained regularly, mammograms and pap exams can reduce mortality and create the opportunity to receive optimal treatment for this disease. For example, the patterns of health behavior among older Black women with respect to prevention have been shaped and molded through their perceptions, experiences, beliefs and expectations, weathered across a life span of having overlapping socially constructed identities that have ideologically sustained and objectively conditioned them as fundamentally different from White women. Thus "race" matters because it is both an enigma and a stigma. "Race" matters because of the significance of



"being" Black i.e., Blackness has been constructed by and produced by locating the "Black as Other" in the Western discourses of science, politics, culture, and history. "Race" matters as an objective condition, and as an ontological and ideological axis of differentiation that has real effects on Black people's lives, e.g., "categories of the mind and categories of power" <sup>xiv</sup>(Hirschfeld, 1997).

In this ethnography, these axis's of differentiation emerge through an exploration of how, when, where and why older Black women may construct, reproduce, access and utilize sociocultural categories, such as the Black womanist culture<sup>xv</sup> to offset the beliefs within systems of power and inequality that are believed to be natural and thus serve to perpetuate gendered racial bias<sup>xvi</sup>. And while, I do not agree with those that would suggest that "being" Black or having a "race" signifies any one set of homogenous practices or experiences of a shared Black identity, nonetheless, "being" Black in the U.S., is defined as having an identity determined by "race" that is a kind of "disputed identity of [being both ] a subject and [an ] object" ( Dominguez, 1989, p. 12).

Therefore, as I continue to review the available literature on health inequalities (morbidity and mortality) and avoidable health disparities among older Black women, and the relationship of screening exams and patterns of health behavior to the prevention and detection of breast and cervical cancer, I would be remiss if I did not include a brief discussion of racial realism that has become part of the discourse in the literature found on breast cancer etiology research to illustrate and discuss two very differing perspectives supported by the health care system.

### Racial Realism: The House that Race Built

"Being" Black in the U.S. is a socially constructed category backed by law that makes "race" real at the site of a Black body. The work of Semmes (1992), Goldberg, (1993); Omi & Winant (1994); Hall (1996), and Omi (2000) have found Antonio Gramsci's (1995, 2003) concept of hegemony useful toward an applied understanding of its association with the racial rule in the U. S., and the resulting ideologies and social constructions of race/ethnicity in culture and society. According to Smelser et al., (2001), Cornell & Hartmann (1998) and Becker (2004), "race" as in "being" Black has become a "multidimensional mixture" of the categories of race/ethnicity which is a reflection of sociohistorical processes that have operated across and through time, in which the nation-state has been the preeminent site of production:

...race is a social category based on the identification of (1) a physical marker transmitted through reproduction and (2) individual, group, and cultural attributes associated with that marker. Defined as such, race is, then, a form of ethnicity, but distinguished from other forms of ethnicity by the identification of distinguishing physical characteristics, which, among other things, make it difficult for members of the group to change their identity (Smelser, et al., 2001, p.3).

Thus, "race" is really about how people assign meaning and value to how you physically appear. Consequently, today "being" Black will often represent an "inappropriate otherness" to Whites.

My discussion of racial realism is also from the perspectives of the literature from critical race theory, namely, racial formation theory<sup>xvii</sup> (Davis, 2002). Racial formation speaks to the durability of an identity by "race" in our post civil rights 21<sup>st</sup> century climate and suggests that it is due to the creation of new racial subjects and the

significant transformation of existing ones that : “far from declining in significance, the racial dimensions of...[sociocultural] life have grown” (Omi & Winant, 1994, p.35).

According to this theory, "race is understood as a fluid and unstable complex of [sociocultural] meanings constantly being transformed by [sociocultural and] political conflict" (Omi, 2000, p.243-263).

According to Hunt (2005) and many others, bodily differences by "race" were key factors, central to the founding of our republic. So, how have these ideas become part of our narratives on "race" and "being" Black, which has been made real at the site of the Black and female body in our society? bell hooks (2003) observes that it is the remnants of cultural apparatuses and processes of 19<sup>th</sup> century racial biases which have had an enormous impact on the construction of the framework on which to build a house. The rooms of this structure have been built using categories of the mind where we can phenomenologically locate White America's imagination in its endless quest to reify Blackness, Black women and Black America as its binary opposite through the use of categories of power. These categories are made up of ecosociocultural processes that continue in the present day, reminding us that "races" exist as separate species and Blacks, particularly, Black women, are perceived to be inherently inferior.

Michel Foucault's articulation of the body (1976) provides the historical evidence for discussing the older Black woman's body as an object of consciousness. As Weitz (2005) notes:

...only by looking at the embodied experiences of women, as well as how those experiences are socially constructed, can we fully understand women's lives, women's positions in society, and the possibilities for resistance against that position... (p.10).

Black women are still regarded by the larger society as the natural expression of a "race" Krupat, et al., (1999) conducted a study on physician decisionmaking among White healthcare providers who interact routinely with older breast cancer patients. The data from this study strongly suggests that healthcare providers were influenced by their own perceptions of "race" and given the same set of presenting symptoms as older White women, expected that patients who were Black and older would be "unhealthy." Thus older Black women were often treated less aggressively thereby contributing to later stage disease diagnosis and poorer prognosis for older Black women.

"Race," like Blackness is one social status category, created by macrosocial factors. Through the practices of discrimination, segregation, and prejudice, "individual values and behaviors [have been shaped ] in ways that can enhance or impair health status" (Williams, 1996, p.1). For example, a "racial" worldview was invented to assign some groups to perpetual low status, while others were permitted access to privilege, power, and wealth. Whites quickly came to see this invention of "race" as a hereditary trait, and endowed it with concepts of racial superiority and inferiority to resolve the contradiction between slavery and liberty in the United States, creating a "racial" democracy. This is the house that "race" has built.

### The History of an Idea

So how did the idea of "being" Black and therefore of a separate "race" become the identification of "inappropriate" other? What is the story that we tell? The construction of a Black identity, as an "inappropriate" other actually begins in the 1600s

when the first African slaves were brought to America. Through the liberal application of the "one drop rule,"<sup>xviii</sup> membership in the Black "race" was thus defined so that anyone having "even one Black ancestor, no matter how remote and regardless of physical appearance" (because you could have appeared to be White) was classified as Black and thus inferior to Whites. After the Declaration of Independence was written in 1776, this rule provided America with a justification for the institution of slavery (Freeman, 2003, p, 233s).

"Race" as an idea has a long history and tradition that is reified by Western philosophical thought and science. According to the literature the "one drop rule" was further supported with the "race" speciation discourses expressed by Gobineau (1856, [1988]), and signification discourses expressed by Hegel (1956, 1967 [1807]), both which further articulated that anyone with "one drop of Black blood" could only be irrational, primitive and inferior, i.e., other than human. According to Wright (2004), Hegel's discussion of the Black "Other" is not to be seen as "an abstraction but rather as a binary disguised as dialectic" (p.28). This concept and construction of a Black identity is inextricably intertwined with philosophy. The notion of a Black "Other" according to Wright (2004) is signified in Hegel's (trans.,1967) dialectic by his observation that "the Negro is all that is as other to the European; the very antithesis to the European subject by lacking consciousness" (p.128-9 ). Thus, a dialectical link is established in late eighteenth and early nineteenth century Western philosophy, giving further legitimacy to the practices of chattel slavery as "righteous and just" in the American nation-state which was initially founded on the principles of democracy. Supported by theories of the White

subject and the Black "Other," chattel slavery was seen as necessary to instruct the Black body, the Black identity and the Black self, who "had no language, because they had no culture, therefore no civilization, and therefore no history...[and could only] become thinking subjects under the strict tutelage of White instruction" (Wright, 2004, p.87). Science not only established but also reinforced this "natural" order of things in American sentiment, through classification schemes which equated "being" Black to having "race."

Thus, bias that had been rooted in the dialectics on nature and civilization became reified by scientific misconceptions that served to systematically account for the anomaly of slavery in a republic, which had been founded on a radical commitment to liberty, equality, and natural rights for all. That equality, however, did not apply to those who had been categorized as "naturally and scientifically" different and now inferior due to their visible traits such as skin color, hair type, and facial features. These visual traits were also presumed to indicate and measure all of the other traits of an individual, such as intelligence, morality, and demeanor. For example, if domination by one group over another was the natural order of things, then biologically Blacks could only be inferior to Whites, e.g., then Whites could only be masters and Blacks could only be slaves (see Byrd and Clayton, 2000, 2002; Feagin, 2000).

These ideas were specifically, expressed within American philosophical thought by one of the framers of the Constitution of the United States, Thomas Jefferson, in his categorization of Blacks as a totally separate species thereby, rendered them visible for work and yet because of the "immovable veil of race" could be denied their humanity.

These ideas, accepted as facts, came at a time when "reason" and "consciousness" were equated with being civilized, and Gobineau's earlier insistence that Blacks were an inferior species fit all too neatly with Jefferson's separate speciation dialogues based on skin color. Thomas Jefferson (who owned slaves and was dependent on a slave-generated economy) compared Blacks to domestic animals and apes in his writings. He emphatically removed all humanity from the Black body, when he stated that "Blacks may mimic human activity, but mimicry does not a man make" (1803/1977, p.193) i.e., Black is to animal as White is too human.

Thus, I am in agreement with the writings of Gates (1986, 1987), Gilroy (1993), Carby (1998), and Wright (2004) and Hirschfeld (1997) when they argue that it is crucial for scholars to recognize that within the history of mainstream Western philosophy there has existed an undercurrent of racial realism, in that "being" Black, evolved out the specific "arrangements" of the imaginations of White people who then took this constructed potential belief in Black otherness and used it to further concretize the identity of Blacks within a White reality in which "race" now serves as both a "category of the mind and a category of power" (Hirschfeld, 1997). For example, the practices of economic oppression, inequality and segregation were ideologically framed and habitually enforced by Whites as "arrangements" designed to set Blacks off from the rest of humanity and label them as an inferior "race" (Morris & Herring, 2000).

According to Wright (2004), Jefferson's views, and the versions that followed it, of Blacks as an inferior being whose lowly position in the United States was essentially biological is now part of the [White] American imagination as the natural order of things.

One group (Whites) benefits from dominating another group (Blacks) and defines itself and others through domination and the possession of selective and arbitrary physical characteristics (e.g., skin color), once again "being" Black becomes a category of the mind and a category of power. For example, recent health disparities research, focusing on the quality of care that Blacks receive in relation to other groups, indicates that the "color of your skin and the perceptions that go along with the color of your skin sometimes alters the care that you get, even if you had the same economic background, the same kind of insurance" (Maxwell, 2004, p.23). I found comparable observations in a body of work on "race, "racial bias, and inequities in health care offered by Janis F. Hutchinson (2005) in which she notes that health literature has:

...a tendency to make Black and White comparisons for diseases associated with promiscuity, underachievement and antisocial behavior. Since such assumptions are not substantiated, this type of comparison may represent a subtle form of racial bias...(p.13)

Thus, another aspect of the enigma of the stigma of "race" emerges reinforced by the sociocultural apparatuses of Jefferson's nineteenth century "immovable veil" ( Jefferson, 1977). Understanding the saliency of the threads of pseudo-scientific and sociohistorical construction of the "racial" identities of older Black women will be a major factor in their recruitment and retention in preventive health interventions.

Other barriers, such as lack of knowledge about testing frequency and meaning of exam type, lack of physician referral, mistrust of the health care system, and underestimation of their personal risk for cervical cancer have also been noted among this population ( Miller et al., 1992; Ries et al., 1997). Furthermore, older Black women were less likely to have ambulatory physician visits, and were more likely to be hospitalized or



die from lack of such services (Chu et al., 1999; Eley et al., 1994; Lannin et al., 1998). Therefore, since preventive care is underutilized presentation for treatment may be delayed well into pathology for this population.

### "Racial" Bias and the Black Female Body

Much research of late from anthropology, public health and, social epidemiology explores the relationship of "race" to health. "Race" is a powerful category; as a socioideological and sociocultural construct it has supported patterns of exclusion and restriction (Fanon, 1967[1952]; Gates, 1986; Drake 1987, 1990; Marable 1991; Ballard , 1992; Hall, 1992; DuBois, 1993 [1903, 1906]; Patterson & Spencer, 1994; Shanklin, 1994; Harrison, 1991, 1995; Hill, 1998). As noted earlier "race" definitions have been crystallized in the United States as a category through a "racial formation" process that depends on a racist sociocultural structure (Omi & Winant, 1994). For example, racial categories are created by those in power to define groups of people in a certain way that benefits those in power, who then proceed to define who is privileged and who is not, e.g., allowing racial hierarchies to emerge to benefit the "dominant" race (Omi & Winant, 1994). Many studies indicate that "racism is structured into the health care system in pervasive and sometimes invisible ways" (Becker, 2004, p. 259).

Beliefs and perceptions that allow a healthcare provider, the health care system or even an older Black woman to speculate that physical differences correspond to distinct, inherent biological differences can be a barrier to the optimal access and utilization of available preventive screening programs. According to Hill (1998), "racism should be a central question for research in [socio] cultural anthropology as race has been in

biological anthropology (p. 680). I believe that the consequences and the legacies of racial bias directed specifically toward the Black body are serious matters. Racial bias is a doctrine of racial supremacy, stating that one "race" is superior to another (Bonilla-Silva, 1996). This type of bias is often enacted as racism and can be institutionalized, internalized or personally mediated. According to Jones (2002), "institutional racism" is structural and refers to differential access to goods, services and opportunities of society by race. Members of "racialized" groups may also accept the negative perceptions, beliefs and understandings of their "intrinsic worth" as valid indicators and this is called "internal racism." "Personally mediated racism" is defined as the differential assumptions about the ability, motives, and intentions of others and differential actions towards others because of their "race." Racial bias has also been associated with differences in health outcomes, for example, according to Jones, (1994, 2002) " race-associated differences in health outcomes are in fact due to racism" [because being in a "race" often indicates] "the social classification of people in a race-conscious society such as the United States" (Jones, 2002, p. 311).

#### Perceptions of "Intergroup" and "Intra-group" Racial Bias

Perceptions of racial bias persist and continue to exert a significant effect on the health and well being of African Americans (Dressler, 1991; Browman, 1996; King & Williams, 1995; Williams, et al., 1997; Clark et al., 2002) Expectations of racial bias, or racist encounters exert an enormous amount of physical and psychological stress for African Americans. As noted by Clark et al.(2002):

The perception of an environmental stimulus as racist results in exaggerated psychological and physiological stress responses that are influenced by constitutional factors, sociodemographic factors, psychological and behavioral factors and coping [resiliency] responses. (p . 321)

In a study among older African Americans, Williams, Yu, Jackson and Anderson (1997) "found that unfair treatment attributed to racial or ethnic discrimination...over the lifetime predicted well-being, psychological distress and chronic conditions" (Clark et al., 2002, p.330). Structural inequalities, such as racism, racialized health policies, and being uninsured are key factors that operate to obstruct the optimal access and receipt of treatment from the health care system (Becker, 2004); for example, stress has also been linked to breast cancer survival (Spiegel & Kraemer, 1989, 2000 ) subjective well-being, and heart disease (Rozanski et al., 1999).

Mammogram and pap exams occur at the site of the female body when it is most vulnerable, naked and exposed. In the U.S., discussions of "race" and African Americans is often conceived of in terms of the Black body. As noted by Shaw (2001):

...from outside of the Black community...[the]Black body is abnegated, racialized in pernicious ways...inside the Black community...the body defines [the Black woman]...and management of the Black body is at the core of [a Black woman's] identity (p.103).

Black womens bodies continue to be a (contested) construction site, the space of meaning and a place of excavation in the U.S., one in which the "racial" positioning of Black bodiliness is a site where experimentation, abuse, and discrimination has occurred based on the systemic rejection of the Black body – color, form, face, and hair ( hooks, 2003). Williams & Jackson (2000), clearly articulate this relationship in their article on the

relationship of "being" Black to "race" and health when they state that "as long as being Black remains consequential for every aspect of life, and as long as racial status [position] continues to reflect differences in power and desirable resources in society, it is important to assess race" (p.55).

Another issue within the topic of racial bias is women's powerlessness. Women's concerns about the loss of control at the site of her body during a health exam may result in feelings that she will receive inferior to the information than White women (Freedman, 1998). The "ideology of free-will" also emerges in the literature on women and health. Although not inherently racist, Clark et al.,(2002) notes

When applied to Black Americans, the belief system of 'free will' is actually racist because of its refusal to recognize or acknowledge the existence of prejudice or discrimination and instead imputes the primary responsibility for Black disadvantages to the Blacks themselves (p. 330)

As a result, victim blaming may occur wherein a woman is blamed for her seeming lack of interest or ability to seek regular preventive screening exams. Miscommunication and mistrust may result in a woman's not following the healthcare provider's advice (Kleinman et al., 1978; Krieger, 1987; Byrd, 1990; Luft, 1990; Harris et al., 1997; Davis, 1998; Staveteig & Wigton, 2000; LaVeist et al., 2002).

An older Black woman's skepticism, anxiety and other expectations of a healthcare encounter, along with her skepticism, anxiety, and individual patterns of health behavior may arise from perceived "racial" differences, funds of knowledge, and "ethnic notions<sup>xix</sup>" about the health care delivery system as conditioned responses to contemporary and historical racial positioning of the Black body (Dressler, 1990, 1991; Feagin & Sikes, 1994; Markides & Wallace, 1996; Krieger, 1998; Bailey, 2000; Smelser

et al., 2001; Smedley et al., 2002). Together, all of these factors must be viewed as fundamental measures of exposure to health risks for older Black women. These will be discussed further in Chapter Five.

### Physician Bias with the Health Care System

Prior to civil rights legislation (Title VI of the Civil Rights Act of 1964) Blacks were denied outright access to "White" healthcare providers, the health care system, and even to emergency care in White facilities. Title VI prohibited discrimination and segregation in most healthcare settings. Many older Black women remember and share the experiences of having faced continual discrimination and racism as byproducts of segregated health care and social service systems (Gordon et al., 2005). And while the legal system has remedied this situation, de facto discrimination still continues in many areas through the persistence and prevalence of racist beliefs, stereotypes and practices which may result in discriminatory behaviors by healthcare providers in the delivery of contemporary healthcare services. For example, according to Smith's (1999) principal findings published in *Health Care Divided: Race and Healing a Nation*:

The selective enforcement of Title VI of the Civil Rights Act of 1964 exerted a profound, unintended, and unacknowledged influence on the organization of health services in the United States. Title VI of the Civil Rights Act was a condition of institutional and professional participation in the program. Yet, enforcement was selective, reflecting the administrative and political realities faced by President Lyndon B. Johnson's administration in launching this ambitious new program. Providers responded selectively — accommodating these requirements but moderating their impact on the communities they served (p. 15) .

These services included screening, diagnosis, and treatment for specific diseases or medical conditions (American Medical Association [AMA], 1990; Massey & Denton,

1993; Polednak, 1997; Waller, 1998; Steinhorn & Diggs-Brown, 1999; Schwartz, 2001; IOM, 2002).

A review of the literature also indicates that the American health care system has a "well-earned" skepticism among many Blacks, not merely because of historic abuses, such as the Tuskegee experiments but also because of contemporary daily encounters and persistent experiences with bias and stereotypes, discrimination, and racism directed toward African Americans in American society. According to Rice and Jones (1987) and Jackson (1991) while it is accurate that barriers such as cost, availability, and access may influence the demand and utilization of medical services by these groups, the healthcare provider may also be unable to respond to the patient's personal needs because of perceived "racial" differences. For example, Finucane and Carrese (1990) found that "race was noted in the vast majority (16 of 18) cases involving black patients...among patients to whom house staff ascribed unfavorable characteristics, race was mentioned in 10 of 10 cases involving black patients" (p.165). Therefore, many Black women are continually conscious and on guard of how they are perceived by doctors because "...the patient [older Black woman] does not come into the relationship at arms length, with equal power to that of the [White] provider. Therefore, the patient [older Black woman] is placed in a vulnerable position in which [she] must trust that the provider will do what is in the patient's best interest" (King, 2003, p.366).

Other research has also found that physician's perceive African Americans more negatively on a number of dimensions when compared to Whites. van Ryn & Burke (2002) , conclude that "patient race is associated with physician's assessment of patient

intelligence, feelings of affiliation toward the patient, and beliefs about patient likelihood of high-risk behaviors (substance abuse) and noncompliance " (cited in LaVeist et al., 2002 p.564) .

According to the literature, the relationships of Black patients with their physicians have demonstrated that provider racial bias and patient awareness of invidious past events, such as the experimentation on slaves, the Tuskegee and radiation experiments, and the forced sterilization of Black women have contributed to less utilization of available screening programs. Equally important are patients "race" and sex "which may independently influence a physician's recommendation" for treatment protocols (Schulman, et al., 2002, p.527). Biases on the part of physicians were also found to be due to "either overt bias or subconscious bias activated by stereotypical perceptions of the patient's membership in a [racial] target group" (Schulman, et al., 2002, p.525). What is most troubling is that the findings from this research were most striking for Black women.

Although differences in the delivery of healthcare between Blacks and Whites has diminished in recent years, a number of studies have showed that these populations still lag behind Whites in getting needed care, even when comparing individuals with similar health care coverage. Blacks also wait longer to see a physician or are more likely to list their usual source of care as a hospital or institution rather than a primary care physician (LaVeist et al., 2002).

### The Importance of Data on "Racial" Difference

Several researchers have noted that in seeking "differences in the distribution of associated attributes which will explain the health inequality very little consideration is given to sociocultural factors among the populations that are studied" (Tyroler et al., 1965, p. 128). As a consequence, "racializing components become part of the report of findings, and may impact individual patterns of health behavior among older Black women and diagnostic, treatment, and screening options offered by healthcare providers and the health care delivery system to this "racial" group.

Recognizing the importance of sociocultural contexts is critical, especially when non-surveillance or non-epidemiological researchers are attempting to discern the sources of inequalities in health status in a review of the literature. This is particularly crucial to understand when using and reviewing data on risk factors for disease occurrence and "race" from the area of public health surveillance and the monitoring of individual behaviors associated with specific diseases, because this data is seldom received in a neutral context ( Bhopal, 2002; Blake et al., 2002 ; Williams, 2002). For example, "race" assumed to be "naturally occurring and not arbitrary" has been central as an analytic category in health research agendas (Blake et al., 2002; Williams, 2002). The use of catch-all categories such as "Black" and "White" as "race" may be harmful in understanding the complexity of perceived "racial" differences in disease etiology and health status because of a tendency to ignore the importance of the (eco) sociocultural environment, which is inextricably entwined with "being" in a Black body and having a "race" (Bhopal, 2002; Williams, 2002).



### "Race" as a Social Construct

"Racial" identity is a socially constructed reality in our society. Anthropologist Fredrik Barth argued long ago (1969) that the critical factors in understanding "racial" identity, i.e., what others say we are and who or what we claim to be, are socially, culturally and historically constructed. Therefore, what kinds of difference constitutes "race" and what difference "race" makes with respect to understanding the patterns of health behavior among older Black women are pivotal questions that are discussed in this dissertation guided by a social constructionist approach (Kuhn, 1970; Guba & Lincoln, 1990; Denzin, 1991; Crotty, 1998; Hacking, 2000; Patton, 2002).

Social constructionism has a strong theoretical basis in the practice of ethnography, womanist theory<sup>xx</sup> and the perspectives of sociocultural anthropology (Geertz, 1973c; Marcus & Fischer, 1986; Crotty, 1998; Turner, 1998; LeCompte & Schensul, 1999; Denzin & Lincoln, 2000b). A brief review of social constructionism will help explain my interpretive approach. Older Black women, as African Americans, have had to construct their own realities with respect to their identities because of the sociocultural environment in the U.S., where "race" is often both a "sign" and a "signifier." Social constructionism is actually an arrangement of theoretical positions that articulate the belief that the mind, our thoughts, the self, and reality are the products of history, culture and language. For example, to more fully comprehend the patterns of health behavior among older Black women, we need to recognize that their health seeking, accessing, and utilizing behavior is culturally - as well as individually constructed. We need to recognize that much of their health behavior is the result of

active, and reciprocal relationships, that have occurred within the ethos of the health care system, healthcare settings, and through interactions with healthcare providers and the ethos of culture among older Black women. For example, in accessing a preventive screening exam an older Black women may become engaged in an interpersonal relationship in which the healthcare provider may often utilize or infer (albeit understanding that it has no significance in biology) "race" as a sign or signifier to reference treatment protocols, discuss health status, define health behaviors and examine health disparities among Blacks (Krieger, 1987, 2002; Jackson, 1991; McBride, 1991; Semmes, 1996; Wilkinson, 1996; Williams, 2002; LaVeist et al., 2003).

In this study, I explore relationships between larger (eco)sociocultural practices, e.g., being "racialized" as Black, having a racial identity, and the lived experiences, expectations, perceptions and patterns of health behavior among older Black women. I have chosen to include two very salient points that reflect a Black womanist/feminist perspective. The first point notes that the experience of being the Black "Other" is not the same for all Black people. While I may use the "trope of a veil" from the work of W.E.B. DuBois, (1986) in the following discussions because it references a common strategy used by scholars to discuss "being" Black, "race" and *invisibility* I will use it in a much different context later, when I discuss, for example, the vigilance and advocacy of the use of "womanist talk" when an older Black woman says that she's had to have "a come to Jesus talk" with a healthcare provider. In this instance, "being" Black within the ethos of spirituality for many older Black women is an attempt to shred the veil of "race"

by articulating "being" Black as a trope of kinship<sup>xxi</sup> that when tied to "race," and gender becomes part of a cultural ethos<sup>xxii</sup> of "being" a Black woman (Wright, 2004, p.6).

The second point is that there is "a unity of diversity" when talking about Black subjectivity; thus I will be addressing this idea within my discussions on the ethos of Black womanist culture and the building of funds of knowledge that are part of "being" categorized as Black. Therefore, "being" Black must also be considered as a referential element that shapes context and meaning with respect to "race" and the access, utilization, and delivery of optimal healthcare service. Thus "ethnic notions" about "being" Black and "race" must also be considered as among the major "fundamental causes of disease" and disparities (Link & Phelan, 1995, p. 93). Throughout the following chapters I have framed my discussions around "race" "being" Black, female as an ethnic identity perceived ideologically, and ontologically the meanings of which have been objectively conditioned through the re-production of and reference to "implicit models for other categories," i.e., categories of the mind and categories of power that may also construct a Black subject (Smaje, 2000, p.77; Goldberg, 1993; Grant & Orr, 1996; Hirschfeld, 1997).

The Black population in Tucson is fairly small, and widely dispersed, rather there exists a resiliently fragmented space that is a cohesively anchored site of African "Americanness" in which this community sustains its sense and reference to "being" Black and American. bell hooks (1990) has suggested that "postmodern culture with its de-centered subject can be the space where ties are severed or it can provide the occasion for new and varied forms of bonding" (p.31). I agree and suggest that due to the geographical

residential disbursement of African Americans around the city of Tucson, older Black women seem to have created and maintained flexible and fluid networks of social and cultural support through formal and informal Black organizations and Black churches. Thus I align myself with the perspective of Weate (2001) who noted that the "Black subject enters the arena of interpersonal encounters in the colonial situation with ...her history already constructed" (p.175). The utilization of a social constructionist approach offers a framework for me to discuss how the realities of health and health care are built and rebuilt, given specific circumstances or series of interactions over time among older Black women. For example, how do older Black women convey their perceptions and expectations of treatment within a healthcare setting largely comprised of "White" healthcare providers? How do these women share their symptoms with those healthcare providers, and does their communicative behavior change or differ depending on whether the provider is Black or White? How do these women share their healthcare experiences with other older Black women, their family, friends, and extended kin?

The women in my study would generally describe "being" Black through perceived racial occurrence's and their responses to these events were often expressed in a cumulative and collective framework (Stack, 1970, 1985, and 1994). We often understand the world and ourselves through the interpretive frameworks that we have adopted by living and interacting in specific communities across and through particular times in history. For example, historical research has shown that the notion of having a "race" for the Black body in relation to the U.S. health care system has always carried more meaning than mere physical differences. Overwhelming evidence exists in the

literature of the inhumane, inappropriate, and racist agendas which have facilitated health research inquiries and impeded the delivery of optimal and culturally responsive healthcare to Blacks since slavery (see St. Jean & Feagin, 1998; Bailey, 2000; Byrd & Clayton, 2000, 2001a & b; Williams 2001, 2002 and LaVeist, 2002). Thus, since most of the women in my study have grown up in racially homogenous families and networks of support, "these environments [have] served an important insulating function in developing identities independent of racial imagery (Stoller & Gibson, 2000, p.87).

A Black community's historical legacy and its contemporary effects on the health and well being of its members may be perceived as a collection of strategies of advocacy and resiliency in response to the specific historical and contemporary Black experience in America (Cross, 1991; Jackson, 1991; Semmes, 1996 and Bailey, 2000). As I suspected, these concepts were significantly expressed throughout my study when the women were asked to discuss their networks of support that are part of the Black community in Tucson, Arizona. According to the literature "the degree to which an individual is interconnected and embedded in a community--is vital to an individual's health and well-being as well as to the health and vitality of the entire population" (Berkman, et al., 2004, p. 137).

Patterns of health behavior, health status, and health disparities are often reflective of issues of power in a society, thus the significance of "racial" identity in our society and the Black female body within it are not entities to be taken for granted, because this idea of "being" Black has also been constructed within a White imagination resulting in socially agreed upon practices of seeing, naming and interpreting that Black

body. As perceptions "of reality [these] are socially constructed and culturally embedded<sup>xxiii</sup>, and those views dominant at any time and place will serve the interests and perspectives of those who exercise the most power in a particular culture" (Patton, 2002, p.100).

In my analysis and interpretation of the narrative data using social constructionism, I also examined patterns of health behavior among older Black women, and their perspectives of "having power" / "being powerless" in relation to seeking, accessing and utilizing healthcare services. For example, experiences over a lifecourse by an older Black woman with gendered racial bias may affect her bodily praxis in seeking a mammogram or pap exam, and her access and utilization of diagnostic healthcare services. Furthermore, her perceptions and expectations of bias to occur may result in mis-communication and misunderstandings with healthcare providers and their support staffs in those healthcare settings. These problems as noted earlier may also be bi-directional, that is, the healthcare providers and their support staffs may access their own socially constructed insights and beliefs about "race" and "being" Black that are part of the ethos of our larger ecosociocultural environment.

#### SUMMARY

In sum a review of the literature of public health and anthropology attest to the existence and tenacity, in contemporary American society and health care, of racist beliefs and discriminatory behavior directed toward African Americans. There is also compelling evidence in the literature that there is a relationship among beliefs and locus

of control, racial bias as discrimination, and racism which may correlate with persistent and often increasing health disparities and inequalities through healthcare provider bias, whether conscious or unconscious, individual or institutional.

Many healthcare providers continue to remain puzzled and surprised by the levels of apprehension and cynicism of the health care delivery system held by African Americans. However, fear, suspicion and distrust of that system can be seen as a natural and logical response to the history of experimentation and abuse of the Black body. For example, according to Gallin (1998), a belief that health care systems are detrimental to African Americans may shape their lives, and consequently their perspectives, and may keep African Americans from getting healthcare treatment, from participating in health and medical research and from donating organs.

As discussed in this chapter, patterns of health behavior among older Black women are determined by a number of factors, including the availability, accessibility, and the quality of healthcare delivery of service. Consequently, in the U.S... “many differences in health status by race... persist, with the members of many, but not all, racial ...minorities experiencing worse health than the majority population” (Smelser et al.,2002, p.17), thereby making "race" a sociocultural and socioideological barrier to the delivery of preventive healthcare and to the patterns of health behavior.

### **III. METHODOLOGY**

#### The Study Setting

The study took place from 2002 - 2004 in Tucson, Arizona a southwestern region of the United States. According to the U.S. Census (2000) Tucson is one of the fastest growing cities in this region (City of Tucson, 2004). The total population for the city of Tucson is approximately 500,000. According to U.S. Census (2000) data the racial/ethnic breakdown in percentages are 54% White, Non-Hispanic, 36% Hispanic (could be any nationality), 4.0 % Black/African American, 2.0 % American Indian, 2.0 % Asian (U.S. Census, 2000; City of Tucson, 2004). Roughly 26, 000 African Americans currently reside within Pima County, with 21,100 of them living in the city of Tucson. Of that population, 10,100 are female, of which a little over 3000 are aged 40 and older (City of Tucson, 2004; U.S. Census, 2000). My research was conducted in the metropolitan area among African American women 40 years of age and older with secondary data collected from local healthcare providers.

#### The African American Community

The Black community is often a conflictual space in which gender, race, and class alliances and relationships to power are made and remade. The Black community in Tucson, Arizona reflects specific culturally deemed geographic sites<sup>xxiv</sup> that emphasize the cultural origins, physical movements and many of the cultural characteristics of Blacks in this region (e.g., their historical development, their settlement patterns, and their quality of life). For example, in the early 1900's, Black settlers in Tucson were restricted to living and owning businesses in certain areas of town and as a consequence



their settlement patterns may have been quite different than other more ethnically dense settlements of African Americans. Furthermore, both legal restrictions and intentional actions of White settlers enforced and continued this discriminatory policy through the 1950's (AAHIP 1989). This is one of the reasons why even today there is very little clear evidence of a physical Black neighborhood unlike the other minority ethnic groups that reside in this area.

African Americans are also conspicuously absent from the general literature that deals with the settlement of Arizona, even though Blacks have been part of the state of Arizona since 1850 (AAHIP 1989). According to the Arizona Historical Society Archives (2004) prior to 1854, American Indians populated the area that is now known as the city of Tucson. Then, with the Spanish expansion west, this area became known as the Frontera del Norte of New Spain, and part of the Republic of Mexico until it became part of the United States through the Gadsden Purchase of 1854. However, the descendants of Africans have been involved for many centuries in the development of what is now called Arizona. The first non-Native American man to set foot across what is now the southern boundary of Arizona, near what is now called Tucson, was an African and a member of a Spanish expedition in 1539. Estevan (variously known as Esteban, Estevanico, or Little Steven), was the front man for an expedition of Spanish explorers under the leadership of Fray Marcos de Niza, Vice Commissioner-General of New Spain.

Over the past 150 years, many African Americans left the southern United States looking for new opportunities to establish roots, raise families, and escape racial persecution. As a result, Blacks migrated to Arizona through a combination of skill, attitude, and outlook, adapting their talents to specific occupations as needed, and constructing Black communities and building social and cultural organizations wherever they settled (AAHIP (Williams) 1989; LeSeur, 2000). The first recorded African American settlers in the city of Tucson were Mr. and Mrs. Wiley Box, who came to this area between 1850 and 1855 (AAHIP (Williams) 1989; LeSeur, 2000). The early Black pioneers were engaged in various types of employment. Some started homesteads or ranches. In the late 1800s and early 1900s, almost all barbers and barbershops in Tucson were Black, according to one of the participants in my study who worked on the African American History Project (1989), a project conducted to recreate cultural awareness by restoring some of the history of the African American contribution to the settlement of Tucson.

African Americans often become a Black community almost by default, due to racial stratification and subordination in a racial democracy. Many of the Blacks who settled in this area have constructed collective memories and identities, which ultimately served as the basis for their assertion of what Lorini (2004) calls "participatory democracy," cultural and physical movements created by ordinary citizens in which they become activists and attempt to effect social change. For example, several of the women in the study knew the history of this kind of activism, one of the women, Ms. Carla noted, after reconstruction, African Americans were actively recruited to come to Tucson to

pick cotton and work in the citrus fields by other Blacks. Furthermore, Blacks migrating from the South were encouraged to come to Tucson and "enjoy more freedom" by the Mayor of Tucson at that time, according to one of my participants, Ms. Carla:

There is one thing I do remember when I was doing the research at the university is old newspaper advertising. I ran across an article that was interesting and it was, after reconstruction. At that time, Tucson was still a territory but that's when Blacks were moving out of the South to the industrial areas. And, actually, Tucson had a niche for them working cotton fields. The Mayor of Tucson in this article put out an invitation to Black folk to come to Tucson. So they were like being courted to move here after [the] reconstruction period when other Blacks were heading to Chicago, Detroit to work in the industry. This article said 'come on out here, we got work for you too.'

Significant numbers of African Americans also worked for the Southern Pacific Railroad that passed through this area. Some performed manual labor by repairing tracks, or worked as baggage handlers and porters. Mining and prospecting also brought other Blacks to Tucson (AAHIP 1989).

However, later segregation and discrimination became pervasive in Tucson in nearly all aspects of daily life. These factors attempted to impede the stability of the Black community by specifically restricting the economic and political power of Blacks. Nonetheless, rising above the hardships and racial discrimination that they experienced, African Americans have added to the growth and vitality of Arizona and helped build the city we know as Tucson today. Subsequently, many African Americans established their own neighborhoods (often challenging restrictive covenants) and built their own communities in this region (AAHIP 1989).

One of the earliest settlements of Blacks in Tucson to construct a physical community was in the vicinity of the southwest side of town called "A" Mountain. Later

other Black communities and neighborhoods were established along South Park Avenue and downtown near Meyer Street. In the early 1960s, "White" flight<sup>xxv</sup> opened a geographic middle class area called "Sugar Hill," according to women in my study. This area was located between Stone and Park Avenues, and between Grant and Speedway on the northwest side of Tucson, and also became an African American settlement. Today, many of these areas are reflexive reminders of a once dense generational and historic residential settlement of the African American population in Tucson that over time has expanded to the eastside and the foothills as new Blacks have moved to this city. The older Black women who participated in my study have been drawn primarily from these sites which represent anywhere from 3.0 to 14.0 percent concentrations of the African American population (City of Tucson, 2004; U.S. Census 2000). (See Appendix A - African American Community/Population Density - City of Tucson Urban Planning and Design, 2004)

Black communities are often constructed in the ongoing battle for expanded democracy, particularly in response to ideas of Black racial inferiority outlined by the theories of "racial science" discussed in chapter two. In this study setting there exists a resiliently fragmented space that is a cohesively anchored site of African "Americanness" in which this community sustains its sense and reference to "being" Black and American (AAHIP 1989). And given that there is a strong relationship between cultural geography, and anthropology, I felt that these factors be considered in choosing a methodology with which to conduct this study.

## THE STUDY POPULATION

Fifty women were interviewed for this study; 8 of these women were key informants and 35 were study participants. In addition, discussion groups were conducted with another 7 women. I also conducted 8 interviews with healthcare providers who interacted with older Black women. These interviews provided background and secondary data on the local African American population's health status and were also used to determine appropriate health-related questions to be utilized within the study with older Black women.

### Key Informants

The purpose of key informant interviews was to explore patterns of health behavior among older Black women, and to determine questions that might be relevant for use with the larger sample. These eight Black women operated as a referral base for many of the other older women in the African American community who agreed to participate in the study. These women were widely known and well respected in the local African American community, and had a great deal of experience navigating the local health care system. Key informant interviews took place at a woman's work site or at her home and lasted about two hours. These women encouraged others to participate and further solidified the importance of my dissertation research to the small African American community in Tucson.

Interviews with key informants were open-ended and focused on their preventive health behavior, their networks of support, and the funds of knowledge among the Tucson Black community. Other questions referenced the way in which Black women

communicate and interact with healthcare providers; the use of a cultural "vocabulary" that I call "womanist talk" as part of health behavior, and the role of agency as advocacy, and the relationship of spirituality, networks of support and resiliency in healthcare seeking and utilization among older Black women. Questions on the type of treatment expected/experienced within the healthcare encounters and the support staff were also addressed. In addition, data was collected on each woman's personal observations on the preventive health practices of women in her community. (See [Appendix B-Key Informant Interview Guide](#)).

### Study Informants

Older Black women who were part of the sample population were referred by key informants and were also identified and approached through existing community health projects, local churches, and local neighborhood centers used in earlier research (Parker et al., 1995). These centers are sites of dense concentrations of generational settlement by older African Americans in Tucson. Each site had several Baptist churches (Grace Temple Missionary, Greater Mount Calvary and Pilgrim Rest) and community centers including the Archer Center, Northwest Neighborhood Center and Quince Douglas Center, where older African American women actively participate in a variety of events. Several potential participants were also identified through existing databases of informal/formal African American civic social/cultural organizations (The African American Town Hall Meetings [AFAS], Tucson Black Chamber of Commerce [TBCC], National Association for the Advancement of Colored People [NAACP], The Black Women's Task Force [BWTF], First Fridays, Tucson Urban League [TUL], and SANKOFA, for

African American faculty and staff as a civic/social network at the University of Arizona) and local health networks which included The Pima County Health Department (PCHD), The Coalition for African American Health and Wellness (CAAHW) and The Black Women's Task Force Health Conference).

In addition, many women approached me at Black church, civic, social, and cultural gatherings because members of the university community do not generally frequent these settings. In these encounters I explained the study and took contact information. However, I also wanted to collect data on patterns of health behavior among Black women who did not attend such venues. These women proved difficult to locate, because the Black population in Tucson is residentially dispersed geographically across the city. Therefore, I used a snowball sampling technique to identify and subsequently approach them. This strategy involved asking older Black women that I knew to make announcements and hand out flyers in their churches, civic, social and cultural activities and events, and to give me names and phone numbers of other older Black women they knew who might be interested in participating in my study. (See [Appendix C- Recruitment Flyers](#)).

The sample pool for this study can best be characterized as a purposeful sample. I collected over 125 names and phone numbers of women who were identified as African American from key informants and from other women who attended health conferences, cultural and community events where I had given a presentation about my proposed research. Each woman who indicated an interest in my study from these venues were required to fill out a "permission to call" card on which she noted her name, phone

number, the best time for me to call, her age and racial identity. This data allowed me to separate out those women who did not meet the criteria (i.e. being African American and over 40 years old) for the study before contacting them.

Seventy-five (62%) of the 125 Black women who completed the form met the criteria for participation in my study. I contacted these women via telephone for recruitment as participants. I explained the nature of the study to each woman that I spoke with, including the main issues of interest, and the number of times I would like to speak with her. Fifteen (20%) of the women declined to participate further before the administration of the pre-screener interview stating that they were now too busy or no longer interested. Of the remaining 60 women, all of them were contacted and completed the pre-screener questionnaire on the phone. Questions in my pre-screening interviews were designed to collect basic demographic data on each woman's current occupation and marital status, date of birth, length of time in Tucson, employment status and educational level and background data on each woman's preventive exam history and family history for hypertension, breast cancer, cervical cancer, and diabetes, including her self-assessment of her present health status, and perceptions of racism in healthcare. (See [Appendix D](#)- Pre-Screener Tool).

Following the collection of screener data, 25 women declined to participate further in face to face interviews due to time constraints or non-interest at the time, although these women expressed support of my study. After completing the screener, 35 women agreed to participate fully in the study, and an in-depth interview was scheduled. As with the key informant pool, a short survey (quantitative) was administered at the time



of the interview. The survey included questions on demographic information, patterns of health behavior, and preventive health care practices.

The interview guide was developed based on emergent issues from key informant and healthcare provider interviews, and existing research. This guide was composed of five sections with questions in each section including: (1) Background (including basic demographic data); (2) Health Access & Utilization (including data on seeking and utilizing mammograms, pap exams, and physicals) and, (3) Social Support & Family (including data on their networks of support and the sharing and utilization of funds of knowledge that reference risk, health history and healthcare experiences, perceptions and expectations); (4) the role of the Black Community in health behavior (including the ethos of Black culture, advocacy, the role of church, spirituality and the connectivity of the mind, body, spirit perspective and its significance to their health behavior) and, (5) Cultural Vignettes (perceptions of and responses to cultural/racial difference). Within each section there were questions designed to collect data on lived experience, as well as questions designed to explore their expectations, and beliefs about "race," "being" Black and the health care system. (See Appendix E- Sample Interview Guide).

Each woman was interviewed one time. Interviews were conducted in women's homes and usually lasted about 2.0 hours. At the close of each interview, I asked each woman if she had any questions for me. If she did, I answered them, and these discussions were often very insightful and produced additional rich narratives. At a later date, I sent each woman in the study a letter of thanks for her participation, stressing the

importance of her contribution toward understanding the patterns of health behavior among older Black women.

Only a small number of the women in my study were indigenous residents of the state with connecting ties generationally to the Black migration west- -only 5 informants had lived their entire lives in Tucson, Arizona. Interestingly, most of the women in the study had moved to Tucson coming from large metropolitan cities as young adults. The data collected and analyzed on the length of time in Tucson indicated that women had resided in Tucson for an average of thirty years with the least amount of time being two years and the longest amount of time being 47 years.

None of the study participants were paid for participation in this study. All of the study participants were recruited over a period of 15 months. All interviews were tape recorded and conducted at places convenient to the participants and later transcribed verbatim. The Institutional Review Board (IRB) at the University of Arizona approved all project materials. Informed consent was obtained from each participant.

### Discussion Groups

Two small group discussions were also conducted among older African American women. Participants in these groups were recruited through the use of strategies similar to those used in recruiting the overall sample. I also contacted women who had approached me after I had given a presentation, who had indicated a willingness to help with my study and I also re-contacted some of the women who had been unable to schedule a face to face interview initially, but who had completed the telephone pre-screener and had indicated their support of my study and expressed a desire to participate

at a later date. None of the women that were recruited for discussion groups had been interviewed previously.

Discussion groups were intentionally kept small, because of the sensitive nature of the topics to be discussed and because I wanted the women to speak freely with each other in a setting that was supportive and non-judgmental (Bernard, 1995, 2000; Morgan, 1992). The first group discussion had 4 participants and the second had 3 participants. There were two moderators for the group discussions, Dr. Sheila Parker, from the College of Public Health and myself. Neither of us knew these women personally, although it was possible that some of the women may have heard about our previous collaborative research in the community. Furthermore, it is possible that the women in these groups knew of each other through an extended family member or through their participation in civic, social, cultural, or church activities.

The women were encouraged through conversational strategies to be informal and flexible and to offer critiques on a variety of topics around "race", health behavior and healthcare that were framed within open-ended questions. The questions for the group discussions were formatted with similar topical focuses that were used with key informant and sample pools, including, trust and healthcare, experiences, perceptions and expectations of racial profiling or racial discrimination in the healthcare encounters, funds of knowledge among older Black women, and self-advocacy.

The discussion groups were held on the weekends in a conference room at the University of Arizona. Each group lasted about one hour. Participants were not

compensated for their time, although we did provide beverages and snacks. (See Appendix F- Small Group Discussion Guide).

Ms. Carla, Ms. Darla and Ms. Wiletta

Overall, 50 older Black women (aged 40 and older) participated in this research study as part of the pool of key informants, sample, and discussion groups. As a cohort of older Black women, the youngest woman in my study was born in 1963 and the oldest woman was born in 1908. Therefore, as individuals and as members of this age, racial, and gender group, many of their perspectives reflect a shared status of "being" Black and female and the long-term consequences of living in a Black body in a racist society. Thus, they form a representative cohort of survivorship, since many of the women were born and raised during a time when the rule of separate and equal was enforced by Jim Crow laws and limited opportunities not only in health care, but in such diverse areas as education, housing and employment, whether these women lived in the North or the South.

In the U.S., African American identity is typically "measured by skin color and a handful of other easily visible physical characteristics...having a racial [identity] status is an important risk marker for exposure to racial bias which could be one of the main etiological factors in producing 'race' differences in morbidity and mortality ( LaVeist, 2000, p. 217). Locating the voices of the older Black women in my study required that I consider theoretical and applied issues related to a study of the interdependence and interrelatedness of "race" and cultural difference to patterns of health behavior among this population and the delivery of equitable care to this population. In the chapters that

follow, I reference data from all of the older Black women who participated in my study but will particularly highlight three women whose observations were poignant and particularly insightful on many issues. They are Ms. Carla, Ms. Darla and Ms. Wiletta.

Ms. Carla is a lively, energetic, "seasoned" woman in her mid 60s who has lived in the Tucson area for over 45 years. She was born in Harlem, New York to a single mother and raised by members of her extended family when her mother died. She grew to adulthood, traveled the world as a part of a career military family and is retired from military service herself. Ms. Carla has held employment in both the public and private sectors. She arrived in Tucson in the early 1960s due to the relocation of her husband's employment in the gas/electric power industry. Although, she has held a variety of employment positions, ranging from U.S. postal worker to a customer service clerk at a call center, it is her work as a practicing midwife and public health nurse practitioner and instructor before becoming a school administrator that made her such a valuable narrator, particularly, in relation to the subtle manner in which racial bias exists. In later years, as an administrator in the public school system in Tucson, she initiated strategies for life-skills learning that focused on a what she calls "processes of success" programs for young Black females struggling in the public school system. She proudly stated that "they used to call it special education, but after they hired me they learned to call it "exceptional education". In her discussions in our interview about her commitment to the "process" when she was teaching high school, she said that she would tell her students "even if you know that the teacher is prejudiced you still speak to them, hand in your homework anyway, but make sure everybody sees you hand in your homework." In her capacity as

an advisor, she would often be faced with situations that were presented to her from Black students that subtly reflected racial bias. She recalled for example, that

We had an incident with a student who claimed [the] African ancestry of Black people in America and the teacher said 'it was a myth,' you know, anyway the students insisted that the teacher was in error and needed new knowledge. So we gave them [the student] the strategies to support [their argument] I told them to 'Go get your bibliography, give the teacher [a frame of] reference...

At the time of our interview, she was retiring after a long career in the local public school system as an administrator, and also from the State of Arizona as a public health educator and excited about beginning a new business venture and working on an business degree.

Ms. Darla is in her early 50s and is very active in the social and civic community of Tucson. She has lived in the state of Arizona almost all of her life, moving from the California coast to a small town in the White Mountains of Arizona in the early 1950s. This town was unique because at the time she lived there its primary residents were the indigenous White Mountain Apache and migrant African American agricultural workers. As a community, according to her recollection it was common place for both ethnic groups to create relationships through intermarriage, creating networks of support in which ideas about health and well being were shared and co-mingled. Ms. Darla later moved with her own family to Tucson and has been here for over 40 years. Contributions of her parents, grandparents and great-grandparents have been part of her Black experience were important in the construction on a history of the Black presence in Tucson documented in the archives of the Arizona Historical Society.

She is currently employed as a community service worker for programs administered by the Federal Government and the City of Tucson. As a young woman

raising her family, she worked in the agricultural industry with her parents and later with her husband, in many rural areas around the state, cultivating, growing and harvesting cotton and pecans. She recalls that when she had to attend school, she traveled by bus round-trip, 30-40 miles everyday. As a young married woman, and part of a large extended family, she recalls negotiating the health care system not only for herself, but also for members of her immediate and extended family, and friend networks. Ms. Darla has been in charge of making appointments, following up with healthcare providers and providing health information for her immediate family and extensive kin network which included over 14 people (five of them her own children), and ten of them females, including her mother, and grandmother. Currently she is active in a social justice church ministry, and many social, civic and cultural organizations in the Tucson metropolitan area.

Ms. Wiletta, as one of the younger women in my study, is in her late 40s and moved to the Tucson area over 20 years ago, as a young adult relocating from the Midwest. She says that she grew up as one of many children in a place that she calls "very southern" and very Black in its cultural ethos. For example, she states of her hometown environment, "there was a need for family [biological and extended] ...coming and staying together, staying close...and being all together...." Consequently, although she and her sibling's have maintained separate residences in the same city since they became adults, all seven of them with their families continue to live within a 2-3-block radius of each other. After many years in the retail sales and customer service industry, she is currently self-employed in a health care oriented venture for older adults.

She also coordinates many activities in the Tucson area that focus on the Black experience. She considers herself an educator and a cultural activist in the visual and performing arts. Ms. Wiletta's observations are particularly acute with reference to "being" Black, "race" and healthcare seeking, access and utilization.

### Healthcare Providers

Eight healthcare providers were interviewed to collect (qualitative) secondary data focusing on their insights when interacting with older Black women in healthcare settings, and to collect background perspectives on the gaps in health education, delivery of health care and health behavior. The healthcare providers or health educators who were interviewed (n = 8) had to be working in either public or private healthcare settings frequented by African American women. A snowball sampling technique was used to identify, approach and subsequently recruit these providers. Each participant was previously identified from various public/private and community health networks in Tucson and referrals from key informants. Racial/ethnic identity, age or gender was not part of the criteria for healthcare providers to participate in this study. It should be noted that although gender was not a requirement for their participation, all of the healthcare providers/health educators were female. In addition, although race/ethnic identity was not a requirement for their participation three were Mexican-American, five were White.

The healthcare providers selected for participation were identified because they had insights, observations and experiences from within the health care system. Of the eight chosen, four had popular and active practices that were frequented by members of the African American community; for example, two were physicians whose training and



practice focused on General Medicine and Women's Health, and two were nurse practitioners whose training and practice focused on Women's Health and Prevention. These participants indicated that they had interacted with older Black women in both public and private healthcare settings (doctor's offices /clinics and screening program sites) in the Tucson area for many years.

The remaining four healthcare providers interacted with older Black women and the African American community through health education, promotion and health intervention agendas. One of the healthcare providers in this group is a director of a health administration and policy office, two others were with the state public health department, and one was the director of a grassroots local health coalition supported by Pima County that focuses on African American health and wellness. All of the healthcare providers indicated that they had extensively utilized both epidemiological and public health data on African Americans, women, screening programs, health disparities and health status in their delivery of care, research, teaching, or health promotion agendas.

Healthcare providers were contacted by telephone to assess their interest in participation, and then an in-depth interview was scheduled. The interview guide used with local healthcare providers included questions on: (a) providers' perceptions of the health seeking, accessing and utilizing behavior patterns of older African American women; (b) what is considered appropriate and/or inappropriate to discuss with their patients, and why; (c) changes in the service delivery of healthcare to racial/ethnic sub-population groups over time; and (d) the degree of perceived effectiveness of local health

intervention and promotion efforts for preventive screening programs that target older Black women (See [Appendix G-Healthcare Providers Interview Guide](#)).

Other questions were also posed on perceived stereotypes and biases within the health care system and observations on the style and manner of interactions and communications with Black women in the healthcare settings where they worked. However, several of them redirected their responses to focus on identifying factors, which might serve to improve adherence to prevention and treatment guidelines. Interviews took approximately one hour and were conducted in a quiet setting, either during lunch hours or after work as deemed appropriate by the participant.

Initially, I saw it as quite useful to draw on a variety of perspectives from different experts in the areas of the health care area so as to understand and gain insights into experiences of healthcare providers serving Black women and their perceptions of this populations utilization of diagnostic tests for breast and cervical cancer. However, once I transcribed and coded this body of data I found the all of the healthcare providers interviewed had insights that were more generally suited to inform my discussions on existing health disparities among older Black women as a population. Particularly, given the shift in the focus of my dissertation as I began to interpret and analysis the coded data. My study shifted, for example, from an examination of the health behavior of older Black women with respect to diagnostic testing , i.e., whether or not older Black women utilized pap exams and mammograms to detect breast and cervical cancer ; evolving into an exploration of their insights on the significance of "race" and the meaning of "being" Black including their view of the health care system, in which I could identify their

beliefs, expectations and perceptions about these factors and how their patterns of health behavior are influenced by their own ideas using the lens of diagnostic tests, such as mammograms and pap exams. Thus, my study now became focused on the experiences and expectations of older Black women when utilizing healthcare settings, in their clinical encounters with healthcare providers and with support staff as part of their perception of a health care system. As a result healthcare provider interviews and discussion group participants insights are used similarly. Thus the interview data collected from healthcare providers is minimally dispersed throughout my dissertation.

#### QUALITATIVE AND QUANTITATIVE DATA ANALYSIS

##### Coding of Qualitative Data

Seventy-five (75%) percent of the data collected during the two-year study period (March 2002 - March 2004) is qualitative. Over this time period all interviews were tape recorded and later transcribed verbatim. The transcribed interviews were coded and analyzed using ATLAS.TI 4.2, which is a specialized "relational database manager" software program package for the management and analysis of qualitative data.

The code book for this study was created using four sources: (a) the semi-structured open ended questions used in interviewing, (b) a review of the literature that specifically discussed healthcare, health disparities, health status, health behavior, racism, "race" and African Americans, and older Black women, (c) my initial inventory review of the transcribed data in which I made notes and highlighted text passages as categories for coding, and (d) field notes taken during the collection of the data and observations made during the transcription of the raw data.

Through the use of a qualitative data software program, I was able to code chunks of text as quotations, and build networks of codes, code families, and produce reports and diagrams on how these codes might be related to one another. All transcripts and notes were utilized in the analysis and interpretation of the data. Emergent themes and issues were highlighted. I identified those voices and situated the contexts, circumstances and situations in which they occurred and were prominent. Key metaphors and terms, such as, "come to Jesus talk," that participants utilized to organize and frame their experiences were further identified. As I expected, I found the interviews among many of the older Black women and a few of the healthcare providers populated by multiple voices. These perspectives transcended the original idea of the study, which was to examine health seeking and utilizing behavior with screening exams for breast and cervical cancer. The narratives that were collected in these interviews seemed to engage and tie in ideas about "race" and "being" Black to subjective experiences and expectations of healthcare encounters. These ideas were thus incorporated into my data analysis, and largely form the basis of my ethnographic analysis.

#### Quantitative Data: Demographics, Health Status & Behavior among Older Black women

Twenty-five (25%) percent of the data collected during the study period is quantitative. Participants were working, semi-retired professionals, or were unemployed with income. They span all income groupings, although most of them were considered low to middle/high income status. Over one-half of the women were married and the remaining participants listed their marital status as single whether they were widowed, divorced or never married. Of the fifty older Black women in this study, over one-half

(64%) were "employed," defined as skilled/professional, (e.g. technicians, administrators, educators). Some women were self-employed, owning their own businesses (e.g. real estate, accounting firms or home health services). Ten (20%) of the women were retired from one career and were either starting new careers or returning to school to prepare for a new career. Eight (16%) women were retired and not employed, although some had other sources of income (see endnote on their Responses to "unemployed"). In terms of education, 13 (26%) of women had complete high school; 18 (36%) had either a two-year degree or had attended some college; 4 (8%) had technical or trade certifications. Ten (20%) had received a college degree and 3 (6%) had received their MA, and 2 women (4%) had obtained their Ph.D. The analysis of the health insurance status among these women indicates that 48 (96%) of the women had health insurance, either through their current employment, retirement, or as a self-carrier of health insurance.

#### Self-Report: Source of Key Income

Analysis of "key income person" data indicated that 21 (42%) of these women were the sole providers of their household. Another 20 (40%) of these women had multiple sources of income, with income derived from part-time employment, spouse, or live-in partners, or extended kin. Only 6 (12 %) of the women received some assistance from their adult children (who did not live in the household) in addition to their retirement funds. Three women (6 %) declined to respond to the "key income" query, stating that it "was nobody's business."

Table 1. Key Income Person (Source of Key Income)

Self Only	42%	Sole key income provider
Self with Husband Income Supplements	40%	Many of the women in this study were in two and sometimes three sources of key income categories, receiving funds from employment/self employment/ second careers, with spouse incomes perceived as supplemental
Both Equal Sources	2%	Both self and husband income considered equal.
Others in Household	12%	Some of the women received assistance from others living in household( i.e., Adult Child living with older parent). Some those women also had funds from investments/retirement annuities.
Declined To Answer Source of Key Income	6%	Other women refused outright to answer this question "nobody's business" "do you mean who brings in the most money? I am not going to tell you that".

### Self-Report: Health Status

Analysis of the self-reported health status data collected from pre-screening interviews among the older Black women in 2002/2003 indicated that 26 women rated their health as good (52%), followed by 15 (30%) who rated their health status as excellent. Only 9 (18%) rated their health status as fair. Approximately 28% (n=14) of the women reported diagnosis/treatment of a serious illness. These illnesses ranged from a tubal pregnancy to hypertension, sickle cell anemia and diabetes to a brain aneurysm and a breast biopsy. Of the 28% (n=14) who reported what they felt to be a serious illness, the illnesses included: Diabetes (n=4) High Blood Pressure (n=4);Hypertension

(n=1); Brain Aneurysm (n=1); Glaucoma (n=1); Sickle Cell Anemia (n=1); Tubal Pregnancy (n=1), and Breast Biopsy (n=1).

#### Self-Report: Mammogram and Pap Smear Data

Data was collected on mammograms and pap exams conducted during the two years of the study. Almost all of the older Black women in this study were compliant, with less than five of them having been referred for further testing. It is interesting to note that among these women with the exception of one woman who never had a mammogram and 4 (8%) of the women who had not had either screening exam in five years, almost all (98%, and 92% respectively), had a mammography and/or pap screening exam within the past two years. In addition, three (6%) of the women who had had an exam had been referred for further testing and all had complied. Thus, despite much of the national literature that suggests that Black women over 40 years of age are not being screened, diagnosed, and referred (regardless of their insurance status / SEP). The older Black women in my study were tested and were compliant with requests for additional tests. It is also noteworthy, that none of the women assessed their health status as poor, despite the [ADHHS] data discussed in Chapter two on the health status of Blacks in which Blacks were ranked the highest for disparities in health across at least seventy-one health status indicators.

Although the vast majority of participants were compliant with tests, having had preventive screening over one-half (52%) of the women in the study reported that they had either been racially profiled or had experienced gendered racial bias in their most recent healthcare encounter, whether it was a screening exam or not. Negative

experiences such as these may have certainly influenced whether the women returned to that healthcare provider/setting for follow-up. Nine (18%) women reported that they were not sure if they had been profiled or discriminated against, indicating that it was difficult to determine whether the behavior was due to racial bias or "lack of home training," e.g., just generalized rude behavior. The remaining fifteen women (30%) said they had not experienced racial profiling or bias or discrimination in their most recent healthcare encounter. Thus, in this small sample, 70% of participants felt or suspected that they had been racially profiled in their most recent healthcare encounter.

#### Quantitative Data: Conference Questionnaire

In addition to the in-depth interviews with women and healthcare providers, I also administered a survey questionnaire to women attending an annual health conference held for African American women on preventive health care and screening programs. Many of the areas explored in this survey questionnaire had been identified as key concepts to explore through earlier ethnographic research. Survey questions focused on use of preventive screening exams (e.g., mammograms, pap and physical exams), as well as, experiences with the health care system including questions on their perceptions of racial profiling, such as stereotyping or different treatment as a consequence of "race." Issues including cost and accessibility of health care, utilization of networks of support as a fund of knowledge, beliefs and attitudes about healthcare were also included.

Surveys were administered in 2002 and again in 2004 to Black women attending these statewide health conferences. Each woman was given a questionnaire at the conference registration table and were reminded to fill them out with public address



announcements. The 18-item questionnaire utilized in Year 1 (2002) proved to be too long for women to answer and the response rate was low (15%). Consequently, in Year 2 (2004), the questionnaire was shortened to include only seven items (including questions used in Year 1) and the response rate was much better (50%). That year over 200 Black women were conference attendees. All women were given a questionnaire, and approximately 100 were returned. Of these, 72 met the study criteria. (See Appendix H-Conference Questionnaire).

Responses described here include responses from all women (over 40 years of age) who met the study criteria in 2004. The mean age of respondents was 42 years. Of the 72 women, only one woman did not have health insurance and reported her health status as poor. Five women (6 %) self-reported their health status as excellent, 58 women (80%) as good, and 8 (11%) as fair. In terms of screening exams (95%) of the women had a pap exam and 84% of the women had a mammogram within the last two years prior to 2004. Two of the women had been referred for further cervical screenings, with which they complied. Notably, only 4 of the 72 women had not been screened in the past five years and 10 (13%) had never had either a pap or a mammogram exam.

In the course of these women overall rating their most recent preventive health exam (mammogram, pap smear or physical) experience these women were also asked two other questions: a.) Have you ever felt discriminated against in a healthcare setting or clinical encounter (a doctor's office, clinic, etc) or that the doctor, the nurse or support staff treated you differently because of your race? b.) Have you ever felt like you were

being stereotyped when you walked in the door of a health care setting (doctor's office, clinic, etc)?

In response to those specific questions asked of the 72 women, it is interesting to note that when they recalled their most recent mammogram/pap exam a significant number (n = 49) of the women (68%) said that they believed that they had been treated differently because of their "race." Yet, only 31% of those same women (n=23) would also agree that they had felt stereotyped in their first contact when walking in door. The other women left question (b.) blank. The different values that these women have given to their perceptions on different meaning of being stereotyped and receiving different treatment that is tied to "race" is compelling because this may suggest that stereotyping is not being conflated with different racial treatment because there is no signifier of "racial" profiling or that these women see stereotyping as addressing much broader contexts than just "being" Black.

#### PERSPECTIVES ON "BEING" A PUBLIC ANTHROPOLOGIST

Older Black women are generally a population for whom refusal rates for participation in research studies tend to be high (Herzog & Rodgers, 1982; Markides et al., 1990; Patrick et al., 1998; Levkoff et al., 2000). Noting their skepticism and mistrust of health research due to past abuses and exploitations (Krieger, 1987,2000; Swanson et al., 1995; Harris et al., 1996; Mooreman et al., 1999; Jackson, 2002; and Vessey, 2002). As a Black woman who is keenly aware of these historical realities, I was well aware of the meanings of "being Black" within the cultural ethos of the Black experience, prior to beginning this study. In fact I was first concerned about obtaining a sample for my

research. I recognized that obtaining the trust of individual older Black women and the Black community would be critical to setting up and conducting the study over time. As noted by Patrick et al., (1998) "given the historical events surrounding the role of research in the African American community...[anthropologists] investigators may be required to counter attitudes of fear and mistrust...(p.296). Fortunately, the Black community in Tucson is quite small, and for several years, I have been an actively participated in many social, church, civic, and cultural activities here and in Phoenix. As a long-time community member for many years, I have raised my children here, and as a woman over 40 years of age, I am also a member of the age and gender group whom I studied.

#### The Ethos of Community Membership is about Relationships

Many people in the community are aware that I have a keen interest in issues of health and well being among Black women. In addition, early in my career, as an undergraduate at the University of Arizona, I had the opportunity to engage in a research project conducted among African American female adolescents in Tucson (Parker, et al., 1995). During that time, I established a rapport with many of the mothers and grandmothers of those young women. The Tucson (Black) community recognizes me as someone who is "at the university" in "anthropology" and teaching in "Black Studies," as one of "their own," as a representative.

Although I was certainly accepted as a trusted member of the community and many of the women who agreed to participate voiced an eagerness to "tell it like it is," I did encounter some problems with recruitment of the sample and some reluctance from

participants in responding to interview questions about "sources of income." This speaks directly to issues of mistrust and a cultural reluctance for letting "other folks know too much their business." Among African Americans, knowing too much about another person's business and talking about it often reflects "no home training." Consequently, despite the general willingness of older Black women to participate in my research study, some of my interview questions, especially those questions posed on their income might have been seen as "my" lack of home training. For example, even though they willingly self-reported their employment, retirement or unemployed status to me, when I probed further and asked them "would you consider (that self-reported status) a major source of your income?" I evoked responses from many of the women such as, "I am not going to answer that!" "Why do you want / need to know that?" and " What are you going to do with that [kind of information]?" I suspect that probing further was seen as me asking for too much of their business. After encountering resistance to this question, I modified my approach to minimize participant's distress by framing the question as "who would be considered the key income person in the household?" The particular reframing of this question was culturally acceptable, because rather than asking directly about the woman's "source of income," which was seen as me trying to "get in their business" or trying to find out *where* their money came from, the reframed question was focused on "who" was the key provider of income and indirectly indicate is the source of their income.

This experience proved to be one of the many self-reflexive moments that I encountered while doing fieldwork, serving as a reminder of my role as both an insider and an outsider in this community. As part of a lived experience in a Black "racialized"

body, having a "researcher" asking for details about one's life (particularly about income) and recording those responses on tape, generated suspicion (based on a specific history of mistrust). Despite the fact that they knew and trusted me, several women questioned me about my intentions when I asked about money. Interestingly, two of my sample participants requested that I return a copy of the (verbatim) transcribed interview and the original tape of their interview, which I did.

Thus, although I was certainly accepted by the community members, I was not beyond suspicion by a few; after all, I am also a representative of a major university (a non-Black entity). I found this to be especially true during the recruitment phase of my study. For example, one woman whom I wanted to recruit for participation in my study was a key stakeholder and a community resource in this community on issues of social justice and Black women's rights in Tucson. Ms. Carla was over 60 years of age, and had in the course of her life span, spoken with "people from universities who are always asking questions and doing surveys about Blacks." She believed that the information obtained through these measures was more often than not misinterpreted or either flagrantly misused or misreported in "research" reports about Blacks, and as an example she mentioned that she recalled the damage done by the "Moynihan Report" of the 1960's" (see Moynihan, 1965, "The Negro Family"). Although I wanted her to participate in my study as I valued the insights she might have about "being" Black, patterns of health behavior, and more broadly about the local community, she was particularly resistant to being part of the sample. Each time we met at civic, social or community functions, she would approach me with very direct questions about the depth,

breadth, and scope of the study. I engaged her in discussions of health disparities among older Black women, the timeliness of my research, and my commitment to the data to not only reflect the perspectives of older African American women but to be of use to the community. Eventually, Ms. Carla contacted me and agreed to participate in my study. At the close of our interview she noted:

This is the first time I've been able to ... I'd like to be able to feel like, okay, this is empowering, or somewhere along the lines it will make a difference ... you know when I saw the first pieces of paper passed out there I was like, Wow! ... What's Colette doing?... It felt good, you know, it felt necessary, and it felt like I wonder if this is going to be what I thought it was going to be and it is ...by the questions you've asked me because I think those are important questions and I don't think there were any questions you asked me where I felt like, well, why'd you ask me that? That's something I have to say about your questions. You know how you go through different things, I felt like it was about the subject. That it was what we're talking about and it wasn't about other things that I felt [were] unnecessary.

Thus, my familiarity as a community member and my "racial" identity proved to be important assets in my fieldwork experience. Not only did this participant (and others) accept me, but I also believe that "being Black" helped me to identify questions and issues for my interviews that put the women at ease. "Being" Black and being part of the Tucson community allowed me to be seen as a woman with a strong ethnic identity, and a sense of community. It was understood that I would not ask inappropriate questions or report findings that could be construed as culturally insensitive. Although few women said so directly, by their honest responses I came to feel that they understood that I had the capacity to understand what they were telling me. This facilitated rapport.

Within the community my study was often referred to as "Colette's Health Study" to indicate to others that it was me and not someone else who was doing the research.

That is, the researcher was not someone "White" from the university who was coming in as an outsider to do this research among older Black women in the community. Based on the earlier experience with the income question as I built the bonds of further trust within this community of Black women, I had to remain aware of the tension as both a researcher and as an insider that comes with a certain level of familiarity. I was, particularly, concerned about maintaining my objectivity when documenting women's narratives. The duality of my roles (as insider & researcher) may have made it easier for me to *assume* that I understood what the women meant when they referenced a specific belief or cultural practice as part of the ethos of Black culture, especially when they said things like "you know what I mean..." and then they would stop talking. I would immediately follow their responses with a probe, such as, "I hear what you're saying, girl, but could you break it down for me so I get it right?" Or, I would say, "I know what you're saying, but you will need to say what you mean, because the tape recorder doesn't know!" Although, strategies such as these might have made me appear like some sort of "cultural idiot" to older Black women, I felt it was important to get women to articulate fully what they meant rather than tacitly assuming that I understood what they were saying (or not saying) simply because I am a Black woman.

And while, there remained a certain tension between being both researcher and insider within my study, as an anthropologist (who happens to be Black, over 40 and female), I did not see these roles as oppositional or contradictory. My training in anthropology has taught me that engaging in good quality ethnographic research is not a dispassionate, impersonal third party encounter; rather, I have been taught to consider

myself to be an instrument of my qualitative inquiry. Therefore, tensions that may have been created in embracing these dual roles were construction sites for the production of new understandings about "being" Black. Good work in anthropology requires that the personal, affective experiences of the researcher be considered self-reflexive often leading to new experiences. I believe that my personal [self ] awareness, ownership of my perspective, and my sociocultural consciousness are to be understood as assets in both my fieldwork, my analysis and interpretation of the data (Bernard, 1995, 2000; Obbo, 1997; Vaz, 1997; Patton, 2002).

#### SUMMARY

My research does not pretend to be objective or apolitical. It is designed to share a global vision of sociocultural transformation, equity and justice. Moreover, I have tried to disrupt the taken-for-granted assumptions about "race," and "being" Black, and patterns of health behavior. Therefore, a civil rights agenda is also part of my research design; in fact, a civil rights agenda is already implied because it is embedded in the preventive exams which as well shall see is a highly racialized topic among older Black women. Furthermore, the design of and the methodology chosen for this research builds on the perspectives of Pan Africanist anthropologists who either embrace womanism or feminism (see Moore, 1988; Smedley, 1993, 1998, 2001; Harrison, 1997; Cole, 2000; McClaurin, 2001; Slocum, 2001; Shaw, 2001 and Hutchinson, 2005). In this study, I have combined a constellation of theories into a social constructionist, Black womanist perspective of anthropology with the traditions of Black intellectual thought in anthropology following in the footsteps of Carol Stack (1974), Loudell Snow (1993),



Leith Mullings (1997), Claudia Gollop (1997) and many others who have used ethnography to offer an insightful understanding of Black women struggling to survive in a hostile environment. To this end, I explore and interpret the various twists, and turns the "race" concept has taken overtime and its impact on the health and well being of Black women. I examine what forces and ideas contributed to the construction of "race," and what effects that construction has had on the patterning of health behavior among older African American women.

My purpose has been to understand how these consequences, conditions and constructions have been woven into those women's expectations, perceptions, and beliefs of preventive health care. These anthropological perspectives may serve as critiques and corrections to those approaches that overlook or minimize the effects of "race" and the attitudes and beliefs that are tied to "being" Black that impact health behavior and health care. The insights shared in this study from the older Black women with contributions from healthcare providers point clearly to the social construction of "race;" however, these insights also must serve to remind us that "race" matters because social facts are also part of an ideology and must always be interpreted; they are never transparent, and hardly ever unchanging because of their construction as categories of the mind and categories of power.

To this end, I next turn to a presentation of the ethnographic perspectives of older Black women as participants in my study discussing their expectations when "being" Black and seeking, accessing and utilizing preventive healthcare services, including their experiences with and perceptions and beliefs on the patterns of practice among healthcare

providers and in healthcare settings with respect to "race." The remaining chapters will outline the difficult and challenging situations faced by older Black women. The reader will notice that although I include a variety of narratives from the other older Black women in my study I will return again and again to the voices of three principal speakers, ( Ms. Darla, Ms. Carolyn and Ms. Wiletta). They are highlighted because of the richness of their narratives, the diversity of their backgrounds, and the wide variety of their health encounter experiences.

#### IV. OBJECTIFICATION AND THE BLACK EXPERIENCE

I am invisible, understand simply because people refuse to see me...because of a particular disposition of the eyes of those with whom I come in contact. A matter of the construction of their inner eyes " (Ralph Ellison, 1952, 1989)

##### OVERVIEW

What older Black women expect during healthcare encounters is influenced by their own past experiences with the health care system as well as the stories of others shared among friends and family members. As recent as 1965, Blacks in the U.S., were forced to use segregated social, public, and governmental establishments, including hospitals, doctor's offices, and health care centers. Health care facilities were labeled "Whites Only" "Colored." As noted by Morris and Herring (2000):

Separate facilities forever reminded Blacks of their lowly status by their wretched conditions, which contrasted sharply with the well-kept facilities reserved for whites only. The "colored" and "white" only signs that dotted the buildings and public spaces expressed the reality of a racial system committed to the subjugation of Blacks and the denial of their human dignity and self-respect...the social machinery had been placed around the necks of African Americans, sealing their fate at the bottom of American society. (p. 207)

Although the women I interviewed were born and came of age in a range of geographic, cultural and historical contexts, they shared a common understanding of racial bias and struggle for equal rights. They shared a social memory of the Jim Crow years of segregation, the pre/post Civil Rights Movement (CRM) and the Black Power Movement (BPM). These memories was passed on and commented upon, it was alive with feelings, and used as a fund of knowledge. Women recalled the past when they spoke of present forms of bias such as racial profiling.

### Racial Profiling

In this section, I describe how the women in my study have experienced racial profiling and gendered racial bias in a variety of social and cultural contexts, including healthcare settings. Several women noted their experiences of racial bias has changed little over their life course. Wherever they have lived they felt racial profiling was the norm. As noted by Carroll (1998), racial profiling is often "mundane and extreme" because it occurs within "an environment in which [racial bias] and subtle oppression are omnipresent, constantly continuing, and mundane; it is an atmosphere in which African Americans must daily undergo the 'micro-aggressions' that this environment breeds"(p.2). The everydayness of differential treatment experienced by Black women was pervasive in many parts of their lives. As one woman, Ms. Darla, pointed out racial bias is experienced by Blacks regularly, such as, when "White cashiers don't put money in your hand because they do not want to touch a Black person."

Many of the women in this study seemed to simultaneously anticipate and interpret the behavior of some Whites as indicative of racial bias. For example, one of my participant's described to me a racist incident that occurred to her during a recent trip to a local shopping mall to arrange for a family portrait. A seemingly mundane comment escalated into a war of words about "doing Black skin right":

I've had things said to me by White people that have never been said to me by any other kinds of people. For example, a photographer once, who was advertising family pictures and my sister was coming to visit, and I thought we could get a family portrait, so I said to him, 'How much?' He says, 'the price is reasonable, I am top notch, and I can do Black skin.' I said, "Excuse me, I don't understand." And he says to me, 'a lot of photographers cannot do Black skin and I can do Black skin very well' I said, 'do you do Black dresses and Black shoes?' He said, 'yeah' so I said, 'is the skin any different than that?' 'I don't understand

you telling me that you can do Black skin.' 'Where did that come from?' If you're a photographer and you cannot do Black skin, there is something wrong with you.' And he says, 'No, I am just telling you...'

Ms. Darla is responding to the privileging of Whiteness and the stigmatization of Blackness in her responses to the photographer. Blackness was not seen as the norm of skin color on the part of the photographer, thus, an "extra effort" has to be taken in order to get "Black skin right." To Black women, these kinds of interactions while seemingly mundane constitute important steps in a progress of "othering" that is not innocent or neutral. As Ms. Darla continued to talk about her experience with the photographer:

So I said to him, 'I'm not coming to you anyway', and he said 'Why?' 'Cause you've got all these portraits of White and Mexican people and no portraits of a Black family, so when you get one I'll come back and think about it..' Then he said, 'maybe you will be the first,' and I said, 'no, not me because I'm not sure you can do Black skin, now you have to prove it to me,' [laughter] and I left.

Although Ms. Darla's response was lightheartedly and offered with laughter, the significance of this interaction was that she experienced it as an intentional act of "othering" of her "being."

Another woman in my study Ms. Wiletta, similarly commented on an "othering" experience that occurred in a healthcare encounter with a White physician. As she recalled, she felt that she was not treated in the same way as a White mother might have been. From her perspective, it was not how she and her family members were treated because of "being" Black, but how they were not treated which was at the root of the problem:

I had a doctor once, when Marcus was a baby and he was really sick. He couldn't keep down any food, he was losing weight and I was real concerned and I couldn't get a fix on it [myself] so I took him in to this doctor and this doctor spent our exam time telling me what his involvement and commitment to the

Blacks and to the Black underprivileged community had been, rather than treating my son. He wanted to sit and shoot the breeze about his contributions to the Black community and my son was sick and needs attention!

In her experience with this healthcare provider during her son's illness, a time when she was very worried and had been seeking a diagnosis and treatment, what she found was a doctor who seemed to be more interested in legitimizing his work with Blacks than providing her with timely assistance. She saw this as a self-involved exercise in White guilt, at the expense of her time, her money, and her worry about her son. It is noteworthy that although this incident occurred over twenty-five years ago (Marcus is now 35), this experience was recalled as a vivid memory. Ms. Willetta considered this "well-meaning racial bias," not unlike Ms. Darla's experience when the photographer stated that "he is able to do Black skin." Both women also saw these as racial profiling incidents.

Although these divergent experiences are drawn from different realms of life, they both are examples of the everyday, mundane and extreme objectification of "being" Black.

Several other women related incidents of racial profiling and being ignored for service as a result of "being" Black. For example, Ms. Audrey owns a small magazine, and travels by rental car frequently in Arizona when she visits advertisers throughout the state. She shared her latest experience at a car rental counter at the airport, where she stood first in line, but felt that she was ignored for service because she was Black:

Well, when I first got there, I am standing in line and it's like I am totally not there. Then somebody else [a Non-Black person ] just walks up in front of me and the people at the counter say to them "have you been helped yet?" And I had to say to them, "Wait a minute, I think I'm here [first] and you haven't even acknowledged me." (2004)

Ms. Renee, who holds a master's degree and is a retired administrator from a school district in Tucson, similarly shared an experience in which she felt "talked down

to her." She said that she felt that they behaved this way because they had stereotyped her, " a lot of people stereotype us as being "ghetto" as soon as you walk into the door...Black people, and Black women in particular, you know... there's a condescending tone when they talk to you whether they are male or female if they're White."

"Being" a Black woman myself I know how and when I have been racially profiled, but not all Black women use the same cues to recognize these practices. In my research, I was interested in investigating more precisely how these women distinguished between behaviors indicative of "racial profiling" and "generalized rudeness." Ms Naomi, who has worked in the public sphere for many years and is presently a city employee, clarified this for me, noting:

When you walk into the room, you're stereotyped. If we'd ever experienced someone else being talked to in a calm manner, you know, and then someone else being talked to in a disrespectful matter, that's how I know. For instance if I'm in a grocery store or doctor's office when they say, 'Come this way, please' and you heard 'Come this way, please' three times and then when you get up it's not 'Come this way, please' you know, for me, I hear something different, I see the same pattern three times in a row, then all of a sudden that pattern was not used for me or in speaking to another African American, that's how I know if I hear something, I've seen it, I've felt it ...

Although difficult to transcribe and capture on paper, Ms. Naomi, talked about her feelings of being disregarded through tone inflections, gestures and hearing the difference in how White people and Black people were addressed in a simple statement, "Come this way, please." These daily indignities directed toward Black women persist as micro-aggressions that ultimately may turn into a quiet rage. I sense this rage daily in myself -- when I am consistently asked to produce more identification by a bank teller than non-

black customers in line in front of me. The subtleties of everyday, mundane encounters with racial bias, of being ignored for service, of being overtly stereotyped, and even sensing a fear of touching your hand because you are Black, are all provided as depictions of racial profiling.

Other women shared observations of being ignored for service in healthcare settings. They described feeling an "unwelcoming attitude," particularly when interacting with the support staff, such as receptionists in doctors' offices. Ms Darla explained, "you're stereotyped, you know, and that's usually the concept when you walk in the door." In the following comments, she expands her statement:

Colette, I'm talking about because you're Black, you know. I am Black, I walk in and you're acting like I'm really not anybody of any importance, so I'm [the receptionist or clerk] gonna have my back to you when I'm talking to you and I'm gonna talk to other people while I'm addressing you. My thought is, you don't want to be bothered with me. That's what I'm talking about.

Experiencing an "unwelcoming attitude" was often a pre-cursor to the expectation of "gendered racial bias" to occur when they actually saw the doctor. For many women, operationally, this meant that a "red flag" comes up, as Ms. Wiletta noted, this meant that "you're automatically gonna get less of whatever they had that would be the best [in that healthcare setting], and probably, means that you're gonna get more of whatever was considered less desirable." Other women commented on this idea as well:

...when you walk in the door you have that gender thing, cause you're a woman and then you're a Black woman so automatically [Whites] feel you're not educated and if you are educated, you're certainly not in the medical field. You are the last on their list, you don't get clear information and people don't talk to you as if you are intelligent enough to understand what is going on...



Women whom I interviewed were all extremely sensitive to the potential racial and gender bias, which appeared to occur seamlessly. Therefore, they would often monitor interactions carefully as they waited for an appointment in a doctor's office. Ms. Darla shared her people-watching observations:

I observe people when I go to the doctor's office and [Whites] get more attention. If the person [is Black] and they themselves did not say they were here first [for service] then they [support staff in healthcare settings] would go ahead and wait on them [the Whites] before those others [Blacks] that had been waiting...

Her observations lend substance to what other women noted earlier when discussing their feelings of being ignored when around Whites. Thus, invisibility or the "veil of race" becomes part of the everydayness of experience of "being" Black because your presence is often ignored, not acknowledged by Whites. This is also an aspect of profiling by "race" because some other group may be, pointedly acknowledged before you. Similarly, Ms. Wiletta also commented on the behavior of the support staff in her provider's office:

...stereotyping [is done] by the receptionist or the little nurses...or whatever they are...[influencing] who they interact with. Because you don't see many Blacks behind that counter you see Hispanics or Whites and their attitude [toward Blacks] is almost like '**Why are you here?**'

Although Ms. Wiletta is the kind of woman who will not allow herself be ignored in any setting, she still felt that the attitudes of "the receptionist or the little nurses" seem to be questioning her right to even be present in that setting.

Ms. Carlotta also shared her experiences of being addressed with what she calls an "attitude" which refers to the tone of voice used by Whites when speaking to Blacks:

You're being stereotyped because of the way the person says "Can I help you?" You have an uncomfortable kind of feeling. Especially since you're most of the

time the only Black person in there, you know, even with some of the other clients in the waiting room because of how they look at you, and you wonder, why are they staring at you?

Observations described by Ms. Darla, Ms. Wiletta and Ms. Carlotta resonated with the comments of other women I interviewed. As Ms. Renee noted "I've heard of it happening to Black people...and I know that it has happened on several different occasions in my family...over the years...more than once." Importantly, these type of disquieting events are shared among families, fostering expectations of racial bias in particular settings.

Ms. Yolanda also described how she felt when she had gone for a mammogram:

I believe that when you walk into a place or you [receptionist in the doctor's office] call us [Black women] into a place, you know, I don't feel that I'm supposed to be there, so I don't feel welcome [because] you talk to me real fast, very short and with no sympathy, not that I need your sympathy...but some concern that I'm coming in...I don't think that they [healthcare providers or support staff] care about the [other] cultures coming in...

In her comment, Ms. Yolanda is referring to the fact that after she had received a health promotion notice in the mail and a phone call reminder for her mammogram, she took a proactive step in making her appointment and showed up thirty minutes ahead of time as requested. Despite this, once she came to the office, she felt ignored. Her past memories of medical encounters were reaffirmed and her story added to the fund of knowledge circulating among members of her community

Similar observations have also been observed by Gamble (2002) in her research among Black women conducted over the years, in which she found "that Blacks felt that Whites are ambivalent and perhaps hostile to the [very] existence of Black people"

(p.40). The older Black women whom I interviewed clearly felt hostility from office staff, nurses and doctors.

### Preparing for the Healthcare Encounter

Many of the women whom I interviewed believed that "being" Black meant that one had to prepare themselves for the possibility of a challenge or a "fight" when going to a doctor's office. They needed to be ready to either be vocally assertive or to decide that it was not worth the headache of engaging in a "fight."

Ms. Wiletta noted that she chooses not to go to a doctor's office where she has felt challenged or felt overt hostility. "You don't want to have to go to the doctor and then have to fight, I mean fighting to be seen after you get there. These are things that you should not have to go through. And so when you run into this kind of treatment, I just say fine and don't go back there." She later returned to her comment and broadened it to explain how an overly challenging interaction in a healthcare setting references other aspects of "being" Black and how a this can be both mentally and physically exhausting:

Blacks have been so beat up on, you know. We have had to fight tooth and nail for every single thing that we get, for any kind of break that we get. Now some of us don't but most of us do, so you get tired.

Ms. Wiletta's perceptions are particularly insightful because although they may reference her specific experience of "having to fight" she has also contributed to part of a general fund of knowledge as she moves easily from the personal "I" to incorporate the experiences of other Blacks "fighting tooth and nail for everything." Such observations evolve into expectations and beliefs that may lead her to decide not "to go back there."

Some of the women felt that they had to be prepared to be vocally assertive in these type of interactions or i.e., put up a "great fight," despite them having "excellent" insurance coverage. Ms. Darla explained:

I'm lucky enough to have good insurance, even having insurance doesn't guarantee me access without a great fight. I have had some interactions with [White healthcare providers] in getting routine care that was not really [positive] They [White workers in healthcare setting] acted like they really didn't want to wait on me, but being the kind of person that I am "You will wait on me." I am paying my money! Other [Black] people, it may offend them and they will go ahead and leave, but then they don't come back, so that to me hurts them in the future, cause they're not seeing about themselves, cause somebody was rude to them coming in and if you cannot get past that it is gonna hurt us (Blacks) considerably.

Ms. Darla's experiences are supported by an observation made in a report from the IOM (2002) that indicated that the decisions that healthcare providers made on who got what kind of care were often based on their perceptions and preconceived racial stereotypes about Blacks despite their income, insurance status or education.

Whether a woman has screening exams may be determined by her early experiences in healthcare encounters. Ms. Carla remembered how much hostility she had felt during her very first visit to a new healthcare facility and their reluctance to engage in even introductory pleasantries. She felt objectified as a Black woman, and noted that if she is not able to establish lines of communication or if she is not made to feel welcome in these type of settings, she is unlikely to return:

It's like they say 'we [Whites] have to take care of them'...the Black women, and eventually they will. They don't take a real interest in the Black women. I've always tried to establish communication with them and it's like they really don't want to get involved in a conversation, like that. So I don't want to go, you know, I won't go anymore if I don't feel comfortable there...

"Having to fight" should not be part of a healthcare experience for any woman.

Comments by Ms. Wiletta, Ms. Darla and Ms. Carla metaphorically echo those of Fannie Lou Hamer (1967) a civil rights activist who made a simple statement over thirty-five years ago about Black people and their interactions with Whites. She noted that Black women, specifically were "sick and tired of being sick and tired" of White ambivalence, aggression and hostility.

The angst of racist experiences exponentially increases when Whites do not perceive that an act of racial bias has taken place or they fail to understand the significance of their behavior. An older Black woman is then she faced with the decision whether or not to educate White "others" about their actions. This is embarrassing when Whites are unaware of what has transpired, and then downplay their discriminatory acts of racial profiling as "no big deal." The stories I heard spoke to me of deeply rooted feelings of injustice held by many Black women.

Many women also felt that diagnostic tests were withheld from them because they were Black, an act they interpreted as racial bias. Ms. Juanita expressed her belief that Whites often make assumptions about Black people's health, just as they stereotyped food and nutrition choices made by Blacks:

It's the stereotyping of us as a people. They know we have some eating habits and with merit, granted, they could be even right, but that's not just the only thing. Another person [White] says how they feel (maybe the same way as me) and the next thing you know, the doctor assumes that they are eating correctly, and they're hooked up to a machine, being tested to find out what's wrong. But when I come in with the same basic symptoms, they tell me it's my diet, and that I am not eating right.

In her perspective, "stereotyping us as a people" is an explanation for why the effort may not be extended to "find out what's wrong" by healthcare providers. Many women were of the opinion that racial profiling reduced a Black woman's chances of receiving appropriate diagnostic screenings for a range of health conditions. One had to demand that tests be done and if necessary remind health staff. She talked about mistreatment of Black women had consequences in the whole community beyond their individual condition. As Ms. Bonita noted:

The other thing...that they need to understand is that we do work together, we will tell...and we do have community and we do support one another...when you mistreat one of us you cannot clean that up by going over and being nice to the next person...cause we talk...

Ms. Bonita's comments remind us of how Black women's encounters with doctors, nurses and others become shared in their community. These women talk with other Black women about what happened, and a fund of knowledge is transferred from woman to woman, and across generations. The significance of these encounters can be far greater than the one-to-one experience that occurred.

It is comments such as these that lead me to suggest that Black women feel the need to maintain a hypervigilant stance in healthcare settings. A Black woman learns, not only from her own experience but from others how she needs to act to protect herself from a host of possible racialized occurrences. This hyper-vigilant stance needs to be recognized by healthcare providers in preventive healthcare settings. It affects how Black women respond to requests for and responses to screening exams.

Over the course of a lifetime, a typical Black woman faces thousands of instances of blatant, covert, or subtle racial bias at the hands of Whites. As seen in the earlier

discussion on racial realism, perceptions and experiences of racist encounters were seen as re-occurring in a variety of settings, including the healthcare arena. A woman's perceptions of being racially profiled occurred through observations, interactions and communications with Whites. For the women in my study, being racially profiled was often precipitated by: a) some type of visual or verbal or non verbal cue from Whites, and b) based on their previous history (ies) of encountering Whites in a broad array of contemporary settings where Black women have often been met with negative beliefs about their abilities, bodies, behaviors, and values.

As the women shared their diverse experiences of being identified as "being" Black it became apparent that interrelations with all public institutions entailed dealing with being prepared to deal with racial profiling. In their narratives women described their interactions with Whites in defensive as well as proactive terms. Women needed to be attentive and never let their guard down. They had to expect that at any moment they might be stereotyped or devalued. This fits common euphemisms used by African Americans to refer to being unjustly detained by law enforcement referred to as "driving or walking while Black" or for being followed by someone White in a department store, as "shopping while Black." These linguistic phrases give voice to the experiences of Blackness in the U.S. today. My participants expected differences in medical treatment as part of a larger experience "being" Black and having a "race." Healthcare encounters became part of tensions and performance subject to constant evolution in racial terms because these encounters were embedded in history.

As a society, we have invented categories of persons marked by skin color, ascribed meaning to these categories through sets of comparisons, and used them to organize and evaluate. In the process of using these categories for “administrative purposes” we continually reify "race" and reaffirm popular stereotypes. We continue to see the world in Black and White terms:

In 21<sup>st</sup> century America, most people still view one another through the prism of race, in which skin color often determines membership in a particular group, with all the differences between humans we could choose to focus on the human mind seemingly insists on classifying others primarily by race and specifically as White or Black. (Begley, 2004, p.43-44)

We have let a racial lens continue to focus attention on the human experience. Consider Ms. Darla’s experience. She wasn’t treated like any other mother who was concerned about her child. Her Blackness defined how her doctor related to her like Ms. Wiletta’s captured by a professional photographer who stated “I can do Black skin,” Ms. Darla’s experience was filtered through a racial lens – for better or worse.

Black and White women may share many similar experiences as women, but they also occupy fundamentally different places or categories in the pecking order of our “racial democracy;” whereas Black women are seen as 'other' in both racial and gender terms, White women are in a position of power and privilege in racial terms (Parks, et al., 1996, p. 628). However, Black women have existed within complex sets of perspectives that supported de jure and de facto exclusion of their womanhood from the social mechanisms of respect and value in which White women were readily included. Furthermore, as noted by St. Jean & Feagin, (1998) "although Whites have the power to discriminate as individuals, much of their power to harm comes from membership in



traditionally White [(eco) sociocultural ] networks..." ( p.158), such as a predominantly White health care system. According to Grillo and Wildman (1997) " part of being a member of a privileged group [Whites] is being the center and the subject of all inquiry in which people of color [Blacks] are the objects" (p.46). Thus, I argue that many Whites have continually instigated gendered racial bias as part of the objectification of Black women's bodies, intellect, character, and culture.

### Perceptions of Risk and Mistrust of Research and the Health Care System

In interviews, women discussed perceptions of risk, mistrust and the health care system, health disparities as well as how they felt about participating in clinical trials and research studies. They had much to say about how comparative statistics were used to focus attention on racial disparities, especially risk factors that suggested Black women had "genetic predispositions" to illnesses. Such statistics were mistrusted or viewed with suspicion because they were seen as omitting the social and cultural contexts of Black people's lives. Ms. Wanda offered the following thoughts on risk information:

I am immediately suspect of anybody that says that we [Blacks and Black women] have a genetic predisposition for high blood pressure, and breast cancer. I think the predisposition has more to do with unequal access to quality healthcare, because when you have access to healthcare providers early they tell you, 'you need to decrease the use of salt, lower your stress, and get screened' in a timely manner so that by the time you get 50 you are not dealing with 'health problems like that.'

The skepticism expressed by Ms. Wanda is important to note because her interpretation of the information provided on risk does not immediately link risk for the disease to her, but rather the risk of not receiving optimal preventive care. She takes issue with a term

like "genetic predisposition" which implies an inevitableness of disease among Black people.

Several researchers have noted that Black women are underrepresented in oncology clinical trials and clinical research. My participants were aware of this and how the lack of their involvement might impact treatment protocols for Blacks. Ms. Renee commented that healthcare providers were unwilling to readily inform, offer or include Black women in clinical trials, or new treatment protocols as often as they did White women:

I don't think that we are informed about studies, clinical trials, new medication or medical options by health care systems, like going to the Mayo Clinic or a Cancer Research Center, you know, those kinds of things. When we get an illness they just treat us in the standard way. They don't think perhaps this person cannot afford [treatment] or, is there a resource available to help me get this patient into a special research program, so we are treated differently. In a heart beat they'll send a White patient off to get an expensive surgery somewhere and it's all free to them and in the name of research and study, doctors from all over give them their time and that doesn't happen to us very often.

Ms. Renee believes, that older Black women are often not told about clinical trials or referred by healthcare providers for several reasons. Racial biases endemic in the system cause health staff to by-pass potential Black candidates and she suspects that doctor's feel Black women are harder to manage or might be less compliant with treatment protocols. Ms. Renee's comments show that she clearly understands the significance and value of clinical trials and research for the prevention and treatment of diseases. She presents this case as just another example of how "being" Black means "we are treated differently."

Older Black women diagnosed with breast or cervical cancer may use their own initiative to seek out clinical trials or research opportunities for treatment. Many drop out

of such trials if they suspect that they are being treated unfairly. When that happens they are labeled “non-compliant,” not healthcare providers although randomized clinical trials are supposed to insure all subjects are treated the same. This is another case of “blaming the victim.” It is important to point out that Ms. Renee’s narrative brings up a paradox created by the lack of trust in the system. On the one hand, if she was asked to join a clinical trial a Black woman might suspect the motives of the doctor. Conversely, if she is not asked to participate in a clinical trial, she may suspect that the good care that is available to others (i.e., Whites) is denied her because she is Black.

Suspicious of possible abuse and mistrust are associated with the lower use of mammography and pap exams among older Black women. These suspicions impact taking diagnostic tests due to what I call a “healthy” paranoia. These feelings were present and shared by many women in my study who described their mistrust of comparative statistics. They explained that they did not find health information that described differences in rate of breast and cervical cancer relevant as they implied a “racial” difference and failed to index the true reasons for disparity, i.e., the quality of care received. As Ms. Carla succinctly noted, “I think because of all the documented atrocities that’s what I call them that has been pushed upon the Black race that we’re very distrustful of these exams.”

When talking about racial bias as illustrated by “body counts” many women went on to index popular beliefs about radiation experiments and the forced sterilization of young Black women, the Tuskegee Study and such. All of these incidents were cited examples of atrocities committed against Blacks. In interview questions specifically

designed to query ideas on "being treated differently," these atrocities surfaced illustrating the long and lasting legacy of these events. These memories continue to be part of their funds of knowledge and continue to be relevant. These racial memories surface during healthcare encounters as well as arise when confronted comparative statistics used for risk assessment, or diagnosis, for breast and cervical cancer. They also help explain Black women's critical appraisal of clinical trials.

Ms. Wanda explained why some Black women are unwilling to participate in clinical trials or research studies once diagnosed with breast and/or cervical cancer, and extended this to include clinical trials for HIV/AIDS:

...a lack of trust, you know, I think that keeps both African American women and men from seeking and obtaining the help that they need, like with the AIDS. And when you hear about the whole managed care process in the last 15 –20 years, and you put that together with the horror stories of Blacks being "guinea pigs," we just don't want to be part of that.

Many other women also used the term "guinea pigs" in their interviews. Several participants referred to the "Tuskegee Syphilis Study" by calling it an *experiment* which I saw as a referential twist made in their perceptions of what a "study" is in relation to what is abuse, i.e., an experiment that is conducted in the name of research. I believe this is an example of how research has come to symbolize the apex of what "being a guinea pig" means to them.

The Tuskegee Experiment is an important historical landmark to Black people for several reasons. It is an exemplar of mistrust and cruel betrayal, not only because the U.S. Public Health Service also used the resources of one of our historic Black institutions, "The Tuskegee Institute, " but because of the use of a Black public health

nurse, "Nurse Evers" to recruit, and retain these participant. Blacks became complicit in harming Blacks for a "science" that is ethically suspect. Promising these men that the "government" would provide treatment for their "bad" blood was a lie invented to render them passive guinea pigs. They never received treatment. The Tuskegee Study extended into the early 1970s, after having continued for over 40 years. The knowledge of what one woman calls "documented atrocities" (although she does not mention the Tuskegee Study by name in her narrative the inference is present) continues to percolate into the everyday experiences of Black people being "treated differently":

I think people have heard on the news, and had personal experiences, you know, there's a lot of documented atrocities that have been done over the years. People have lost confidence in the healthcare services. I've seen it myself where the healthcare workers tend to treat Black people differently than the Caucasian people. I don't know if they feel that [Blacks] wouldn't speak up or if they [believed that Blacks] don't know any better or expect any better.

Being "treated differently" reaffirms "ethnic notions" of "what it is that we all know."

"Different treatment" is to be expected, and is believed to regularly occur. When it does occur, it re-affirms expectations and triggers a cascade of memories – personal and collective. Many of the comments shared by the women I interviewed share collective experiences in healthcare encounters that spanned time. These "ethnic notions" impacted their health behavior. These ideas will be more fully discussed in the following chapters that follow.

### Perceptions of Comparative Statistics and Risk

I am in agreement with Kass et al.,(1996) who suggests that the "differences in the health of older Black women may result from differences in their experiences with our health care system"( p.2). When asked why Black women did not get screening exams and the differences between Black and White women in their healthcare seeking, Ms. Darla said:

You know, I think there maybe something to those statistics on our disparities and as much as I truly think in my heart, even though I don't want to feel this way, I think maybe there are a lot of Black women that maybe don't have the opportunities to get in and see their doctors and when they do get in it's usually too late so a lot of them are not aware of preventive stuff. And for that reason, by the time we get there a lot of times it's too late and we become a statistic. Whereas, White women a lot of them, I'm not saying all but they just have an easier way out and usually they go in and get their screening exams and their physicals and they get checked and that has not been a big thing with Black women...

The question remains, " Why has "not getting checked been no big thing" with older Black women? As will be discussed in chapter five, what Ms. Darla refers to in a very real sense is that timely and routine prevention for themselves, as Black women, has often taken a back seat to more pressing needs to acquire preventive health care for others. In addition, "getting checked" may not be an option due to socioeconomic constraints, for those with limited resources and no health insurance, as well as a lack of preventive health knowledge, and negative experiences of Black women of being ignored within healthcare settings or when interacting with healthcare provider's who have made them feel unwelcome. Nonetheless, despite difficulties encountered in seeking tests among my sample, most women did have regular screening exams.

Women in my study discussed reasons for health disparities among Black women for other health concerns., such as diabetes. Ms. Carla related her mother's experiences of going to the doctor (reluctantly) for several visits and having family requests for diabetic screening be ignored by the healthcare provider until it became evident that she was diabetic which was too late to prevent the loss of one foot and one leg:

I know it's in my best interest to go, but, like, my mother she just did not like to go to the doctor at all but she went cause we kinda pushed her. Her life style was totally different from mine but I think she was a stronger specimen than I am. And all of those years when she did finally go and no one told her she was diabetic, even though my sister was a nurse and had asked them to test her for diabetes, so then my mother...she lost a foot, then a leg ... and within 3 years she was just in rapid decline ...and I think there's still a lot of older Black women out there that don't go... each generation of Black women to me has broken down...gotten weaker...and it's because we are still not being taught how to care for our bodies and to go to the doctor...and it's because of that fact that they don't get in early enough that we have become part of those big statistics...

In this case, "being" Black may have resulted in not being given risk information early enough or getting the information and still not wanting to go through the system In either instance, when Ms.Carla's mother finally did go for preventive care, it was too late. In noting the generational decline of Black women, along with lack of preventive health knowledge, Ms. Carla is also talking about factors that may impact the "no big deal" perception among older Black women of not getting a screening exam that Ms. Darla spoke about earlier.

These discussions are particularly insightful because they put forth one of the key arguments of this study, that many older Black women operate from their own cultural belief system when making decisions about healthcare seeking. One of these beliefs, for example, is that a Black women is "strong." As one woman stated, Black women are

often perceived to be the "fulcrum of a Black community" (Ms. Yolanda). Needing to be seen as "the strong Black woman" may have cost us dearly as a people because this image may be a mask behind which a woman has to live. If the mask is worn for a long enough time, a woman may start to believe that it is real; in this way Black women become "legends in our own minds" (Ms. Latrice). The embodiment of Black women as "legends" may bear an enormous weight. This may be what Ms. Carla attributes to when she explains how each generation of women are "breaking down" as they may place themselves last in line for routine, timely care.

Many of the women I interviewed explained that the perceived "high risk" attributed to Black women in the literature should not just be attributed to "race" because risk factors are not due to any inherent or innate biological deficit of the Black body. Rather, risk may be "increased" because of their self-denial of the need for preventive care and the systemic denial of receiving optimal care even when they do go through the system. As Ms. Wiletta observed that the source of disparities in the health status of Black women can be found in the enduring mistreatment by a health care system as a consequence of racial, historical, cultural, and structural positioning of Black women in American society:

It's the way that they [the health care system] have treated Black women for so long. It seems like it's really crazy that still in this day and time they don't really see us as whole people. It's like well, "she's Black it's no big thing" like we don't have concerns, our health doesn't matter. It seems like to the big world out here this is just a Black person and that's the way I feel still. You know, it's no big thing to them, you know, we're less than human so that bites me a lot and I think it does something to the kind of care and treatment that we get based on the fact that they cannot see past our skin. They don't understand that we are human just like they are, and we just have different skin pigmentation. And it's not good for me when they do this because I won't get the best of care as long as they lookin' at



my skin. Sometimes it pisses me off in the fact that I'm human just like they are. For the health industry to look at us [Black people] like that, you know, I believe that it does something to the kind of care and treatment that we get.

Ms. Wiletta's observations are insightful because she believes health disparities are the cumulative result of both past and current racial bias in a society that uses skin color as a marker of difference. Her recognition that these are part of the practices of the "health industry" provide me an opportunity to suggest that an ethos about "race" and "being" Black may exist at the institutional levels of health care systems that has shaped individual provider's ideas about Blacks, thereby permitting individual practices of exclusion, discrimination and prejudice to occur. She is angered by these occurrences.

Ms. Renee's observations seemed to concur with Ms. Wiletta's assessment on the cause of disparities:

On the whole, I think we've been neglected. Nobody cared about our health; we're at the bottom of the totem pole. I can speak from personal experience. See my daughter has called me on the phone and said "Mom I sat there all day and I had an appointment at 9:00 A.M." And at 5:00 P.M. she had still not been seen. She said "everybody that walked in that office was seen before me." See those are the types of things that we go through. You see it, and you hear about it.

Notably, it is the healthcare experience of her daughter which has informed on Ms.

Renee's idea about "being at the bottom of the totem pole" which has become part of her shared fund of knowledge. Her daughter calling her from the doctor's office to talk about being ignored for service was more than a complaint, because her experience has now become part of "what we all know."

Ms. Yolanda's experience in a preventive healthcare setting seems to align with those shared by Ms. Renee's daughter as she shares how she was made to feel in a

doctor's office and more importantly, how this influenced her decision not to go back for another exam:

I just feel that when I go to a doctor I don't feel that I'll get the best of care. It's just a sense that I felt, you know when I went to the Women's Health Center for my mammogram and it's like they looked at me and really didn't want me there so I just never went back.

Ms. Yolanda's "sense" connected with previous experiences within healthcare encounters over her lifecourse in her decision that she did not receive optimal care. Thus a tension or expectation already existed when she accessed this preventive healthcare setting for her mammogram. However because of the behavior of the health professionals in that setting that referenced her existing expectations of bias, she decided not to return.

Black women in the U.S. suffer disproportionate risk of ill health in part because they are Black women. As one participant observed, a culturally conscious, responsive and respectful medical environment is critical for making Black women feel that they were in charge of their health. As Ms. Carla noted:

I've heard from other women about doctors' mistreatment of Black women and I do think that its quite prevalent among Black women from what I've heard that they [White doctors] overlook Black women, that they are quick to write prescriptions and look annoyed. I think if you have a physician who you feel treats you different because of your race, you should be looking for another doctor. Personally, I would never have a doctor that I was not comfortable with, or if I was treated different, but then neither would I purchase services from anyone who I thought treated me different because of my race.

In her discussion, "race" and "being" Black can be "mistreatment" by the healthcare provider. Furthermore, Ms. Carla's comments about what she has heard, what she thinks, what she has observed, and what she will do are clearly associated feeling and being mistreated, and consequently looking for another doctor. Her observations lend saliency

and meaning to insights, and beliefs about "race" and "being" Black, and it is these are the kinds of perspectives that I suggest may act as virulent agents or toxic substances to infect the (often shared) expectations and perceptions of White healthcare providers and older Black women alike.

Ms. Sharon, one of the participants in my study who works with visual and print media in the local area, recalled a recent campaign about breast cancer in which she observed that only White women were depicted:

Now, Colette, you know only White women get breast cancer. Think about it. Because when you look at the advertisements for that little pink ribbon they all look White. Lily White. That pink ribbon, and pink skin... and when they have that big race for breast cancer I only see one or two Black women. When it comes to breast cancer its always with White women, you know. They don't advertise. They only use White folks and it's kinda' racist. I don't think the regular doctors tell women. Maybe Black women in my age group feel that if I haven't gotten it by now then I won't get it. In my immediate support network, I only knew one woman that had breast cancer and now it's two so we do need to know.

First of all, Ms. Sharon doesn't really believe that it's "only White women who get breast cancer " or that there is some sort of secret coding with those pink ribbons. However, her depictions are well taken, as they speak to how Black women may interpret visual information about breast cancer prevention. Another woman, Ms. Renee similarly described the absence of health information that depicts Black women:

I can't recall seeing anything other than one book that came to me by way of Essence or Ebony [ Black publications] and that is the only thing I have ever seen ever. We are not part of the target [health] market. Advertising is a powerful medium. They advertise about so many other things but they never advertise about our health care needs. We are in the *Meridian* weight loss commercials but not seen with a migraine or with osteoporosis or any of the other medical conditions that they target every day. You don't see us [Blacks] in vitamin advertising. We are not part of the target market. They don't consider us as having the financial resources that support whatever it is that they are advertising and they are wrong [because] \$40 billion Black dollars are being missed.

Several of the women in my study were well informed about preventive health care. For example, Ms. Wiletta shared with me excerpts from articles that she read in two of the more popular national Black publications, *Ebony Magazine* and *The Crisis*, which talked about risk factors for breast and cervical cancer among Black and White women. She noted that:

Colette, here's this article that I read that said that White women are more likely to develop breast cancer, but Black women are more likely to die of this disease and to also have a much lower five-year survival rate.' It also says that "the death rate from cervical cancer is more than twice as high for Black women as it is for White women" ( From Randolph, 1997 [Ebony] and Howell, 2004, p. 28 [The Crisis] ).

After reading this excerpt to me, she told me that she accepted these comparative statistics as useful knowledge particularly because she read it in a trusted Black publication, which targeted Black women. However, at the same time, she questioned the integrity of presenting a health disparity statistic that compared her to White women, because she felt that it served to further objectify her Blackness. She also felt that such a comparison somehow predisposed her to be sicker than White women. She continued her discussion:

I have a problem with them saying that African American women have more cancer and diabetes. I think America has a problem with health and not just Black women. Just because you do a study with White women doesn't necessarily mean that you can take those results and use them with Black women. They need to target Black women and be more inclusive in health promotions that talk about heart diseases, and heart attacks, and another thing, just because some one is Black you cannot assume that they are of the African American experience because you have people from all over and there are also women from Africa living here...

Ms. Wiletta further notes that the only times she saw Black women visibly depicted in breast and cervical cancer prevention materials was during *Black History Month* :

Sure, risk information is thrown out there about high blood pressure, obesity and diabetes, but I don't see me when they're talking about cervical and breast cancer, unless its Black history month. I *am* somewhat of a skeptic so if I did, it that would prompt me to do additional reading.

Interestingly, she suggests that she might be inclined to be more proactive about seeking preventive exams if she saw Black women as being part of these social marketing campaigns.

Ms. Latrice was another participant who attended many local health promotion initiatives in the area as part of her duties with the Pima County Health Department. She commented on the contradictory relationships between obtaining risk information that infers that Black women may be at a higher risk for breast cancer, and at the same time having this population of women being excluded from participating in prevention initiatives, clinical trials or new treatment protocols that focus on breast cancer.

Her perspectives focus on what she feels has not been made available locally in Tucson to Black women:

Black women are excluded from most of the health information that is given except when they want to say that we are at the highest rate of mortality in many instances, of uterine and breast cancer. But there is nothing here [in Tucson] that really targets us so that we can prevent this from happening. Yeah, we have the African American Coalition on Health and Wellness but that's all. I brought this up a long time ago at a YWCA health promotion when they were talking about how we are dying in big numbers and I asked, If we are dying at those levels "Why don't we have a program?" I saw a study in the paper where they were comparing the incidence of uterine and breast cancer among Hispanic and American Indian women to White women, so why weren't we [Black women] in that? I think it has to do with the [population] numbers.

Such comments from the women in my study illustrate that early diagnosis is not simply a matter of individual choice; rather it may be a matter of the invisibility of Blackness and the lack of information and of access to programs. Blacks are the smallest minority of all of the other minorities in Tucson, which may be a factor in their exclusion from prevention efforts. In other words, they are too small a group to be formally included in research studies, clinical trials and even as a comparison group for health campaigns so they are omitted.

She recognized that the consequences of these omissions can be devastating because exclusion from these programs may result in late diagnosis. For example, an older Black woman may not recognize the relevance of health materials directed at a non-minority audience or another minority group. On the one hand, older Black women are widely cited as having the highest mortality from many diseases. On the other hand, Black women seem to have very little or no targeted visible health promotion information directed specifically toward them to prevent these diseases. As Ms. Renee explained:

I think getting information early is important. When I am sitting in my doctor's office there is no information that is particular to Black women in the rack. It may say something about which groups are more prone to certain things but I can't remember being in any health place where there was a pamphlet or risk information geared strictly toward African Americans. How do we [Black women] go about doing something about it if we don't get [health information] early and that's the reason I think prevention is so good, because we can prevent some of these things, like getting the screening for breast and cervical cancer and high blood pressure. For us to know about what's going on early, you know, then maybe we can save some lives.

Her comments echo Ms. Latrice' s observation noted earlier about the lack of preventive programs offered to Black women that has something to do with "the numbers." I think both women are referring to what may be a tacit assumption in health promotion efforts

in Southern Arizona. What is targeted in health promotion efforts is *minority* health, but the emphasis of the information on risk, prevention and vulnerability may be placed on reaching a *visible minority* (Latinos or American Indians) with the idea that other (smaller) minorities, such as, African Americans, will "just know" or assume that they are also included because they used the term "minority" as a sort of catch- all category.

Risk factors were also discussed for other diseases that are characterized by the term "racial" disparities. Ms. Juanita shared her thoughts on risk factors not only for breast cancer, but for diabetes and high blood pressure specifically noting how these comparative statistics are also perceived in relationship to "being" Black and having a "race":

...my mother, she is a 12 year breast cancer survivor. She has diabetes and high blood pressure and it makes you more aware, like with the breast cancer thing. But to me when [health statistics, healthcare providers] say cancer, diabetes and high blood pressure runs in the Black family, it's no such thing. Your recipes run in the family not your illnesses. I don't think there is a predisposed disease for cancer. It's how you're living, what you're eating. Your grandparents, your parents, and we follow those diets so we are not born with cancer but of course they single us out. No matter what we do we are always singled out, you know. We are the less of the population but we are the highest with all the illnesses. I just don't buy it. It cannot be true. I believe that if we got preventive care, early detection on some illnesses, and instructions that "you need to change your diet or your lifestyle." Doctors like to throw out those numbers to us all the time. Yes, we have these illnesses, but it doesn't happen because we are pre-disposed to those illnesses. It happens because of the way society has constructed our access to health care, to quality healthcare, to preventive care, so that by the time we realize something is wrong, it's too late for us to make the changes.

Her comments suggest that it is the inequality experienced by Black people that affects their health outcomes not their predisposition to illness. Her comment that "recipes run in families" and not "illnesses" or disease belies the notions of hereditary risk while at the same time highlighting the potential importance of Black culture in contributing to the

development of some diseases, such as, the traditional ways of preparing food among older Blacks. Thus, racial disparities in health and well being are located not only within inequities in health, but also in sociocultural contexts, which may place an older Black woman at risk. These are key factors because it is often assumed Black people are predisposed to certain diseases because of "being" Black, rather than being tied to particular cultural practices, such as our recipes, which speak to what *it means* to be Black.

#### MISTRUST, SKEPTICISM AND THE POWER OF LIVED EXPERIENCE: AN ANALYSIS

Several of the women in this section noted their mistrust was part of perceiving that "race" has historically meant that different and negative practices were used with Black people that were not used with Whites. Furthermore, perceptions of "being treated differently" seemed to also contribute to constructions of contemporary conspiracy motifs of Black genocide, with respect to "being a guinea pig." We saw an example of this type of construction in Ms. Wanda's narrative. Even though she and I were talking about "racial" disparities in breast and cervical cancer and the in the use of clinical trials and research, she chose to specifically apply the sociocultural memory of past abuses to contemporary "racial" disparities. She used HIV/AIDS's as her referent to talk about her perceptions of the kinds of things that could go on in clinical trials and research to illustrate her point about Blacks as "guinea pigs." For example, in Tucson and in other Black communities, although it is well known that protease inhibitors have been shown to reduce the level of the virus in some patients' blood, these treatment protocols for the



HIV/AIDS's epidemic among Black women has generated suspicion. Some women believe that those who take protease inhibitors are "guinea pigs" for the government.

Other women made direct connections between mistrust and the documented historical abuse of the Black body in health research. Many of them referred to the much publicized Tuskegee Experiment. As a post-slavery experiment, Tuskegee is a symbol of ethical misconduct with respect to Blacks by the U.S. health care system, and is one of the most widely recalled atrocities. During discussions of mistrust and the development of righteous skepticism<sup>xxvi</sup>, many participants associated this atrocity with the unwillingness of some Blacks to participate in clinical trials and research on HIV/Aids today. This is particularly noteworthy as Tuskegee ended over 36 years ago, yet its memory was very vivid among the participants.

In the Tuskegee study, hundreds of Black men with Syphilis were left untreated for over forty years. These men had wives and girlfriends, what of them? The lack of treatment obviously impacted their lives too. My Aunt Genevieve posed this question to me when she heard about my study, "So, Colette, what happened to the women?" I had to answer her that I didn't know, and that I had not seen any research that talked about the women who were no doubt infected with syphilis. However, recently I ran across Evelyn Brookes Higgenbotham's *African American Women's History and the Metalanguage of Race* (1995), in which she notes:

The Public Health Service's willingness to prolong syphilis despite the discovery of penicillin discloses not only the federal government's lack of concern for the health of the men in its study, but its even lesser concern for black women in relationships with these men. Black women failed to receive so much as a pretense of protection, so widely accepted was the belief that the spread of the disease was inevitable because black women were promiscuous by nature. (p.12)

Thus, I can now answer my Aunt Genevieve's question. Instead of saying "I don't know," I can tell her that "absolutely nothing was done to help them." I don't know which answer is worse because either would speak volumes about the continual negative and stereotypical sets of meanings that have been ascribed to the Black female body. For example, an enduring belief in American society is that Black women have a heightened sexuality and that they are "promiscuous by nature." It is not clear how these stereotypes impact women's experiences in the health care system. However, I suspect that these may be tacit assumptions about Black women made by some healthcare providers and they may significantly impact treatment.

Suspicion and mistrust are also part of a collective re-memory that has been a shared, understood, and accepted "ethnic notion" that may become internalized as an expected experience of abuse. As noted by Corbie-Smith, et al., (2002) a legacy of distrust "is rooted in experiences of Black women and their bodies extending back to slavery and continuing to the present day" (p.2458). The connections made between their feelings of mistrust, the knowledge of Tuskegee and suspicions of future abuse became intertwined and impact women's everyday experience of being "treated differently."

Several women also used the term "atrocities" when talking about mistrust, and abuse along with "guinea pig." It is interesting to note that many of the women who used these phrases did not have the specific dates, persons, or even a documentation of the abuses committed specifically against Black women yet these were part of their fund of knowledge. When I pressed them for elaboration they spoke about "numerous incidents of exploitation" or "all kinds of experimentation." This culturally held body of evidence

of "what we all know" may serve to support their perceptions and expectations of mistreatment at the hands of health care. Hence, these women exhibited an almost bodily sense and reference<sup>xxvii</sup> of apprehension. This mistrust references a history of Whites using Black women's bodies as sites for abuse, experimentation, and exploitation, beginning with Dr. J. Marion Sims (1889), the father of modern gynecology, who used female slaves to perfect gynecological surgical techniques. As Gamble (2002) notes:

[Sims]...used slave women to develop an operation to repair vesicovaginal fistulas...between 1845 and 1849 before the days of anesthetics...and only after his experiments proved successful on Black women did the physician attempt the procedure, with anesthesia on White women who volunteered...(p.36)

Several of the women in my study are also old enough to at least have heard about the collaborations between family planning clinics and involuntary sterilization initiatives which began in the 1930s called the "Negro Project." As part of a joint health and welfare initiative, the project agenda was designed to limit the reproduction of African Americans who were perceived to "still breed carelessly." For example, Margaret Sanger, a White feminist considered the mother of reproductive freedom and one of the founders of Planned Parenthood, was noted to have "supported and promoted the use of reproductive technology to diminish the reproductive liberty of African American women" (Randall, 1996, p. 3-4). In the 1960's these family planning clinics were subsidized by the government and the number of clinics in a Black neighborhood interestingly were proportional to the number of Blacks in that community. Looking back I can understand why, in my neighborhood, in Los Angeles there were quite a few family planning clinics concentrated in a very small area. It seemed like there was one on just

about every other corner, far more than the offices of dentists, doctors or pharmacies and hospitals that offered general health care services.

It is clear now that these clinics were spaces in which to locate the Black female body in order to monitor reproductive freedom. The commonality of these clinic locations was not to provide optimal healthcare for Black women; rather, they were an attempt to reduce the number of Black women on welfare because it was thought that Black women were getting pregnant to get paid or to increase their welfare benefits. Some doctors would only deliver babies or perform abortions on pregnant Black women if the woman consented to be sterilized, threatening the withdrawal of welfare benefits if they did not agree to this sterilization. As Randall (1996) notes, "in Alabama, an estimated 150,000 poor, young, Black women were sterilized without their consent under federally funded programs in the 1970s and 1980s" (p.32).

In addition, these "atrocities" were committed against future generations of Black womanhood. For example, when White healthcare providers tricked Black mother's into having their teenage daughters sterilized because the women were welfare recipients, and it was thought that a "cycle" would repeat itself among these adolescents (Randall, 1996). As a matter of fact, it was also during this period that many adult Black women living in Georgia, Alabama and Mississippi who were not on welfare, but accessed services at these family planning clinics, were sterilized without their informed consent so that medical residents could gain additional experience in performing tubal ligations and hysterectomies (Randall, 1996). Even today, Black women from the South have the highest rates of hysterectomies and tubal ligations in the United States.

Many of the issues raised by my participants about expectations of abuse while receiving mammograms and pap exams, and the suspicions that they generally have of the health care system are often labeled by others as "hypersensitivity," a term which carries negative connotations of "being unreasonable or paranoid." However, what I suggest is that for many of these women, being skeptical and suspicious is not only very reasonable, it is also unquestionably valid, having been validated through the actual occurrences of these abuses on the Black and female body in the name of research. Their experiences and knowledge of the collective past of Black women have created a "reasonable fear" of the U.S. health care system. And these factors are what make their mistrust and skepticism *righteous*. Thus, I argue that this is actually a "healthy" paranoia which serves as components of agency through self-preservation, self-advocacy, vigilance and a Black womanist consciousness which will be discussed in more detail in the following chapter.

*Righteous* skepticism and mistrust may support a belief among these women that they are placing their bodies at risk because of past abuse of the Black body. For example, *HeLa cells* grown from the flesh of a Black woman are still used today to test potential cancer cures and new drug therapies and are considered "the world's most enduring line of human cell cultures," according to Byrd and Clayton (1996). Henrietta Lack was a Black woman whose flesh was taken without her informed consent when she went to Johns Hopkins Hospital to be treated for cervical cancer in 1951, and this line of human cell cultures lives on today in labs throughout the world. Therefore, I think it bears restating here that the responses of older Black women to personal risk for breast

and cervical cancer must be considered within the sociocultural contexts of those risks that are tied to living, on a daily basis, with gendered racial bias in which their bodies have been perceived as expendable.

Mistrust was also expressed by women in discussing their perceptions on the use of comparative statistics, the use of identifying disparities as "racial," or factors of risk and the value of that type of research are insightful. Those reactions may have also been extended over time to influence their patterns of health behavior with respect to the continuation of access and utilization of screening exams, such as pap smears and mammograms, because this is the site where the very private and vulnerable parts of the Black woman's body--her breasts and her vagina--are being scrutinized, usually by Whites.

The women in my study also clearly understood that a number of factors affect a Black woman's health status, health care, and health knowledge including income, occupation, education, environment, and access to services. Most of them felt that their attitudes and beliefs about breast and cervical cancer survival and screening exam efficacy are constructed through comparative statistics presented in doctor's offices, in television commercials, and in pamphlets, including those in popular magazines read primarily by Black women.

Various women noted that preventive knowledge and information specific to the African American population was either unavailable, unreliable, non-existent or non-representative in their city. Locally, I too have observed that many of the health promotion/prevention initiatives use billboards, pamphlets and television spots with

pictures of American Indian and Latino women and not Black women. African Americans are not pictured unless it is during the month of February (Black History Month). The manner in which media advertising on billboards, printed materials, pamphlets, and sandwich boards, including bus bench advertisements are used in promoting health knowledge has an impact on the way that people engage in certain health behaviors. However, when my participants discussed this kind of preventive health information that was supposed to specifically target "minority" women, they felt that were left invisible even though this is the population noted to be most at risk by extension, thus most in need of preventive care with respect to breast and cervical cancer. Their insights on being left "out of the picture" speak to the perceived power of Whites in relation to the powerlessness of "being" Black. Truth be told, it is a fact that Black women over 40 years of age have the highest rate of mortality from breast and cervical cancer, and it is also true that these figures represent "avoidable" disparities that could be mediated or nullified through the access and utilization of routine and timely screening exam. What will it take to make Blackness visible? How can preventive health promotion initiatives reach their target if Black women don't "see" women in these ads that look like them?

Most of the women in my study did understand the importance of presenting research and comparative statistics on various ethnic groups regarding risk factors for disease. However, several of the women were distressed that this was framed using the language of a "genetic predisposition" of Black women to disease at the exclusion of other factors. Several women noted that such information might make it likely that their

Black and female body would be perceived as a "diseased object" by a doctor because of gendered racial bias. This may serve to fuel their existing mistrust about the health care system and makes them less likely to go for preventive treatment or believe risk factor information provided to them. Some even suspected that information given to them would be inferior (i.e., less detailed or inaccurate) to that given to White women.

As noted in the introduction, anthropologists have expanded epidemiological models of public health to examine risk, vulnerability, and "racial" disparities in the health of various populations through ethnographic research. Recently, "biological expressions of inequality" have been noted to impact an older Black woman's personal assessment of risk factors for disease influencing her decision to even access preventive screening measures over time, for example, healthcare providers may not recognize "biological expressions of inequality" as the ideological and ontological misinterpretation and/or misrepresentation of Black women in comparative statistics when this data uses "race" without definition (Krieger, 2002). In this chapter, I too have argued that as an "axis of ontological difference," "being" Black becomes a site where reciprocal tensions around "race" are re-constructed by the subtle and coded sub-texts of beliefs about "race" in healthcare encounters that signify a "difference" without having much content or context, in which having a "race" becomes embodied and misinterpreted within "racialized" comparative statistics that are then used to encourage the adoption of preventive health behavior among Black women.



## SUMMARY

Many of the perceptions that were shared by women in this section arose within notions of cultural difference and their feelings that Whites viewed them as inferior beings simply because they were Black. The observations shared by the Black women in this chapter seem to suggest that the significance of comparative statistics, health information, and research studies that indicate disparities as "racial" have been interwoven with their mistrust, suspicion, expectations, and perceptions of bias and racial profiling. Many of these ideas seem to be shared across participants. In these narratives, one hears issues of mistrust emerging, as part of "righteous skepticism" internalized toward the American health care system. The ramifications of ensuring mistrust interferes with the interpersonal relationship necessary in a healthcare encounter. Lack of trust may distort a Black woman's perceptions of what went on in a doctor's office and impact here willingness to accept a doctor's advice.

Several women on spoke about "micro-aggressions" that they experienced across settings and interactions, through being ignored for service, or having staff assume that they are non-paying or "going ghetto" and thus not worth acknowledging. These experiences were often shared with other Black women in their support networks added to an existing fund of knowledge, as Ms. Juanita and Ms. Darla noted in the introduction "we do talk to each other and we will tell if we are mistreated."

Earlier I used the terms "behind the veil of race" and "radical subjectivity" to describe how Black women are caught in a double consciousness as both a subject and an object. The narratives in this section attest to this idea because, once classified as

"African American in America, you can never become un-categorized" as Black (Freeman, 2005, p. 233s). Therefore, having thusly been situated behind the veil of a "race" Black women are subjectively as Black and objectively as female (DuBois, 1920). I argue that negotiating "being" Black, gender, and "race" is accomplished by sustaining a "double consciousness" and this is hard work which is emotionally, mentally and physically taxing. It is exhausting, to routinely come face to face with racial bias. The level of this exhaustion increases when others around us do not perceive that an act of racial bias has taken place.

As Block (2003) has noted in a study among older Black women and their healthcare encounters with Whites "there are times when [Black women] are in the exam room when they feel like they are being treated by the enemy" (p.1). In this study many of the women in this study spoke candidly about feeling that they needed to be prepared to "fight" in their interactions with Whites, especially in healthcare settings. As one woman explained that although, "not every healthcare person would treat a Black woman differently ...there are enough that do so its not to be underestimated if that woman tells you that she or the family was treated badly."

## V: THE NATURE OF EXPERIENCE AS A CUE TO BODILY PRAXIS

The Black woman had nothing to fall back on; not maleness, not whiteness, not lady hood, not anything. And out of the profound desolation of her reality she may well have invented herself" (Toni Morrison, 1987, p. 142)

### OVERVIEW OF THE BLACK EXPERIENCE

The term Black experience in my study is defined as the consequences of a common historical significance to "being" Black and of having a racial classification in the U. S. that sustains culturally specific beliefs about this population. In addition this term also refers to the source of many of the shared understandings that seem to hold prominence among older Black women. The Black community is often represented as a collectivity of the experiences of Americans of African descent and Blacks as part of a cohesive sociocultural and political group. Racial bias has often shaped the individual identity of an older Black woman, it is important to note that racial bias has also shaped the collective identity for many African Americans in the form of community expressions of advocacy and resiliency. For example, "memories of negative experiences with White Americans, accumulated and communicated by individuals, families, and communities, web together memories of contending and resisting racial oppression" ( St. Jean & Feagin, 1998, p.31). Furthermore, older Black women are perceived by others and often by themselves to be members of a distinct "race," identified primarily by skin color and other bodily features. At the same time, these women also have become:

...part of a self-conscious population that defines itself in terms of common descent (Africa as homeland), a distinctive history (slavery in particular), and a broad set of cultural symbols (from language to expressive culture) that are held to capture much of the essence of their peoplehood (Cornell & Hartmann, 1998, p. 33)

Thus, a having "race" has been established and produced by human perceptions and classifications, King (1981) notes that "both, what constitutes race and how one recognizes a racial difference is culturally determined" (p.156). The way in which an older Black woman may racially view the world is important in understanding her health seeking, accessing and utilizing behavior because it may ultimately influence her expectations and experiences within the health care systems.

The Black community is composed of webs of relationships that offer networks of support, socially, culturally, and spiritually that "surround an individual and the structural characteristics of that web" is a consequence of "being" Black (IOM, 2001, p.145). Relationships can influence health outcomes, including patterns of behavior and person-to-person interactions. Thus far, in exploring the ethnographic insights of older Black women, their narratives have indicated that "being" Black has ecosociocultural implications, and what a woman may perceive, expect, and experience within the health care system may be influenced by those implications. Being racially identified externally is an imposition that makes "race" matter. Whether racial identification becomes internally accepted or not, the result has been that cohesion within differentiation becomes possible as generational cohorts among this population of women share similar experiences (Stevens, 2002). Common threads of experiences with and expectations of micro-aggressions seemed to weave more tightly together the ethnic notions and beliefs among the older Black women in my study, regardless of the differences in their socioeconomic positions, education, political persuasion, and ideological orientation. As

Ms. Wiletta observes:

I think we come from a common background and if you go back in history you know what that story is about. And we're survivors but at the same time we have a number of issues that we are still sort of plagued with, and whether they're social issues or health issues, they are things that we are still dealing with as a cultural group, particularly here, in America.

Ms Wiletta's comments resonated with my own recollections and those of the women that are part of my networks of support. I too have grown up with a knowledge that was shared with me that the world may not be especially kind to me-- based solely on the color of my skin. I have had generations of Black women and men share with me the consequences of having a "race," forewarning me that "being" Black meant that I would most probably have to challenge micro-aggressions, misinformation and misrepresentations about this identity over my lifecourse. These experiences helped me interpret and understand my participants as they made connecting ties to other Blacks and other Black women elsewhere. I too remember perspectives of self awareness as being collectively accepted, constructed, and shared among Blacks, and more importantly, deemed as necessary to "hand down" to others. For example, generations of women in my family would teach us the importance of getting things in writing when interacting within predominately White environments (so that these discussions could be recalled for their accuracy) or when making appointments get the names of whom you are speaking with so that later the conversation could not be denied, and be at least 15 - 30 minutes early so as not to be overlooked. This are all aspects of a hyper-vigilance which enables Blacks to mediate / overcome the penalty of having a "race" and thus being exposed to

racial bias that could damage not only the physical body but, more importantly the mind, and spirit.

For many of the women in my study, spirituality is a connectedness with self and others that includes an acknowledgement of belief and faith in something greater than they are as part of the Black experience. Several women have noted that their awareness of a shared past and present experiences are key components in their individual health-seeking behavior.

Black women have long recognized the importance of social memory as often the reservoirs of Black agency and keepers of culture knowledge that is readily shared. They have often shared the experiences and consequences of the toxicity of racial bias in the lives of Black people. These experiences are their own encounters, personally witnessed encounters of others or those shared from other Black women. It also part of the ethos of culture, not nature, which influences their healthcare-seeking behavior. For example, healthy paranoidias reflect a steady diet of the experiences of racial bias across the life course, in which older Black women have come to understand that they are often devalued by White society. Beliefs that the health care system is detrimental to Black women may shape their perspectives of the healthcare provider and the quality of health care encounter. In her essay entitled "Why It's Not Just Paranoia," Lorene Cary (1992) explicates what I have termed healthy paranoidias held by some Black women of some Whites:

... Americans continue to value the lives and humanity of some groups more than the lives and humanity of others. It is our historical legacy and present fact; it influences the daily interactions of millions of Americans with Black people. That is not paranoia. (p.23)

And, while I will not argue that every single factor that has negatively impacted preventive health behavior among older Black women is the result of gendered racial bias. I do propose, however, that many older Black women share a group condition (as African Americans) of oppression and cognizance of that condition which has had a determinative role in the development of healthy paranoid and the conditioning of responses to experiences of racial bias over the lifecourse.

Black women whom I interviewed perceived, at times correctly, that they are treated differently in the health care system solely because of their “race,” and such “perceptions fuel mistrust of healthcare providers” (Gamble, 2002, p.41). Healthy paranoia may serve to modify the health behaviors of these women over time, because they or others in their networks of support have personally faced racial profiling, poor treatment, and disrespectful treatment in their daily lives.

#### Experiences with the "Gatekeepers" of Healthcare Settings

Many of the women spoke about their apprehension, and expectations of being misunderstood or being misidentified as biologically and "racially" different or inferior as a consequence of "being" Black from the moment of first contact in a healthcare setting. "Racial" identity and racial signification are socially constructed inventions that operate to condition the ethos of a health care system, thereby influencing the health status of older Black women. For instance, "being" Black has consequence and meaning based on beliefs that we as a society can perceive and define another human being as a separate different species of human, e.g., as a "race." The health care system uses these

established racial classifications, which have often been extracted or constructed from perceived racial characteristics such as skin color. Consequently, many of these ideas are believed to be part of the behavior of the support staff within a healthcare settings, especially when delivering service to older Black women, as Ms. Latrice noted, "I mean health care is just after all a microcosm of an overall racist America."

One of the critical issues identified in women's narratives about their experiences in healthcare settings was the perceived (or generalized) rudeness that they encountered which began while waiting to see the healthcare provider, for example, Ms. Juanita shared her observations from a recent visit to a cancer treatment center with a friend who had been diagnosed and was being treated for breast cancer:

When we walked in that office they were just rude from that point on... with all those questions. First of all, it's the idea that you're Black and then it's like, they think we don't get cancer. When you go to a "Cancer Clinic" a lot of people can pay and then some insurance has to take over and so then it was like questioning us with "why are you here, cause this costs money?" They don't even know what we got.

Ms. Juanita's discomfort at the clinic is based on interactions between the receptionist and her friend, who she described as having "excellent" health insurance coverage. Ms. Juanita felt that her friend was being questioned a little too directly about what she perceived to be personal information. Among many older Black women, being asked direct and personal questions from someone met for the first time is considered inappropriate and rude. Questions about their income, insurance and employment status and how payment for services will be rendered, from their perspectives, needed to be prefaced by an explanation of why the questions are necessary, and, whether these were questions asked of all patients. Otherwise, such questions were interpreted as racial



profiling or intrusive, disrespectful, and rude. They were also taken as evidence that the person asking the questions “lacked appropriate or sufficient "home training."

Living in the Southwest, many Black women have interacted with Mexican-Americans in healthcare settings. Ms. Sharon discussed her experiences when interacting with this population:

Some of my worst encounters are with ethnic minority [Mexican] people at the front counter. I changed dentists because of the people on the front desk. Anglo [Whites] people sometimes are more trained on what is professional behavior. They are not sitting on the phone talking to their friends or carrying on a conversation in Spanish while I am standing there, discussing me, because sometimes I hear my name. Appropriate behavior has a lot to do with culture and the Mexican culture is very laid back and very manyana.

Although she herself is stereotyping Mexican-Americans, she raises an interesting issue that crosscuts the insights shared by other participants - that is, it is not only Whites who are viewed as unwilling or unable to communicate appropriately with Blacks in healthcare settings. This has been discussed by other researchers who note that "the negative attitudes of Latino immigrants toward African Americans and the negative attitudes of African Americans toward Latino Americans—are part of the much larger system of white-managed racial bias," (Feagin & Feagin, 1999, p. 135). Later in the interview, Ms. Sharon amended her earlier comment and noted that some of her "worst encounters" were not necessarily just when interacting with Mexican-Americans, and that "being" Black meant that "the majority of the time...I'd say 99.9 percent of the time I have not had a good relationship or experience in a healthcare office whether there were mostly Latinos or mostly Whites in that office."

Ms. Latrice's observations speak to Ms. Sharon's comment, as she noted that most of her interactions with "gatekeepers" (if they were not Black) have seemed to be overly challenging and difficult for her as a Black woman:

Even trying to get an appointment through the office staff to get in to see the doctors, I think that African Americans are treated differently. In terms of what I've observed, it seems that we are met with a lot of discrimination when we are trying to access healthcare. [Blacks] go to the doctors and providers and they're just not treated the same and I think for certain amount of Black people that's one of the reasons they don't go, because they don't feel like they're not going to be treated the same as Whites.

Another participant similarly explained:

We [Black women] do not get treated right away. Other people come in [to a healthcare setting] and they are treated ahead of you, you know, and you are just treated badly. I can tell you that almost everyone that I know has had some kind of negative clinic or hospital experience, where you've had to go in and fight for care or fight for service and here you are sick as a dog, and you've got to contend with racist nasty receptionists, nurses, and technicians.

These experiences have led several Black women in my study to assume that interactions with "office staff" will be unpleasant or that they will also have to fight with the "gatekeepers" of the healthcare setting. These experiences and the "sense" that negative encounters will occur often prevents women from seeking healthcare services.

Another woman, Ms. Juanita felt that she was prevented from being her own best advocate in the treatment of her diabetes by the scheduling of her self-healthcare training to manage this disease:

I have been diagnosed with diabetes, and I wanted to schedule an appointment for the self-training on how to manage my diabetes and they told me it would be a year before they could see me for diabetes training. I had to wait over six months to find out how to take care of myself. In November, I found out that I had it and I couldn't get in [the class] until that next February, and then they gave me wrong dates so then they had to reschedule it, so I didn't get a chance to get in the class until May. That's sort of like "selling us down the river" on several levels.

She interpreted the postponing of an appointment, as an example of being "sold down the river" which is also a reference to the historical practices of Whites buying and selling Black people up and down the Mississippi River during slavery.

The nature of these experiences with a "gatekeeper" only seem to solidify perceptions of racial bias, i.e., that Black women may be intentionally blocked from accessing a healthcare provider by support staff in healthcare settings. As Ms. Naomi explained:

I do think that Black women are being treated differently when you walk into the office, and you say to them, "Could you get me in to see the doctor?" And, they say "No, we cannot see you till next week." Then you have somebody else, a White woman, comes in right behind you and he or she says "Oh, just wait over there, and I'll see if the doctor can see you." Colette, it's the privileging of them over me that also makes a difference.

The "difference" that Ms. Naomi is discussing is how the nurse or receptionist appeared to have placed a higher value on the White woman's request than that of a Black woman.

#### Disrespectful Encounters: Experiences and Hyper-Vigilance with Doctors

Being respected and having others show deference to their status is expected among older Black women. Signs of respect often begin with how they are addressed. Noting that they would be disrespected many women expressed the need to be prepared for verbal or non-verbal disrespect in healthcare settings. As Ms. Wiletta noted:

We like to have, you know, the respect because we worked so hard to earn the right to be called Mrs. [Ms., Miss]. Until we really want that respect right then and there ... now after you earn my confidence and if we choose for you to call us by our first name, it's okay. But just don't assume that you can because we're so used to being called Auntie, Uncle, and Boy, and Girl.

Ms. Renee provided another example of how disrespect may create problems in the healthcare setting recalling an experience with a new dentist in which he failed to properly introduce himself:

I went to a new dentist about two or three months ago and the nurse came in and prepped me, and then he walks in and right away starts putting his hands in my mouth to begin working on me, and I said, " Excuse me, I don't know you. What's your name?" He says, "Didn't I introduce myself?" I said "No." See, Colette, this is what I mean. When you're Black these doctors don't give you respect or even understand that you're a human being. He didn't even take the time to even recognize me as a human being.

In describing the lack of introduction of her dentist, Ms. Renee is also highlighting an arena where Black women may feel particularly powerless. "Being" Black has meant that others have historically defined these women. For example, due to the processes of racialization, a historical re-memory of the enduring "code of racial etiquette [which] directed Whites to treat Blacks as inferiors and directed Blacks to act deferentially toward Whites" surfaces in present intercultural communications within healthcare settings (Cornell & Hartmann, 1998, p.33). Consequently, fully adult, older Black women who grew up within the ethos of de facto or de jure segregation have faced a continuity of racial biases expressed through acts of discrimination, including verbal interactions with Whites in which they were addressed with disrespect as "Girl."

Similar to my findings Gordon, et al., (2005) writing about older Black women from *Health and Health Care among African American Elders* noted:

...it is extremely important to show respect to [Black women] in [healthcare settings] in order to put them at ease and establish rapport. This includes; at least, using respectful titles (e.g., Mrs., Ms. or Miss) before their surname unless they give you permission to do otherwise...(p.3).

Many healthcare providers / office staff may racialize a healthcare encounter because they do not understand the significance of using these titles when interacting with older Black women. Within the Black community, it is expected that one should address an older Black female with a deferential tone of voice using respectful word choices (this is why in this dissertation I have chosen to use a culturally appropriate form of address, i.e., "Ms" to preface each woman's pseudonym). Ms. Renee's statement of "when you're Black these doctors don't even understand that you're a human being" serves to identify the relations of power that often separate "being" Black from "being" human.

The gap in cultural knowledge with respect to discussing risk factors for disease with this population of women has been discussed earlier, however it is interesting to note that many of the women in my study felt that the choice of words or phrases used by doctors in sharing this information could be evidence of them being "treated differently" than White women, particularly when doctor's attempted to discuss health risks to specific illnesses. Thus, "being" Black has also meant that they would not only be disrespected as adult women but also denied the freedom or opportunity to readily engage some Whites as equals in these encounters, as Ms. Yolanda stated "I believe if I was White they would have talked to me differently..." she says, when describing a one-sided question and answer session during her routine physical exam (in a predominately White healthcare setting) where her healthcare provider had discussed risk factors for breast cancer and hypertension. In this encounter, Ms. Yolanda felt that had she been a White woman some of the doctors comments about risk might not have been expressed in the manner that they were. She explained:

I know "race" plays a large part in how we are dealt with when dealing with the healthcare. I've had doctors ask me questions that I don't believe they would ask if I were White. I would flat out ask him "what does my [skin] color have to do with that?" Maybe it's my ignorance, I don't know. I know you should have a good rapport with your physician, but he has said things to me...maybe he was focusing on it being a health issue for us, Black women, when he said "you people" but it was the way he phrased it that it did not come across that way. They [healthcare providers] need to be educated on how to say things to Black women so that they don't turn them off, cause maybe he was trying to help me professionally but he didn't come across that way.

The doctor was trying to explain that older Black women like herself were at a "high" risk for disease as a result of obesity. However, Ms. Yolanda interpreted his misuse of the term "you people" as a racial slur. "You people" when used by a White person in talking to or about African Americans is perceived as a derogatory signifier for "being" Black. As a result, I suspect that she stopped listening to anything else he had to say, as he has appeared to be racist.

Several women noted that healthcare providers failed to understand their descriptions of their symptoms, which made them feel that they were not being listened to and thus disrespected. As Ms. Sharon describes her feelings and behavior when reporting her symptoms:

Me, I just leave, it's not worth it to me...to educate White people. I don't want to have to be served by someone that I have to set straight. If they don't get it right away I don't have to be there. A lot of it is how we [Black women] convey how we feel some of the times because we don't always come across conveying what's going on. I say, well "you know I got a pain" and I am trying to discuss and trying to show you what's going on with me, like when I say, "I feel a little light headed" they ask me "what does that mean" and then I say, to you "I have those little lights before my eyes" but they don't get it. I think it's how we describe what's happening with us and maybe they don't understand our descriptions. I think each different culture has a way of conveying what's going on with their body. So it's sort of like they [healthcare provider] need to be interpreting it.

Many participants believed that not only did they have to wait longer to be seen but that their diagnoses and ultimate treatment was also delayed. Ms. Darla seems to attest to an ethnic notion of "what we all know:"

I've heard some stories of Black women who have been unfairly treated. I was watching a program that said when it comes to cancer and other diseases we are not well informed, appointments are set way back and they [appointment schedulers] don't try to get us [Blacks] in as soon as possible.

She further reflects that when these women finally did get in to see the doctor, they are not treated properly. Thus what is described here is almost a reciprocal cycling of miscommunication, misinterpretation and miss-care.

Being spoken to in an inappropriate tone of voice can be interpreted as having racial connotations and thus engendered skepticism and mistrust. Ms. Carlotta described how the use of a condescending tone to discuss an abnormal pap result with her healthcare provider was interpreted:

You know, they talk to you as if you have no idea what your body is about, you have no idea of what they are talking about, there's a condescending tone when they talk to you whether they are male or a female if they are White and that's usually the experience from the time that you walk in the door. See, I had been already diagnosed . The doctor, she asked me for my sexual history, and then boom! She decided for me right then and there that I wasn't gonna have any more children and told me that I would have to have major surgery. I asked her, if there were any other options and she flat out told me, No, so I said okay. Later on, I did some research on my own and found out that I could have had an operation or minor surgery to correct it using a contraption inserted into vagina and it would snip it out. That's what I mean!

These kinds of encounters are why some Black women may see the necessity of sustaining a healthy paranoia and using hyper-vigilance when interacting with White providers, as part of their preparedness. As one woman noted, "It's just scary. I go into an exam with that in the back of my mind and I wonder 'how am I gonna be treated'?" I can

go in there feeling like okay, "I'm a woman, I'm a person but how are you looking at me?"

Several women also noted that because of the nature of their experiences they tended to listen very carefully, especially when there were suggestions about invasive procedures or treatment options "but since we may not have exposure to other kinds of information we're not always so sure that what they [healthcare provider] are telling us is something that we should get done." Several participants noted that when an older Black woman gets a referral for further testing after an exam, she might be very skeptical, particularly if referred for gynecological surgery. As Ms. Juanita noted:

I think about the [Tuskegee] syphilis thing...and who's to say that it won't happen anyway...but you increase your chances because you're Black and that's the mistrust we have in our health care system, and what they tell us because if "we on the table and all of that's going on we still a done playa" that's just how we feel.

The necessity and value of Black women sustaining vigilance and skepticism also emerges in the following narrative when Ms. Sharon recalls a clear reluctance of a healthcare provider to discuss non-surgical options that were available as optional treatment protocols for her fibroid tumor with her:

I had a tumor once and she [White healthcare provider] said she would be doing surgery as the first thing and that bothered me so I spoke to one of my friends and she said, had I been blond haired and blue eyed she would have made sure she would not have tried to cut you. She would have explained to you other options that you needed. So, I didn't go back but someone else recommended another doctor, and I went and got treated, but I was really bothered by the quickness of my other doctor to cut on me.

Ms. Sharon had shared the proposed treatment plan from the first doctor with other women in an attempt to figure out what she should do. She was skeptical about the



doctor's quick suggestion for possible treatment options. After talking with other Black women she decided not to go back right away and her tumor went untreated until she was able to get an appointment with another doctor recommended by her friend. However, during the eight months from diagnosis to treatment, she became quite ill, so that when she finally returned to see a doctor she had no other options but to have surgery. Now you can imagine that when Ms. Sharon shares her experience with other women ( and she will) they may begin to expect a negative experience to occur during a gynecological procedure such as this, subsequently impacting whether they would continue to seek care.

Mistrust and feeling disrespected seemed especially poignant among their narratives, with respect to experiences in these exams. Quite a few of the women noted that being disrespected in healthcare encounters was often a precursor to skepticism, mistrust and a signal to be vigilant especially when referrals were offered by healthcare provider's or how doctors addressed their health questions. Women indicated that mistrust was used to filter any suggestions from healthcare providers about procedures or treatment options that resulted from having one of these exams. This is also where the conditioning of a response to racial bias occurs.

I'm sure that just like other groups of women have in other studies, Black women in my study indicated that their skepticism was heightened if when they questioned or probed their healthcare provider for information and responses to those questions were ambiguous, uncertain or controversial in nature the value of what their doctor was telling them decreased and engendered further mistrust of the intentions of that doctor. However, since these women also happen to be Black, as Ms. Willetta observes "when

you ask them something about a gynecological procedure and they talk around you and at you using long sentences, then you put two and two together when you hear about those in-office procedures or surgeries that have gone wrong with us, well...you just know."

Ethnic Notions: The Meaning of Fear, Opening of Pandora's Box and What We all Know

Ethnic notions, fear and fatalism are part of the nature of an experience within a healthcare encounter. Several of these factors were noted in chapter one as posing barriers to this populations health seeking behavior when deciding to access a mammogram /a pap exam. These perspectives also emerged in the narratives of older Black women specifically when we began to talk about their experiences with mammograms, pap exams and diagnosis. Opening Pandora' Box seemed to emerge in the narratives to mean that once a Black woman was diagnosed with breast and/or cervical cancer these diseases were bound to be fatal because they personally knew of very few Black women who had actually been treated optimally once they had been diagnosed. Many of the women in my study agreed and also noted that fear of the unknown may keep other older Black women from utilizing mammograms and pap exams. For example, Ms. Karen shared her cultural belief on the causes of breast cancer:

I examine my breasts myself every time I get in the shower. As far as mammograms are concerned, this is my own personal opinion, I always [believed] that most women came up with cancer after the mammograms were started because they *smoosh* your boobs and it hurts. I've always believed that if you punch on your breasts or hurt your breasts, that can cause cancer...that can cause those lumps to form in the boob and stuff. Then I keep thinking about breast cancer and I think of chemotherapy, that is pretty potent ... it's pretty deadly, it can kill the good cells as well as bad ones.

As a matter of fact, many these beliefs were present among several women in my study who did get both exams, as this fear would surface in some of their narratives. Ms. Darla was one of first participants to use the term "opening Pandora's box" to describe her feelings about these specific exams observes:

Going to get checked is important, but more personally I think it's critical in many diseases, like breast cancer and yes it's Pandora's box, a lot of times if you get checked you now have more choices, you have to get something done early. Then you do what? And that's the Pandora's box. What do you do about what you find out from that information? Because some of the things that have happened to us... and we then think to ourselves, "are they using me as a guinea pig?" The first thing that doctors want to do is cut, even if they don't need it, now I totally grew up with that. Then thinking, well, he [healthcare provider] can only one or two things kill me or make me a little better. So you have to kind of pick and choose your exam to take, pray and try to use the wisest decision that you can use but a lot of us don't even go we're just so afraid.

As Ms. Wiletta observed, "that's just the thing, the fear. I've heard some women my age say that they never got a mammogram and that they aren't gonna get one now. It's fear, and they just don't want to know."

Ethnic notions emerged as part of the narratives when several women said that they felt that they were made acutely aware of their body during a pap exam or a mammogram. Once inside the exam room, particularly in gynecological healthcare setting, women expressed concerns about receiving equitable care in relation to what they had heard or knew about these experiences that were tied to "being" Black, "Colette, like I heard about that Black woman who got the speculum left in her while the doctor went to see about another patient, now that wouldn't happen to a White woman. It's a true statement." These are the kinds of observations that are routinely shared among Black women.

Ethnic notions about mammograms were also often associated with having large breasts. For example, several women connected their belief of expected harm to the Black body that was related to the breast size and getting a mammogram:

I have a cousin and she is a 44DD and she has never had a mammogram and she's 43 years old. She heard that heavy women who have their breasts squeezed (that the tissue) can pop out of the nipple. She was going to go to UCLA medical because they have a program where larger breasts can be accommodated, but she said she doesn't trust the doctors cause they never said how they were gonna do the test...

I suspect that if a healthcare provider had explained how larger breasts could and would be accommodated in a screening exam, some of the anxiety may have been reduced.

Ms. Wiletta explained:

We didn't self-exam our breasts until recently, so like when they [technicians] smash them [breasts], and are not gentle with them; we probably think its weird. You know, I had a cousin who died of breast cancer and she had the biggest breasts in the world, like mm, pushed up in this dress, and she used to say "I'm not gonna be feeling on myself" and you know what? She died of breast cancer. She found a lump and had it taken out but it was too late to save her.

Other women shared other concerns about mammograms. Ms. Bonita, a large bosomed woman had undergone three mammograms within one year. During her interview, I probed why she had needed repeated mammography and she said that she wasn't too clear as to why she had to have so many mammograms in one year, but noted that it was quite possible that all of her breast tissue was not clearly defined with the "outdated" equipment used at her healthcare setting:

I had to have three mammograms in one year. And the exposure to those x-rays, was my concern. How much x-ray can you be exposed to? One of the doctor's flippantly said "You'd get more x-ray from the Sun than from a mammogram." I don't think so! Cause, I'm thinking that you're really concentrating lot of x-rays right here in my body and if it doesn't affect my breasts it's going to affect something else. I know that other women are concerned too. So most of our

[Black women's] concern may be about the radiation and thinking that all you are is a guinea pig to some of them.

One would have thought that when she asked about x-rays her doctor would have used this as a "teachable" moment to enhance her knowledge of how mammography actually works. Instead, this particular healthcare provider made a joke about the rays of the sun, which did not help her to connect the dots, so she made her own connections using beliefs about being a guinea pig.

Ethnic notions sometimes evolved from / reinforced righteous skepticism as part of mistrust because of what women had heard and what they felt they knew. The significance of mistrust was extended by some of participants to the expectations for treating cancer if as a result of a mammogram / a pap exam cancer was detected because of what they had heard or knew. Several participant were skeptical about their level of their participation in the treatment decision- making process if they were diagnosed with breast or cervical cancer, suspecting that the information and choices provided or offered to them by a healthcare provider would not be among the best options available. Ms. Cathy shared her perspectives on mistrusting diagnosis from mammograms:

Women like myself I know what happened. I am the older generation. It's a big thing in terms of trust. I have been labeled high risk for breast cancer so to be on the safe side I get my mammogram, but I' m not quite sure I trust them.

Although Ms.Cathy has contextualized her beliefs over a lifecourse with her experiences of racial bias and feelings of mistrust, she stills seeks and utilizes mammograms, because somewhere along the line she has been given risk information which she trusts.

Ms. Sharon, and Ms. Renee shared with me other women's convictions on what happens once a Black women is diagnosed with breast cancer:

A young Black woman told me that she wasn't going to do it because "if they found something," they just might cut off her breast. So, Colette, it's not just us older woman who believe this. And what's so bad about this is that it is because of the way we've been treated for years.

Ms Renee also had something to say on the subject:

I've heard women say that the treatment is very, very bad once you been diagnosed and that's why a lot [of Black women] won't go because they don't want to be mistreated. They're very fearful because of the study, the Tuskegee that we knew about [shared among Blacks] by word of mouth even before it was written about and distributed over the news. They are distrustful.

Ms. Wiletta was another participant who shared her own ideas about the treatment of Black women's bodies and gynecological procedures as a result of a pap exam " I believe that if something was found within a Black woman, and it comes down to hysterectomy I know that they snatched out women's uteruses without giving any other treatment or test or stopping or, anything." Another woman also spoke about what she heard about doctors "leaving things inside" a Black woman's body:

I've heard those stories where the doctor left the office and left the instrument in a Black woman. I have been told by Black women that they wasn't going to do it cause they just might cut on them or cut off the breast without having foundation for it and it is not just an older person that thinks that way.

Ethnic notions about pain and discomfort may also pose a risk for late detection, diagnosis, and treatment for breast cancer as Ms. Bonita gives her reasons why some women may not return for another exam:

The reason why they won't go back is that they know that it hurts which discourages them. The one thing that I don't like is that they share this with the younger ones and when they go to take a mammogram with fear like, "Oh its gonna hurt" I wish I was in the background saying "No, it's not gonna hurt that much, cause you ain't got that much for it to hurt (laughter).

The observations of these participants clearly offer us some reasons why Black women whether over or under forty years of age may not regularly access these screening exams.

Although aging is often considered a factor for heightened risk of some cancer (s), many of the women that I interviewed knew other women who did not see advanced age alone as a mitigating factor. Specifically, many of these women felt that they knew that regular sexual intercourse was the reason for seeking a pap exam. In fact, several participants had friends who felt that younger, more sexually active women were more at risk for some cancers. As Ms. Yolanda stated:

I find a lot of women my age, especially those who are without a partner, believe they don't need to have a pap because there's no activity in that area. I find that disheartening, because it isn't whether or not you're active [sexually], I tell them it's whether or not you're taking care of yourself.

One of the participants admits that she too has been reluctant in the past to seek screening exams, as Ms. Latrice notes:

I am one of those women that waited until they were 46 till having their first mammogram and that's just because I was trying to stop acting stupid and go ahead and get it taken care of. I was more scared of getting cancer so I did it even though breast cancer doesn't run in the family on either side. That's it. I was scared of the unknown.

These perspectives construct patterns of utilization behavior around "what it is that we all know" with fear of the unknown, thus, together these may also be key components in late stage diagnosis or in lower (reported) rates of mammography and pap exam utilization by older Black women.

So we see that emic and etic perspectives, alone or in tandem may impact patterns of health behavior, and thus, are to be considered factors in late stage diagnosis or in lower (reported) rates of mammography use by older Black women. Consequently, an

older Black woman may embody the power struggle of the relationships between emic and etic perspectives along with their collective re-memories as part of her fund of knowledge and ethnic notions about the kinds of things that go on in mammograms and pap exams.

### The Nature of Sexual Stereotypes and Gynecological Exams

Women were concerned more broadly with negative sexual stereotypes of Black women and saw evidence of this in their everyday lives. These stereotypes are capable of generating multiple perceptions about biological "racial" differences " while at the same time contradictory stereotypes may emerge (Comaroff, 1985). For example, "mammy" dolls and Black female figurines with exaggerated physical features such as big lips, or in naked poses, with big butts and breasts can still be found in antique shops and popular culture across the United States and Europe. In her research Diane Roberts (1994) notes how the imaginations of some Whites have incessantly depicted Black women loaded with sexuality:

...beginning in the 1600s, Whites often portrayed Black women naked, and with exaggerated sexual organs. Whites have perceived Black women's bodies as excessively and flagrantly sexual, quite different from ...the ideologies of purity and modesty that defined the White woman's body. ( p.2 )

Granted the women in this study represent only a small sampling of older Black women and their experiences. Nonetheless, in the everyday world of these women, it seems that they grapple with the meaning of what is appropriate and acceptably female in a society that has often been inscribed, contoured or embellished their health status through White supremacy and White privilege.



One of the major barriers noted to screening exam utilization among the older Black women in my study was their knowledge of a pervasive stereotypical belief held within the larger society which I noted earlier but bears restating in this chapter, that Black women are amoral, and promiscuous by nature, and thus, hyper-sexualized beings. These beliefs may in turn create expectations among older Black women when they are utilizing screening exams to detect / prevent these diseases, and they may feel the need to assertively respond because of their knowledge of the existence of these stereotypes. As one woman noted that she pointedly admonished her doctor to be gentle during her pap smear exam because she is "not like a rubberband down there."

Participants felt uncomfortable during mammograms and pap exams, noting that women of their generation sustained a cultural practice of modesty, morality and were sensitive to the ease with which some Whites asked them to disrobe or touched their bodies. These actions were seen as disrespectful and precursors to possible mistreatment. That is they expected to be "treated differently" because of the stereotypical assumptions that they felt some Whites have made about Black women bodies and sexual behavior:

They [healthcare providers and staff] need to understand what an African American woman of a particular age group might be going through or has gone through and not only our feelings but having some core knowledge of what it's all about. They don't get it, we are different, and there are differences in cultures. Like if you're a White woman, you probably don't care if parts of your body are shown. It's not an issue for you. But if you're a Black woman, you are much more concerned with being covered up.

Part of the discomfort that Black women experienced may be that they are made to wear "one size fits all" paper robes that may not cover their body appropriately. Many of them also discussed how exposing one's body made them feel that they were somehow not

viewed as moral or chaste as White women. In other words, because of the stereotype of Black women as highly sexual, it was assumed that they would be comfortable sitting in public in scantily (flimsy) paper robes.

Several women said they felt that were "touched" in a culturally inappropriate manner during a mammogram / pap smear exam because they were Black. As one woman stated, "We are not like everybody else, there is a difference about how we like to be touched. It's our own comfort zone. You don't just start the exam as if it's a routine thing 'down there'." Another woman shared one of her experiences in which she felt inappropriate touching not only resulted in her vocally assertive response but also made her feel that she herself had exhibited "racial" bias. She explained how a White healthcare provider had to be "set straight." She said, "When I go to my White male gynecologist I tell him straight out about stretching me" (she felt that he was a little too free with his pelvic examination in the past). So, you see, I have to be racist to get the service that I need cause my health is involved." Ms. Naomi's concern is an echo of another woman's comment about "not being a rubberband down there." To both women, references to "stretching" and "being a rubberband" implied that the doctor thought that they must be extremely elastic due to excessive sexual intercourse. These types of experiences shared among a community of Black women have led them to anticipate negative encounters and to become assertive and sustain vigilance to ensure that they were not touched, disrespected or otherwise treated in a manner that was inappropriate. One woman noted: "I don't think we are very comfortable when we go into the doctor's office for these

exams. As I see it, we have learned to be more aware of our bodies. And by the time you're over 50 you know what they think about you." She continued:

They want you to take your clothes off, right away. We're still are not comfortable with exposing ourselves to them. It's a cultural issue. Even though they try to paint us as having early [sexual] experiences, as young girls. No we do not. If an African American girl becomes pregnant early it's because it was her first time, and she did not have the information for prevention, cause we [Black females] are not promiscuous by nature.

Ms. Sharon is one woman who felt that older Black women often suspected that they were being compared (often to their detriment) to an "ideal" e.g. White woman within these types of exams:

We Black women feel so vulnerable, and were so taken advantage of in the past, I mean, America has just done a job on us. In our health status and not taking care of us physically and not were being concerned about our healthcare. And it's also made it so we don't really value ourselves. We don't think much of ourselves. African American women, we don't, because we are so compared to the White women, and what they do, how we should look, how we should feel and how we should act. That we ignore a lot of things about ourselves because it doesn't measure up to what we feel we should be.

This participant, like other women in my study, is describing a process that may have become an expected occurrence among many Black women. What is largely unrecognized in the literature on Black women is how a devaluing of the self may lead to a lack of caring for one's self, particularly in an arena where one is made to feel uncomfortable or is actually "treated differently."

### Experiences Shared Through Networks of Support

Remembering the experiences of mistreatment or of being "treated differently" shared by previous generations creates a space in which older Black women become

"cultural subjects." In this role, they use the experiences of others as part of re-memory to guide their present day perceptions, expectations and beliefs about what will occur in healthcare settings (Chavez, et al., 2001, p. 1114). These experiences sustain a legacy of mistrust as part of "righteous skepticism," because although past experiences may be rooted in the atrocities extending back to slavery, they are believed to continue in the present day. Ms. Carlotta recalled an experience in the clinic of a teaching hospital in which she felt that she was used as a teaching tool and test subject without her consent:

My age group remembers using Black people as guinea pigs to test syphilis. Going into hospitals that had Black people in it and using those places as teaching hospitals. I went to the doctor once for a test and I don't think he was treating me as a patient. My test was for the student and that's what I believe and so I never went back to find out how the test came out. I felt like he was using me and that's why I never went back.

From her comments it is clear that the legacy of Tuskegee is still being deeply woven into the tapestry of Black cultural life. More importantly, her experience and ideas about tests have been filtered through the memories of being a "guinea pig" in the past, which influenced her decision not to seek the outcome of her test results. Nor does it seem that administering her diagnostic test in the presence of medical students was communicated in a culturally appropriate manner.

Other women knew about healthcare experiences that were passed from generation to generation within their families. As Ms. Latrice recalled:

When I was growing up there was not a hospital in the town where I lived that accepted Black people. My Grandmomma had a fibroid tumor that ruptured, and really she died because we had to travel 45 miles to the nearest hospital and she died before my dad could get her there, so there are just a lot of things that go on with us [Blacks]. Even with the dentist, I can remember my Grandmomma going to the dentist and having teeth extracted that today could have been filled and

saved, and my great granddad never had any teeth. There was like no prevention for us, and that kind of thing, and I think having grown up in that environment I am very skeptical when I go to the doctor.

Thus in this quote, we see how past history becomes ingrained and embedded in these womens narratives. She continued:

I know that Black African Americans aren't treated very well. It's still there. Like for three years my 16-year-old niece went to try to get tested for headaches and the doctors said it was all in her head, and she had no tests. Recently they found a tumor this year the size of a grapefruit and she has been given a year to live, all this because she was not taken seriously.

Several women believed that the treatment that Black women may receive after diagnosis would be inferior to that given to White women based not only on their perceptions of inherent racial bias as being part of the health care system, but also as part of the shared experiences of others in their networks of support. As Ms. Naomi recalls one of her girlfriend's recent hysterectomy:

I have a friend in Phoenix who went through a hysterectomy because of an abnormal result from a pap exam. Get this, she was told after the operation that maybe she could have gone another route. Now, this is what has led her to mistrust. This woman is an educated professional, but her experience has led to skepticism. In some ways we [Black women] have been burnt so bad as individuals and hearing the horror stories from family members and friends that we are just generally very skeptical because we believe that we are not seen as real people to them [healthcare providers].

As part of a fund of cultural knowledge, the experiences of other Black women have a correlative relationship with decisions made on individual health behavior. No doubt, the experiences of Ms. Naomi's friend have been shared within this community of women just as she shared her girlfriend's experience with me during our interview. As another participant summed up the significance given to the shared experiences of others:

Someone goes to the [White] hospital and dies and then a lot of information is built up and shared among us about that death, which is not necessarily based on fact. We [Blacks] also don't ask a lot of questions, we don't stay on top of what's going on so sometime, and we just go on what's being said. But, Colette, I was told about a group of Black women from someone who knows that they were at King's County hospital clinic and they had pap smears done, and the women didn't hear from the doctor so they thought that they were okay. But years later, it was found that these pap smears were still in the refrigerator and were never analyzed and some of these women had died of cancer. So that taught me to never wait on them [healthcare providers] and to call and call till I get my results. Even though they say if you don't hear from us its okay, I still follow up.

Ms. Yolanda's observations are insightful; first because she is talking about how specific inaccurate information about pap exams may be "built up" as a storehouse of knowledge among older Black women as another aspect of (ethnic notions) "what we all know," such as of how one may enter a White hospital and not coming out alive. Secondly, she is also referencing the fact that having lived their lives simultaneously as members of and participants in sociocultural contexts and realities which are constructed through "being" Black shared experiences even if they may be contradictory or untrue are not explored further because they are seen as supporting the documented realities of past abuse and mistreatment of the Black and female body by healthcare.

Several participants believed that Black men and women are constantly denied what should be basic human rights. Ms. Juanita recalled how one of her family members was treated:

I have seen it [mistreatment] personally. People in my family have been victims. My ex-mother-in-law went to a clinic and she had cancer in the carotid artery. They would have to actually reconstruct her face, so when she went to a clinic they told her she had to come up with \$600.00 dollars cash money before they would do anything for her. She lived in the projects and she was very, very uneducated, so she called me, and I have refused to take no for an answer always. Anyway, her husband had died recently, and I asked her if he had insurance from his job and she said "no," because he was dead. So I called the place where he

used to work [he was one of the few blacks that worked there] and they had not shared with her that three years of health coverage was for family even after his death. I mean no one told her. So the neurosurgeon was paid, her face reconstructed and the cancer removed. But nobody bothered to tell her about the insurance coverage. That's the trust thing. It's like she wasn't worth it but it was okay that her husband had worked there for 20 something years and they had not told her what her benefits were so the idea is set-up for us to not being able to trust White people.

In this instance, mistrust arises because the hard-earned health coverage of a Black man was either not shared with or not known of by his widow. Ms. Juanita also read the employer as not believing that a Black widow of an employee should receive the same benefits as a White employee's widow. Similarly, another woman, Ms. Yolanda shared her own past experience as a young student going to a White dentist for care:

To this day I still have a space there [ in her gums ] where I should have a tooth... because I was a little Black student, a little Black child with a check [ a cash allotment for her dental work] It was a quick fix for him [ the White dentist] it was easier to take the money than treat me several times. I think that one experience really set it off for me because I didn't realize until years later how his pulling that tooth affected the rest of my teeth.

Importantly, despite the fact that these experiences occurred over 30 years ago, it appears to have colored the perceptions of these women adding to their present day expectations of preventive healthcare delivered at the hands of Whites. These are important perceptions to note because they reference the source of some of their mistrust as part of their fund of knowledge based on a lifetime of "being" in a Black body.

The "racial" composition or landscape of the environment (i.e., a Black neighborhood versus a White neighborhood) in which the healthcare setting is located may also impact ideas about receiving less than equitable care. Ms. Carlotta, shared her

beliefs on why Blacks are mistreated and how this resulted in the death of her stepfather at a predominately White hospital:

Take my Step-Dad, for instance, he had insurance and he had a heart attack and he went back to drinking, ended up in the hospital again, and he died. I think he died because the hospital said "here's this big Nigger in here again, still drinking and smoking...oh well, let him go." Now a friend of mine, her ex-husband is an alcoholic, and a heavy smoker, he had a heart attack and he went into the hospital, and he had no insurance and he got surgery. He got top notch treatment, had his lung removed and he went back smoking again. His legs were swollen and he goes back to the hospital again, oh no they won't let him die because they will take care of him even though the man has no insurance and he's a drain on society. They took care of him because he was White in a White hospital.

In recalling these two different experiences (one White and one Black), Ms. Carlotta saw not only how "race" matters but also how "being" Black may be directly linked to having a negative health consequence. This is a good example of how being "treated differently" because of "race" lays the groundwork for expectations for mistreatment. Similarly, Ms. Latrice shared her beliefs about the differences in the lengths of her husband's hospital stay when they lived back East:

I believe that we [Blacks] have a tendency to be on the low receiving side of quality preventative care. I could see it happening in the way my husband was treated in his exams. He is diabetic and when at a hospital in the Black neighborhood the treatment was different and he was there only 2 – 3 days, but when we went to a hospital in a White neighborhood, the care was better and the stay was longer.

Many women openly discussed the absence of Black healthcare providers serving their needs in Tucson:

I've noticed here [Tucson] it seems that there are not a lot of African American physicians and clinics that seem to focus on serving Black health needs. There doesn't seem to be a centralized place where we go to the doctor or to a clinic and that's been part of the challenge. Even when we go to health fairs, there are not a



lot of Black's there to give us information or that come to the health fair to even learn about a lot of the services so that's been another challenge for us.

Another woman noted:

We are rushed in or rushed out and nobody talks to us or takes the time, we don't even see ourselves in the healthcare profession particularly here in Tucson. There are a few Black nurses, a few Black doctors. But when you go in [to a predominately White healthcare setting] you're trying to tell somebody about you and your health who has absolutely no frame of reference, absolutely no clue about the Black experience or your history, they probably have never even seen a Black person. So for us it doesn't make it important to go get checked out because of how we are treated.

### Experience with Medical Training

Women in my study who themselves had trained in the health care system were skeptical of the type of training that they had received. For example, Ms. Juanita, in recalling her own training as a health care professional noted that although she received her training in the late 1960s (over forty-six years ago) many of those providers and professionals that were trained with her are still in practice, or are now educating and training other public health professionals and healthcare providers. She believes that they are still perpetuating their outdated ideas about Blacks:

First of all, there were very few of us [Blacks] that happened to be at that particular school because they were just starting to let Blacks attend and the instructor would say stuff like Nigra male and Nigra females not Negro or Black or African American but Nigra when discussing Blacks. I think of those kinds of terms as influences that are taught about us, because providers that work together they talk and the same perceptions and language that they heard, of course, would be shared with their friends.

She suspects that misrepresentations based on "race" are still part of the language of education and training of doctors and nurses. Although it is doubtful that this slave term for Blacks (Nigra)<sup>xxviii</sup> which was used in the 1960s is still being used today, what is

important to her is that this utterance was used in an educational / training setting of new healthcare providers who are still in practice and providing care today, and thus her comments speaks volumes to the continued processes of racial hegemony and reification of the Black body.

Another woman, Ms. Carla, described her training experiences while in nursing school where there were Whites in her classes:

Girl, when I went to nursing school at the medical school in North Carolina, it was appalling to me sometimes. I'll share with you some of the videos (if I can find them) that they used and I don't know why they used them, but racism, that's why they did it. I'll just tell you that there were videos shown of African Americans in a very demeaning way and they would show it in the classroom as a training video. They would use videos where they seemed to find Black people that were like illiterate to do interviews or they showed very negative things about us, and it was appalling. Now I don't mean that in a negative way but they didn't seem to have videos of other races, like White people, that were demeaning like that. Blacks would be at the clinics, and there were a lot more African Americans there that did frequent clinics and sometimes my White classmates would ask me "do Black people really do \_\_\_\_?" I'd say, "Of course they don't." But I know most them would wonder, so why do they use these videos and everything that shows Black people that way?

This training may have left negative perceptions about African Americans, which could still last in the memory of a healthcare provider.

Other women shared their perspectives from friends, for example Ms. Darla has a friend who is a White doctor, whom she frequently talked with. She shared with me the information that he had told her about his medical school training:

I have a friend that went to medical school. He's a doctor right here in town and he says when he was in school and learning about Black people and their health they gave him a different animal to dissect. He said that he didn't get the same animal as when they were learning about Whites. I think what he was saying was that they [the medical school] felt that doctors couldn't learn what they were learning about on Blacks so they gave him the animal that was close to Blacks,

like a monkey. So what he meant was that they [Whites] haven't studied our bodies. That's why I believe that they just don't know too much about us.

Repeatedly what surfaced in my interviews were women sharing negative experiences of medical school training of themselves or others. These stories were well circulated in the community. As "what we all know" about the practices of a health care system and the training of healthcare providers that continues to exhibit a legacy of disregard for the Black body is not to be trusted.

Screening exams using radiation were discussed by some of the women in my study as specific exams in which vigilance was needed because of their own training. One woman, Ms. Carla had been an x-ray technician in Chicago and saw first hand how racial bias in training became part of diagnostic techniques and practice of the White technicians that she worked with:

I can say that as little as 10 years ago there was a firm belief among many of the radiology technicians that I worked with that the cranium of Blacks was thicker so we had to increase the amount of radiation needed to take an x-rays of their skulls. Boy, this really pissed me off. That they would make a difference in techniques based on that ["race"]. So I called them on it and refused to do it until my supervisor could show me in our manual that it said to do that. He couldn't show me this documented in any of our training manuals that this is what we had to do, but they had been doing it anyway because in their training they had been told to do so. So if you look at the big picture, if they had that type of ingrained prejudice based on how they had been trained or told in their training and you multiply that by the number of healthcare providers and diagnostic technician over the world or just limit it to the U.S., then they have to have these bias, so when we walk in for a test it's ingrained, whether it be true or not because you're Black, and you will get different care.

In her understanding of screening exam settings, "race" as in "being" Black becomes based not only on physical distinctions, e.g., skin color, but may be extended to affirm internal physical distinctions.

Several women commented about the practice ramifications of receiving your medical training from a historically Black College or University [HBCU] as opposed to a predominately White institution. Ms. Bonita who has two physicians in her extended family observed:

I know that when Black doctors are trained at historically Black universities their [White] colleagues do not treat them with the same level of respect and dignity as White doctors who graduate from other colleges. Black doctors are often asked to take additional coursework before they come to practice their profession and they are always questioned in terms of their skill and ability.

Furthermore, being a Black healthcare provider trained in a predominately White setting means that you may also have experienced "micro- aggressions" of racist behavior. In my literature review, I ran across an excerpt from a volume of personal stories of young Black doctors trained in predominately White institutions that exemplifies Carroll's (1998) definition of the mundaneness of exposures to daily oppressions that are tied to "race." In the narrative below I have excerpted Dr. Ugo A. Ezenkwele's experience. Ugo had recently finished his emergency medicine residency at the University of Pennsylvania and is now an assistant professor of emergency medicine at New York University-Bellevue Hospital Center. In a recent article, he was asked to share his experiences as a Black healthcare provider. In his narrative, Ugo recalls the unexpected comments of a White patient:

I entered the patient's room with a bit of apprehension. I so wanted to make a good first impression on both my first urology patient, and Dr. U (who was overseeing his residency). The patient was a White, short, heavysset man. I could see that he was sizing me up. I smiled stretched out my hand, and introduced myself. Arms folded, he glared at me, looked away, and cursed under his breath, "What the f---is this? Who the f---are you? I don't want to talk to you! I f---don't want any affirmative action working on me, let alone a Nigger." He continued,

"What the hell is going on? I'm getting the f---out of here!" With that, he stormed past me through the door and down the hall, all the while swearing and mumbling something about "the world being crazy to have let Niggers into the medical field." I was floored...I had done all the right things, all the right exams, years of training and represented my family well, had numerous degrees and all had been rendered meaningless in a matter of seconds. I was torn between wanting to follow and educate him or knock him on his ass...to have him suggest that I had no right to be here...simply because I'm a Black man, having to defend myself to him, to myself or to anyone else? (2003, p.16)

Thus, "being" a Black doctor in a predominately White healthcare setting may also influence the type of verbal and non-verbal cues and vocal engagements used by White patients when a healthcare provider happens to be Black. The kind of reception that Ugo received may be why we see so few African American doctors as healthcare providers.

#### UNDERLYING CAUSES OF NEGATIVE HEALTHCARE EXPERIENCES: AN ANALYSIS

Disparities in older Black women's health and well-being are often constructed and filtered through "non-clinical" influences, such as cultural differences, individual experiences, and beliefs about "race," or "being" a Black female (Geiger, 1957,1996,1997, 2002). The adoption of timely and routine access to screening exams could ensure the provision of the best possible care. However, there is an inequality in the delivery of health care to "racialized" populations within these settings, as noted by Sullivan (2005): "...something is contributing to a real difference in the way minorities are being treated in the health care system..."(p. 3). R.J. Blendon noted of this back in 1989, as did Gamble in her research in 2002:

African Americans were more likely than Whites to report that their physicians did not inquire sufficiently about their pain, did not tell them how long it would take for prescribed medicine to work, did not explain the seriousness of their illness or injury, and did not discuss test and examination findings. (p.41)

For example, the nature of the experience of an older Black woman within a healthcare setting is constructed from ideas about difference, for example, unfamiliarity with intercultural communication may cause misinterpretations, and misunderstandings occur. As such, cultural differences are critical elements in the ability to mediate risk factors to their health and well being. Despite declining death rates over time, African Americans have reportedly had consistently higher incidence and mortality rates than Whites. The accumulation of negative healthcare experiences contribute to the poorer health status of Black women, and that status is indicative of larger ecosociocultural issues that operate to give meaning and substance to their patterns of health behavior. Older Black women are a particularly vulnerable segment of this population and are at higher risk for chronic diseases and more disabling conditions as they age. According to Geronimus (2001)

...African American women experience early health deterioration as a consequence of cumulative and repeated experiences of exclusion...and continue to experience health outcomes that suggest, at least metaphorically, an accelerated aging process... (p.133).

Avoidable inequities occur in the quality of care that an older Black woman may receive in a healthcare setting. Many of these factors may influence actual health behaviors according to the women in my study, and thus increase the conditions of risk for late diagnosis or the receipt of less than optimal care among this population, simply because the significance of these behaviors is not well understood by Whites (Bailey et al., 2000). For example, it has been my experience that Whites are often at a loss when they hear Blacks complain about racial bias because they may not believe that racial stereotypes influence their own personal interactions with Blacks. As noted by Williams (2003)

earlier " ...since Whites themselves also may encounter rude behavior from other Whites in public settings, they might conclude that Blacks are simply mistaking unmannerly behaviors for racial bias...(p.17). Yet the women in my study have perceived, at times correctly, that they are treated differently in a healthcare setting solely because of their "race," and such "perceptions fuel a mistrust of healthcare providers" (Gamble, 2002, p.41). In addition, others in their networks of support who have personally faced racial profiling, poor service, and disrespectful treatment in healthcare settings have shared their experiences. Thus it will be important for healthcare providers "not to ridicule but to pay attention to" all of these factors (Gamble, 2002, p.40). Together these elements are contributing and co-creating factors to the existence of "avoidable" inequities in the health of older Black women because they are created out of misinterpretations, misunderstandings and miscommunications.

In previous chapters I have offered evidence from both current research and the participants in my study that has explicitly linked perceptions, and expectations about the "race" and "being" Black as key factors that become part of beliefs that sustain vigilance and skepticism among older Black women. These ideas become part of a "mindfulness" thereby influencing individual healthcare seeking behavior (Geronimus, 2000; Musgrave 2002). I suggested that the receiving less than optimal care because of one's "racial" identity is a result of gendered racial bias. Engaging in such practices creates inequities not only in the quality of care but also in the health status of this population. As Geiger (2002), notes, "it seems reasonable to conclude that neither the health care system as a

whole nor individual providers are fully insulated from attitudes toward race...that are prevalent (though often unacknowledged) in the larger society (p.440).

The nature of experiences based on "race" occupy an important role in the creation of a negative encounter that will no doubt impact individual behavior, and the deliver of that care. Racial bias is part of hegemony. Antonio Gramsci (1995, 2003) has observed that our human subjectivity in general is the reflection of a consciousness "of what one really is [and entails] 'knowing thyself' as a product of the historical process to date which has deposited in you an infinity of traces, without leaving an inventory (p.324). Stereotypes maintain their discriminatory value at all costs, i.e., becoming rigid and fixed as part of the foundations for the construction of institutions and processes within the larger ecosociocultural environment, and within the ethos of that cultural group. For example, several of women seemed to have adopted a style of hyper-vigilance, preparedness that reflects their righteous skepticism, collective re-memory, mistrust, and fear. They bring historical and philosophical significance to their individual and collective advocacy and resiliency, with respect to utilizing healthcare. In other words, they have constructed an "interpretive community"<sup>xxix</sup> that also helps them deal with the micro-aggressions of racial bias that may arise when they present their Black and female bodies for care (Said, 1985).

Gramsci's statement referred to earlier is also significant here because several of the older Black women, specifically noted that it was not only Whites but also other ethnic minority groups, such as Mexican Americans who seem to be oblivious to the significance of "being" Black. Living in the Southwest, the women in this study talked



about their experiences with office staffs who were non-White, such as Mexican-Americans. In the Southwest, Mexican-Americans may carry anti-Black images and attitudes as part of their acceptance of their non-racial but ethnic identity within the cultural milieu of our "racial democracy." The racial and cultural hegemony of the nation state internally, as well as externally, constructs and recognizes racial identifications as strategically necessary because of their use in the functioning of power institutionally, socially, economically, and ideologically in our society. As noted by Feagin (2000) "in one way or another, all Black Americans continue to suffer discrimination because of White domination of Black Americans ...as part of a major organizing principle for group life in the United States" (p.128). Experiences and expectations of racial bias seemed to accumulate in the day-to-day living of older Black women. Thus older Black women have made these "ethnic notions" part of their collective social memory.

Kinesic (body movement) factors were also part of the insights shared by older Black women on their less than optimal healthcare experiences. I argue that race and gender also influence these factors. As Weate (1997) notes, "the corporeal capacity of the body allows for a communication with the expressive patterning of the cultural traditions to which it belongs or has attached itself" (p.171). For example, some of the specific variables of healthcare settings described by the women in my study were non-verbal cues such as the lack of or too much touching that engendered mistrust, created expectations of being "treated differently," being disrespected, and demonstrated a lack of cultural appreciation for the Black female body. The women also shared insights on their experiences with verbal/ non-verbal cues from Whites in healthcare settings that seemed

to routinely express disrespect, and a belief that, "being" Black meant that specific diseases could not occur, nor could Blacks afford to pay for treatment or care when these diseases did occur. The factors were discussed as impacting decisions to seek, access or utilize healthcare. Several of the women in this chapter described non-verbal cues ranging from "a lack of eye contact," "the tone or speed of voice," "a lack, a hesitation or overly excessive physical touch," and "facial movements, twitches and lip curls," exhibited by doctors, nurses or receptionists and how these were interpreted as having "racial meanings." I concur with Shelton (2000) that while healthcare may be a "service that is provided based on solid science; it is also a social transaction" (p.4). In addition, these communicative "fronts" function to define the situation or the circumstance by using appearance and behavior to tell us of the performer's status as well as to "warn us of the role that the performer will play in the oncoming situation" (Goffman, 1959, p.118).

Many women, having little sense of competency and knowledge about the events that will take place in these exams, expressed feelings of not being fully informed on procedures and treatment options when going to the doctor. Consequently, women, who may be strong and authoritative within their families and communities, become silent in healthcare settings, rendered passive by their lack of health information and knowledge. This is an avoidable inequity in health. Inequalities and inequities in the health and well being of older Black women may reflect the existence of subconscious bias. For example, according to Smedley et al.,(2002) in the Institute of Medicine (IOM) report, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care," evidence is offered of doctors working in healthcare settings rating African Americans as

"lazy, less intelligent, less educated, less likely to comply with medical advice and more likely to abuse drugs and alcohol" (p. 1-6). The IOM report (2002) noted that generally healthcare providers did not seem to engage in an intentional or overt act of racial bias when it came to African Americans and healthcare delivery. However, the report did find clear evidence indicating that the decisions that healthcare providers made on who got what kind of care were often based on their preconceived racial stereotypes about Blacks, despite the income, insurance status or education of the particular Black patient. By the same token, an older Black woman operating on the assumption that the healthcare provider is influenced by those stereotypes may in turn enter into a state of hyper-vigilance in a health encounter as a result of expected bias.

As has been discussed in this chapter, medical training can also be a site for the development of racial bias. Beardsley (1987) was observed that "Negro medical students, even at Black colleges, were subjected to training and education that viewed the Negro race as a sick race and that its ills were grounded either in wasteful living or in some inherent physiological weakness" (p. 150). Black and White medical students continue to be socialized into the "reductionist biomedical theory of disease," which downplays the sociocultural origins of illness and tends to blame the victim for his or her health problems (Baer & Jones, 1992).

Although miscommunication could also occur between African American healthcare providers and Black patients, a recent study on racial concordance and patient-provider relationships found that regardless of the income level, years of education and insurance of the patient or the knowledge, specialty, degree of training and

years of experience of the doctor, Black patients seen by Black doctors received better care than Black patients seen by White doctors ( King et al., 2004). Verbal and non-verbal cues may be better understood between an older Black woman and a Black healthcare provider, and as a result the woman may feel that she is participating more in decision-making. Further, she may not delay treatment options and ultimately be more likely to trust the provider. As one my participants stated earlier, "If we see a Black doctor, or we have a Black nurse, a Black receptionist ...we feel a little bit more comfortable."

One of the main arguments of my dissertation is that a lack of culturally responsive knowledge exists among healthcare providers about older Black women. For example, Freimuth, et al., (2001) in an effort to recruit older African American women for a research project on hormone replacement therapy could not get participant because (White) researchers initially denied that the Tuskegee Study would have any impact on their recruitment efforts, describing the Tuskegee Study as old, obscure, and a study that only physicians remembered. However, these researchers later recognized their error, stating, "each woman [African American recruiter] related a story about Tuskegee passed on by parents and grandparents...These were educated, talented women who were deeply affected by it and I thought only researchers knew about it" (p. 799).

As a factor in the cultural ethos of Black women the significance of "ethnic notions" and "what we all know" may also mean that "knowing" is seen as a form of agency. As one woman noted it was "them not knowing about us" that caused her to decide that it's not worth the trouble to "set them straight" or to "educate White people."

Knowing that you don't have to put up with mistreatment or being "treated differently and "just leaving" may be seen as self-advocacy by some women. However, this behavior may also impact her ability to get an early diagnosis for breast or cervical cancer.

In sum all of these factors may influence their utilization of mammography and pap exams. Particularly, ethnic notions as non-clinical influences have become part of a fund of knowledge that are shared and reinforced by Black women. These ideas may reference the legitimacy of having mistrust, fearing the receipts of less than optimal treatment if cancer was diagnosed, or a fear of the unknown as well as fuel expectations of experimentation, and radiation abuse. Within the context of health behavior the beliefs of these women have interpersonal consequences to their access and utilization of screening exams and play an important role in defining their expectations of these interactions. These experiences were mostly negative and had occurred to either another member of their family, or to a member of their networks of support. The women used this knowledge in order to locate and discuss their own individual health behavior and their personal perceptions, expectations, and beliefs about screening exams. For example, if you believe that most Whites are racist, and that accessing a predominately White screening exam setting for a mammogram or a pap exams means that you will most likely be subjected to abuse and experimentation is becomes difficult to consider and try out untested alternatives, because mistaking the intentions of Whites has historically proven to have dire consequences to your Black body, e.g., the spin that women gave to the meaning of "opening Pandora's box." Consequently, I suggest that the health behaviors

among the women in my study are not just matters of choice, but must also be viewed as matters of culture.

## VI: GUMBO AS A CONTEXT FOR WOMENS HEALTH BEHAVIOR

Being mindful has "taught us how to spin that feeling out, to analyze it, to accept what is true" and to discard what is not all the while being able to show why each is so, thus the ethos of a Black women teaches her to be brave. (Trina Grillo,1995)

### OVERVIEW

The essential building blocks of Black culture are part of the hybrid processes by which cultures have always been formed in which their sense and reference are palpable. In other words, to "know " about Black women and their health means that you have to have a taste of the essence of their Blackness, you have to talk about their history and explore their cultural awareness. Gumbo is used as a metaphor in this chapter to discuss recipes as part of the cultural ethos of older Black women. Gumbo is a hearty soup that is composed of layers upon layers of complex flavors and ingredients. It is the relationship of a variety of seasonings and ingredients that create a unique flavor every single time. Gumbo never tastes the same as it did the last time that you made it. In order to prepare this dish you must have roux. The roux gives gumbo its particular character, and you must stir it constantly, working pretty hard the whole time. The making of roux is something of an art. As described in chapter five, meaning and context were conveyed through the nature of experience. Thus, I view experiences as shared *ingredients* in a sort of cultural *gumbo* that feeds patterns of health behavior.

In this chapter I explore those *ingredients* that are located within the Black cultural spaces of language and bodily praxis as agency. Particularly, it is the cultural practices of Black women which are analogous to this hearty soup because these practices as a *gumbo* are constructed from whatever is available (usually leftovers) and is

seen as a source of sustenance for the mind, the body and the spirit as it nourishes the soul. Patterns of health behavior among older Black women are intricately connected to these cultural practices as internal and external ethos that references "being" Black, in which a woman's life is as much of a "journey of the spirit, as it is of the body and the mind" (Parham, White and Ajamu, 1990, p.xiii). The first is referenced by the larger society that continues to use "race" as a reality of classification and otherness, and the second is within African American culture that uses "being" Black as a source of agency, resiliency, and advocacy. Consequently, the Black experience may also serve to mold or shape the "taste" of intercultural contexts. As one participant noted earlier when speaking about how "bits and pieces" of culture and knowledge are shared in the community, "You put it all together and you got gumbo." These are cultural components that reference the purposeful use of spiritual, cultural, social, economic, and political perspectives that are brought to bear even within healthcare settings.

#### THE MIND-BODY-SPIRIT CONTINUUM RELATIONSHIP

The power that is part of the culture of Black women is drawn from relationships: the relationship with self; with others; with their networks of support which are an interconnected collection of family, friends, and community including a relationship with God. As the embodiment of an ethos of Black culture, power is defined as African American common sense, which means that the mind, the spirit and the body are tied through cultural practice. Freedman (1998) noted that this type of bonding among Blacks is "experienced as belonging to a larger, more inclusive, spiritual kinship system" (p.943).



Exposures to racial bias over the lifecourse have created a unique sense of self for Black women who have a strong sense of “spirituality, self, and community” ( Moore, 1988, p.6). Black women have been conditioned to believe what our minds, our bodies and our spiritualities tell us. These beliefs have kept us safe. This is our ethos. We have been taught to check for the deep, internal discomfort we feel when something is being done to us or stated as gospel about us but does not match our ethnic notions of truth. This mind-body-spirit connection was one of the more persistent themes that I found expressed throughout the narratives of my participants. Ms. Carlotta defined the essence of this concept in relation to "being" Black and female:

We are a very spiritual people, we are spirit based for the most part. We have a lot of faith and we are a very strong people. The women are very strong in the Black community because we are the survivors. We don't know anything else but to survive. That's what's bred into us from our mothers. We don't always know that we can do the things we can do, but once we apply ourselves we get them done!

Through networks of support, funds of knowledge, resiliency, advocacy, religiosity, and spiritual connections, women have managed to thrive and succeed in difficult situations. Faith in something greater than the self is seen as necessary to mediate the schism that arises when Black women attempt to accept and become part of the dominant culture's worldview, while at the same time they are being made to feel separate from it (Collins, 1990, 1991; Peterson, 1992; Semmes, 1992; Mullings, 1996; Vaz, 1997; Parham, White and Ajamu, 2000).

Black womanhood has been socially constructed through an ethos of Black womanist culture that incorporates strong community ties, spirituality, extended kin, and networks of support with a reciprocal reliance on other Black women (Stack, 1970,1985,

1994). This ethos focuses on agency, advocacy, and resiliency, and living life in America through courage, creativity and perseverance, e.g., “makin' a way outtah' no way.” This concept for Black women is about them "using what they know about their lives as a basis for critique of the dominant culture and for creating alternatives...it is a call for change and participation in altering power relations" (Hartstock, 1990, p.172). Thus it is important to recognize that the same power of persistent external forces developing over many generations of Black women has also created an internal power for them. Hence, I view that internal power as part of the mind-body-spirit continuum that operates as a sociocultural bond within the Black experience of being Black and female. This idea of the continuum is particularly useful because it is grounded in a womanist perspective that has been holistically defined earlier as a theoretical framework for exploring the powers of Black women through a re-definition of the Black self in contrast to the stereotypical perceptions about "being" Black believed to held and perpetuated among some Whites. McClaurin (2001) among others, has noted that, as part of bodily praxis womanism among Black women may:

...claim a consciousness that identifies "race" as a social construction bolstered by a structural reality that is harsh and striking in its economic, political and [sociocultural] ramifications and the interrelationships between men and women, community, and role of gender in structuring human societies, their histories, and ideologies...(Pp.49-76)

These relationships are said to bring power. For it is within these relationships that older Black women feel comfortable enough to act and to express themselves, knowing that they will be affirmed for who and what they are.

The Power of Faith & Mindfulness: GOD

As discussed earlier, part of the ethos of African American culture includes the connections made by older Black women along a mind-body-spirit continuum. Musgrave, et al. (2002) has noted that "taken together or separately, religiosity and spirituality provide a framework for making sense of the world and coping with life" among Black people (p.557). Spirituality, as a God consciousness is a "mindfulness" that is expressed within the autonomous institutions of the Black church, and networks of support within the Black community. As a consciousness, spirituality in this sense encourages African Americans "to develop and sustain a strong self identity in order to mitigate, resist, or undo the adverse effects of racial bias" (Geronimus, 2000, p.867). For example, the merging of mental, physical and spiritual realities by the women in my study served to connect agency to advocacy and resiliency and then to their patterns of health behavior within the contexts of "being" Black, female and the ethos of an African American collective consciousness. Church involvement of older Black women accesses power as an aspect of religiosity, faith and spirituality as part of relationships within networks of support:

Black churchwomen were there to keep communities functioning. They created orphanages and launched philanthropies. They taught Sunday schools, did missionary and civil rights work, and participated in endless fund-raising drives to pay off church mortgages. The church rests most securely upon the backs of Black women...and has remained the most important institutional agency in Black America (Hines, 1994, p.5).

Churches were noted as one of the major word of mouth information-diffusing agencies of the Black community in Tucson, as Ms. Latrice observes:

The church is the number one place in the Black community. If you want something to get out [information] take it to the churches. That's the first place. Not everybody goes to church but there are enough people who do go and they can spread the word with word of mouth. The church also has the better outreach because every Sunday we get announcements. Like, Sister P, she works in the health field when she gives us the announcement, she always gives us a tip a health tip as part of the church service announcements. It helps cause once somebody mentions something you say, "yeah, well okay maybe I should..." but if nobody ever mentions anything about the health or the wellness then we don't think about it.

Her attendance at church supports her behavior in adopting timely / routine preventive care and reminds her to spread the message to others. One woman recounted how her relationships with other women in her church may have saved her life:

When I went to the hospital in December 1998 and I had that first surgery, I was in the hospital most of that month and then I came home. I told them "please don't give me too much morphine." I kept telling the nurse before I was discharged because they gave me so much morphine until I was just crazy, I would just started crying. They discharged me but something wasn't right I was in so much pain, then I tried to get a hold of my doctor and he was out of town. Thank God, I have two nurses in my church. They came the next day to stay with me and they continued to stay with me, and they started threatening the doctor's office and that's when he finally said bring me in. And you know what, I had to go back to the hospital on January 15. What was hurting me so bad was what they should have cleared out of my chest--those drainage bags. Now if it wasn't for the women in my church, oh yes, thank the Lord I know, because if you don't have nobody to talk for you then you are in trouble cause they don't care about your Black body...

Perspectives of fatalism / fear of the unknown also emerged when participants were discussing their acceptance of God's will as part of their spirituality within their community of women. As Ms. Carla recalled a friend who said "if I'm gonna die, I'm gonna die." Ms. Carla later explained that this sentiment was often spoken with reference a faith perspective and used to mediate a fear of the unknown, because it is a belief in God's will as to whether or not these diseases could be prevented or even detected with

routine and timely utilization of screening exams. Thus, fatalism also seems to be part of faith based beliefs that subscribe to a mind-body-spirit continuum but through an individual's submission to the will of God, which adds another holistic ingredient to our simmering pot of gumbo. As Ms. Bonita observes:

I believe that whatever problem you have, God is in control so if you hear something early about your health and it's bad news. It's all in God's hands anyway, and you try to do whatever you can. Colette, there are places in the Bible that will say God will give you more time but if not ...it doesn't matter what you do because it's out of your hands anyway.

The will of God operates here as consciousness that may "represent the divine expression and belief in a higher power that governs one's existence" (Bowen-Reid & Harrell, 2002, p.4). As Ms. Bonita continues:

When my mother was diagnosed with breast cancer and my daddy tried to keep it a secret and it has a scientific name that I don't remember but it's real long, but it boils down to inflammatory cancer of the breast. And my mother saw it and just went and got the medical dictionary and looked it up and I heard them talking. I wasn't supposed to be listening I asked her "Why didn't you tell me? Why did you try to keep it a secret? And she said, " well I didn't want you to worry about it and she says, "When God gets ready we're going to go. Man's extremity is God's opportunity, so I'm not going to go until God says so."

Nonetheless, many of the women in this study believed (God ) consciousness was also given to them so that they may engage in their intentional acts of agency and advocacy (as part of their patterns of health behavior) by reinstating themselves as active agents of resistance and resiliency, rather than accepting the status of passive victims to the consequences of a disease.

The power derived from faith and mindfulness, as well as, from their networks of support has also given individual Black women the ability to transcend, never compromising her beliefs. Woemn stressed their relationships with the self; with God;

and with family, friends and community. Networks of support, particularly those within the family, extended kin, church and civic and social groups are important within African American culture, and spirituality and religiosity have been associated with a variety of positive health outcomes. (see Chatters et al., 1992; Levin et al., 1994; Eugene, 1995; Levin et al., 1995; Erwin, et al., 1999 Hoffman-Goetz, 1999 and Musgrave et al., 2002).

#### TCB: THE AGENCY OF BEING HEARD AND SPEAKING TRUTH TO POWER

Culturally Black women are often perceived as both the ship and the safe harbor for members of the Black community. TCB is short for *taking care of business* and for many Black women TCB has usually meant her letting the world know what's on her mind. This perspective was particularly used when Black women felt that they must "speak truth to power." Older Black women use a womanist "voice" as agency, taking what they consider to be the power of faith and mindfulness into settings that seem to mandate its use. In acknowledging the connections that they seem to make between the self, culture, and the creator, these women combine spirituality and womanism in a communicative tool that I refer to as "womanist talk" used as a protective mechanism against racial bias (Williams, 1993; Ani, 1994). As indicated earlier, I use the term "womanist" to describe the ethos of culture that has been expressed by my participants and the term "womanist talk" to describe linguistic shifts including use an assertive tone, pitch, or word choice. I relied on my participants to define the meaning and context of this "talk, " realizing that it was an important part of the mind-body-spirit continuum.

The interrelationships of the mind-body-spirit have always played a central role in the African American community. These factors are also some of the foundational

frameworks for the development of the agency of a Black womanist culture. Thus a womanist perspective can clearly be expressed as the "voice" of agency both as part of taking an action in order to be heard, such as "speaking truth to power" and also a part of a consciousness of bodily praxis, such as the power of a relationship with faith and spirituality. Several women offered definitions of this practice: "It means that you are standing behind what you say. You speak with a strong sense of self and spirit" (Ms. Carlotta), or "that a woman is speaking out and not be afraid of speaking your mind to anyone cause you know God's on your side"(Ms. Darla), or it can mean "getting to the heart of the matter, speaking with authority, intelligence and the common sense God gave you"(Ms. Wiletta) which meant that you were standing behind what is being said by "speaking up" for one's self or for other's with a healthcare provider or within a healthcare setting.

Another aspect of a womanist use of language as agency was called "having a come to Jesus talk." "Come to Jesus" talking was about "speaking out" or acting up on one's behalf. "Having a come to Jesus talk" seems to have been used to demand further tests, or to insist on second opinions and referrals from doctors in which "Jesus" was used as a call to or for action to occur. I argue that this is how an older Black woman is not only conceptualizing the healthcare interaction, but is also defining its context and meaning so that the work of understanding can occur between herself and her doctor.

### Black Womanist Talk in Healthcare Encounters

Many of the relationships used to access power among older Black women have been constructed within the cultural ethos of "being" Black and significantly affected by a mind-body-spirit consciousness (Terborg-Penn, 1983; Collins, 1990; Williams, 1993; Mullings, 1997 and Ebron, 2001). Literature on African American women (Smith, 1999; hooks, 2003 ) noted that they are often stereotypically viewed as being angry (most of the time) or having an "attitude" especially when talking with Whites. One of the healthcare providers whom I interviewed noted that there is a demonstrable difference in the way older Black women have spoken with her compared to women from other ethnic groups. She stated, "in my experience African American women are very clear and articulate about their needs and their issues but I don't know if that articulation is something that I've always liked or appreciated in this population."

In interviews, participants noted that their agency, advocacy, and resiliency was needed in order to obtain equitable, and quality healthcare. I suspect that the use of a womanist inspired 'voice' as agency by Black women has often been mislabeled as a "chip" supposedly carried on the shoulders of some Black people simply because the person being addressed happens to be White. Several participants noted that their vocal assertiveness and hyper-vigilance was sometimes misinterpreted as them being angry or having an "attitude." This has led some Blacks to attempt to educate some Whites on the reasons why a Black woman may use an "up-front, in-your-face" assertive voice to convey her expectations. Several women noted that they would try to give Whites the



benefit of the doubt instead of becoming angry then for what they perceived to be racially stereotyping them "having an attitude" or "being perpetually angry."

Ms. Latrice is one of the women who tried to educate her White co-workers on some of the realities of the Black experience in America as the source of this form of agency. These women had told her that Black women seemed to have an "attitude:"

I tell them, to take me for example, as Black women the education and all that I was not allowed to have. I remember that we couldn't go to school until it rained because we were in the cotton fields. We were sharecroppers so we had to work in the fields. We had to work the White people's land that we lived on, so we couldn't go to school till it rained. So after being passed over again and again we know the we need to speak up to make sure that we get ours. And that's what has been passed down from generation to generation. So I try to help them understand that's why Blacks have an attitude about a lot of things...

In using her own personal story of being denied access to an education because of having to work for Whites, Ms. Latrice explains why some Black women may be vocally assertive when speaking with Whites. Her reasoning of why these women may project their voice using clarity and a business-like tone is that they are ensuring that they will not be overlooked, and that attention would be paid to what they said or asked because there is a history of Blacks being either denied access to being heard or not being allowed to speak up, even if they wanted to.

Many of the older Black women in my study have spent considerable time in waiting rooms or reception spaces where they have been able to observe the actions of Whites toward non-Whites. In chapter five I identified these sites as physical spaces where the tone of the actual intercultural encounter to follow will often be set through interactions among older Black women those in the front office. Many of the women in my study spent significant time interacting with Whites, several of them have worked

with, or traveled with large numbers of Whites over their lifetime. In contrast, they felt that relatively few Whites have done the same with Black women; thus a lack of contact may feed negative perceptions.

Cultural difference operates to closely modify or enhance verbal/non-verbal styles of communication and behavior of both the healthcare provider and the older Black woman. Meaning in language is often indicated unconsciously by the "paralinguistic" features of a culture (Schott & Henley, 1996; Hecht et al., 1998). Meaning and context are important sense making factors among older Black women. As a protective strategy learned within the ethos of womanist talk, being forthright seems to have helped these women mediate the external realities of their lives in "being" Black and female. Being assertive vocally and having an "attitude" (but not being angry) when interacting with some Whites, is part of the use of voice as the agency of womanist talk. Ms. Juanita described what this sounds like:

See, when you get in their [White's] faces and tell them about their tone with you or you begin questioning them about what they are saying to you...it's when you speak up like that...

I suspect that the use of intonation (no nonsense or engaging), emphasis (pregnant pauses), volume (whether raised or lowered), pitch, and pace (whether fast or slow) in the speech of an older Black women are ways of indicating their attitudes toward what is being said to them and their attitudes toward the person (s) to whom they are speaking with.

Several participants indicated that they felt that this type of "talk" was part of their agency, thus I in turn accepted it as part of their mind-body-spirit continuum to be

employed in any situation where they believed that they needed to use a "flat footed," "straight up" vocal engagement about their expectations. This type of behavior may be a consequence of the "conditioning" aspects of culture and being identified as a "race." Some of the women said that they felt that they had to be assertive with their healthcare providers in order to reinstate themselves as active agents in a healthcare encounter:

I have heard from other Black women in general conversations that they would go into a doctor's office and the doctor would act like they weren't even there. They didn't talk with them, just kept writing and then recommended a prescription. Now, see that could never happen to if it did and me I would stop it immediately. I won't allow them to dismiss me. If you're my doctor you have to talk with me. You have to tell me exactly what's goin' on.

It is within the ethos of Black culture that there "emerges [an] assertive, determined, confrontational, "pushing style of verbal communication" (Hecht., et al, 1993, p.104). Some Black women may move in closer during verbal communication than some Whites may be comfortable with. The assertiveness of womanist talk may be reflected in a variety of other behaviors, including interrupting to ask questions and using their hands while talking. As noted by Smith (1983) in conversations "Black females lean more toward each other and look at the conversational partner less than White females" do (p.58). Older Black women may also maintain direct eye contact when an individual is speaking, and look away when responding, another difference is that "...older Black women may not use eye cues to indicate whose turn it is to speak; these patterns are often reversed among Whites" (Hopper,1993, p.240).

Some Whites may misinterpret this style of communication as signaling a confrontation when none is intended, particularly when the behavior includes a raised voice or animated gesturing. For example, a woman who shows little reserve in stating

her feelings may be misperceived as hostile, or even dangerous. Seen from the perspective of the Black woman, she may see herself as showing a willingness to be open with a healthcare provider in sharing her feelings about a health concern as a necessary first step to getting it resolved. Ms. Darla offered an insight to this type of interaction when she described a recent healthcare encounter in which the doctor seemed to be afraid of her:

I think I coerced a physician one time 'cause I was Black. I went to this doctor and I remember sitting on the table, and I was explaining the problem that I had with this jaw. And the doctor sat down on one of those chairs with wheels and I don't know if I flinched at him like this [she gestures outwardly with her hands] or what I did cause I use my hands a lot when I talk, or if I scared him or what because he backed up so fast that he banged his head on the wall and then he says "oh well there's nothing wrong with you, I can't see anything." And I remember thinking to myself well that good, cause I didn't want him touching me if he was banging his head on walls. Colette, I don't know what else could have caused him to react like that except that he thought I was gonna hit him and so I thought okay well ... he's not for me ... I just remember not wanting to go back to that particular doctor ever again.

Ms. Darla's experience highlights the lack of cultural awareness on the part of the healthcare provider and the kind of miscommunication that can occur. The provider seems to have misinterpreted her lively speech, and her non-verbal cues as anger or a threat and tried to get out of the way of her "talking" hands. A culturally responsive healthcare provider might have better understood that her gesturing, volume, and tone were differences in communication style, and a culturally appropriate way for her to use in getting her point across.

Misunderstandings and misinterpretations on the use of the assertive womanist voice as part of agency by older Black women may interfere with a diagnosis by a healthcare provider, as well as interfere with a woman's decision to seek or utilize a

healthcare service. By appearing too assertive or outspoken, older Black women may reinforce stereotypical ideas about "racial" difference, and a healthcare provider may be either unable or unwilling to respond to or understand the need for such directness within an clinical encounter. These factors may also be misinterpreted by healthcare providers as a Black woman "being difficult" or non-compliant.

### The Power of "Word of Mouth" Relationships

Most of the women in my study did not grow up in "racially homogenous" cities or towns, although several of these women did move to Tucson from larger and more densely (Black) populated metropolitan areas, such as Detroit, Chicago, Los Angeles or New York. Many of them expressed concerns about the lack of central meeting places, spaces, or physical sites of highly visible Black community life marked by a city grid, by street name or neighborhood of concentrated, owner-operated African American commerce (healthcare facilities, hospitals, clinics, doctors offices, banks, theatres, insurance companies, restaurants, grocery stores, shopping malls, or newspapers). As noted earlier, in Tucson there is no physical site, e.g., a "hood" that resonates with multiple networks of Black support and Black community life.

While conducting preliminary research for my dissertation, I asked many of the women, "where and how do Black people receive and share information with other Blacks since there is no central cultural place?" Ms. Darla shared her experience of arriving in Tucson and of having to shift her ideas of how to transmit and receive information within this new setting:

I had to change my way of thinking when I came to Tucson. I am not used to everybody knowing everybody's business. Everybody talks here. My mother-in-law can sit down and give you the whole histories of people in this town. That's how this community shares information, its word of mouth.

Ms. Darla's observations are similar to what other women said about how most information is shared within this community. For example, they noted that while some of the knowledge and information about healthcare services--for example, the appropriateness, availability, and accessibility of health care services -- may come from the dominant society, most of the information like anything else (among Blacks in Tucson) is spread by "word of mouth." The power of this kind of "talk" was routinely used within networks of support as key components of Black cultural life, particularly, in relation to "staying healthy," being self-aware, and finding out about risk information:

Word of mouth tells you what's going on when you don't know what's going on. Like when I first came here, and they were talking about the bad water and found lupus attached to the water. I had some sistahs voluntarily tell me that "you might want to get bottled water." That's the value of it and you can't put a price tag on it. It's like when we start to share, I mean, really share our stories we feel "I'm okay." I think it's wonderful. It's good information for me. I take note of it. Especially if she is doing something good then I try to do that too. I know I gotta' go to somebody's healthcare and the experiences of others cause me to treat everything they [healthcare providers] tell me with a grain of salt, so I always say to sistahs "what are doing to stay so healthy?" And I find out that she walks everyday and takes vitamins, and gets her physical exam, mammogram and pap. And then you have to put it in the right perspective. I document anything that I think is pertinent to me and I look it up and ask other women, I just don't take your word on whatever I am going through.

Several women agreed with her assessment and noted that when information and healthcare experiences are transmitted as a fund of knowledge through "word of mouth" relationships, this knowledge is translated into action because it is routinely passed

among the generations of Black people who have lived here. It is also readily shared with new Black arrivals in Tucson. As Ms. Carla commented:

I've been here 30 years. And it's still word of mouth when they [Blacks] see each other, in the grocery store, at the park. This has happened to me and that's how we network. I get on the phone and I lose my damn voice to make sure that they [Blacks] ain't got no excuse [for not knowing] and the same little group may tell others that are here.

The "reigning registers"<sup>xxx</sup> are accessed through "word of mouth" relationships within networks of support. They often serve to warn and remind women that "being" Black and female means that they must be vigilant, prepared and even expect that they may suffer mistreatment at the hands of Whites. For example, in relating her perceptions of racial bias and the receipt of less than optimal care received from healthcare providers, Ms. Darla notes that she has shared her refusal of service experience (discussed in an earlier section) with the other Black women in this community:

I will definitely tell. I've bandied that one doctor's name all over town, you know the one who wouldn't see me when I was so sick. I made it very clear to all the women that I talked to, not to use her.

The purposefulness with which she shared her experiences with other Black women about whom, how and why she was refused service in a local preventive healthcare setting is seen as a contribution to the fund of knowledge as a responsible member of this community. This type of verbal sharing is often called "bad mouthing" and forces the "reigning registers" of other Black women to record and include this new information from another woman's experience as part of the social memory on mistreatment or racial bias in healthcare.

The use of word of mouth to spread information also helps to sustain a womanist perspective in advocating for the optimal health and well being of older Black women.

Ms. Bonita recalls changes in her patterns of health behavior after speaking with her networks of support:

You know, in the past I didn't always check on what I was told by the doctor. I would just go by what they told me because they have the credentials and they have the knowledge, so I would just pretty much follow their advice, but then I found out that some of the things that they said I needed I didn't need and some of those things had adverse affects on me so now I'm talking to other women on the phone about it, or getting on line or asking women in my church so I can hunt down information because I need to. Like when I told you about my mom's heart surgery and she told me that my aunt who had breast cancer was told that she had to have both breasts removed when she really didn't need to...those kinds of things make me check now.

These relationships are used to share information and are part of the legacy of having a shared history with other Black women. Ms. Naomi described her networks of support

For me, first, I think I ask friends and family, and I mean all friends that I have here. And I will even call out-of-state to get support and information, asking family members, "Do you remember when so and so had such and such and then this happened? Do you know anybody who has had...?" You know, it's just to kind of confirm and find out some of the family health history. There are also a few women who are in my support network who are actually in the medical field and I ask them as well. Right now, I am getting information on menopause.

Among African American women, word of mouth relationships are a source of bonding as well as a way to transfer knowledge across generations of Black women through oral history. As Ms. Latrice noted:

It's all the mothers of the family and then for me it's my older sister. I think that other family member's and the members of our community influence us older women and then I think it's also an individual choice in terms of how we look at our health habits. I think that sharing of our experiences has to do with the history of kinship in the Black family, with women. We have in the past tended to be very supportive of each other and have a rich history of caring for each other,



particularly the matriarchal area of mothers, grandmothers and daughters, and passing health information along from stage to stage helps other women.

Specifically, several women indicated that it was these kind of relationships that helped them recognize the importance of obtaining mammograms and pap exams. Ms. Carlotta described how Black women access these relationships:

For some of the women that I know, asking family is number one. Outside of that, then it's the girlfriends and the women in church groups for those who go for church support, or some women have friends that are co-workers and they get support there also. Like they start talking about their mammograms and then other women may remember that's time for them, too. Also, knowing someone that has had, for instance, breast cancer or someone who died of that who was close to them, whether family or friend...it just reminds you that "I need to make sure that I am okay..."

It is important to note that within this type of women-centered sharing, meaning and context are given to the timeliness of exams in relation to their Black body, which may encourage other women to adopt a pattern of behavior with respect to access and utilization of a screening exam. Several women noted that when you're older, you may use "word of mouth" to double check health information after a visit to a healthcare provider:

Some of us who are much older don't always understand what you are telling us in a doctor's office, I know, because when some of them come home the first thing that they do, they are going to ask the first person that comes in...."Can you understand what the doctor said here?" or "Can you tell me what the nurse meant by this?" I think it's cause they [healthcare providers] just gave it to you in writing and they are too busy to talk to you, like, one nurse will say this and then you hear them questioning themselves. So, like, when I call and repeat what I heard they will say "No, that's not what the doctor said"...when I know that is what I heard. It doesn't make you feel secure when they argue with themselves...

I see the older Black women in this community as carrying an invisible, self-affirming pocketbook with them at all times. Inside is a wallet that holds their "sense and

reference" to Black culture and a Black community, with cards identifying them as "Blacks," because they are never allowed to forget their "race." The wallet also contains currency in the form of the "funds of knowledge" insured by the wealth of the "Bank of Black Women's Experiences and Culture."

### The Power of "Talk" In Taking Care of Business

Power and agency within the Black community is also part of the use of womanist talk in "taking care of business." This type of power is shared by all members of that community because there are limits to what one as an individual can do. Many of the participants in my study felt that "being" Black meant that as women they must always "be taking care of business." Taking care of business within Black culture often occurs through the uses of a womanist "voice" as part of resiliency and advocacy. Accessing this type of vocal power has given Black women the ability to maintain integrity in the face of injustice and to resist compromising their beliefs.

Resiliency and advocacy emerged as other important components of agency within women's narratives as another way of "speaking truth to power." One woman, Ms. Yolanda talks about the resiliency of Black people and how she verbally responds to denigrating self-talk:

I don't perpetuate the myth of Black inferiority. I don't allow it, and when I hear you say, "Oh, girl, you know how we are," I say, "No, I don't know how we are tell me so that I can tell you that it's a lie, so that I can tell you that for the experiences that we have gone through with slavery, segregation and racism, just look how far we have come. Now, tell me that is who we were and look at who we are now. We have come so far and we just don't know it, so I remind them.

Similarly as Ms. Renee notes, she actively discourages negative self-talk among Blacks:

I don't allow people to tell me how bad we are, even from other Black people. I don't want to hear how stupid we are, how dumb we are. You know that expression "Oh, you know how we do girl, or you know us." I say, "No, I don't know us and I don't allow that talk. You have to explain yourself to me and why are you putting yourself down? Why are you putting us down?"

Ms. Renee is referring to a cultural practice of self-affirmation shared within networks of support. Many of the women said that they needed to be reminded through positive self-talk because of a lifetime of contending with the damaging impacts of oppression. As noted in my earlier research (Parker, et al., 1995), this is the means by which Black females resist negative definitions of the self and gather and provide support and encouragement; that is by identifying spaces and places for advocacy and resiliency to offset the negative contexts of "being" Black in a largely White culture.

"Race" and gender will often influence the context in which a Black woman asserts her voice as advocacy, resiliency and resistance (Collins, 1990). One of the common statements I heard was "having to get one's mind, body and spirit ready for dealing with 'those' people [meaning Whites]." This meant that as Blacks and as women, they felt that they had prepare themselves mentally and spiritually before going into these interactions, especially when going for a mammogram or pap exam because they had to maintain the integrity of their bodies, and they had to be able to sustain a sense of faith and trust after the healthcare encounter about any results or diagnosis. Thus, the mind-body-spirit continuum is seen almost as protective armor for the Black body when interacting in an often-hostile environment.

Ms. Latrice offers an insight into how "dealing with those people" may mean that feelings of mistrust or even beliefs about genocide are being accessed as part of their

knowledge and experience. She spoke her mind about how she views organ donation through a lens in which she believes that organs are intentionally harvested from Blacks because this population is seen as expendable:

I think the medical field is practicing legal genocide. I know that if someone *of mine* was in the hospital and the doctor said they were not gonna make it and then wanted them to donate their organs, I'd say, "Hell no," because, see, now I feel that just cause this person was Black you're not giving your best care or doing your best work, so you've written them off.

Several women indicated that they knew they must be resilient, prepared and watchful in a healthcare setting where Whites are in charge, as a result of their knowledge of historical abuse of Black bodies.

Other women felt that by refusing to be talked down to, or simply taking their business elsewhere, was proactive and evidence of them "taking care of business." As Ms. Sharon notes:

I am kind of rude. They really need to have a bedside manner. They need to have a one-on-one relationship with every single patient. I don't care if they have 500 patients. If they don't have that in the beginning that sets the tone...for me...Their action is my reaction...It was something my mom taught me and she was in the medical field all her life.

Some of the participants felt that making their expectations of a healthcare encounter explicitly known within that setting or with the healthcare provider was part of their uses of this strategy:

When I walk in the door I tell them what I am expecting of them. I say, "I'm gonna respect you as a physician but you must respect me as a patient and I am here for a reason." When I meet with a new healthcare provider I always bring *the timer* to remind him that I am paying for this service and I want my full time.

Ms. Cathy's reference to "the timer" means that she understands how appointments are scheduled within healthcare settings, e.g., as in 15, 30, and 45 minute intervals, and expects her full measure.

Women also felt that they needed to verbally assert their expectations of receiving their full scheduled time with their healthcare provider in discussing diagnosis or treatment options. As Ms. Karen' shares how she talks with her doctor:

I tell them, "Okay, you take time and talk to me about your diagnosis and ask me questions about me and then we will make a decision about where we are going to go with my health and care." Now, if a doctor cannot give me enough respect to give me time enough to find out what is going on with me, then I don't need that doctor.

Ms. Juanita noted, "I don't want a doctor to be condescending to me, and I don't want a doctor to discuss stuff over my head." Intercultural communication skills were seen as critically important in the doctor-patient relationship, especially since many women believed that they were purchasing a service from the health care system.

Taking care of business was also expressed in the act of hiring / firing of a healthcare provider as part of putting them on notice about the manner in which the doctor communicated with an older Black woman:

I am getting ready to fire my primary care doctor , right now. The only reason that I am with her this minute is because of this health problem that I have. I know this sounds crazy, but this is my guideline for dealing with a doctor. I think the doctor needs to talk to the person, needs to give the person credit for having some sense of what their body is about. A lot of people cannot tell you in medical terms what's wrong with them, but they can say I ache in a particular place or I feel like this and if you learn how to ask the right questions...

Sometimes women noted that there was no need for them to verbally assert their expectations. Ms. Darla noted how she used non-verbal cues in the way that she carries herself when entering a healthcare setting:

I don't trust them. So I go in with the attitude that says "I am not someone that you can just kick around, and I don't want to be here every 5 minutes either." I don't like being in the doctor's offices and that has contributed to me trying to be more conscious of preventive care. But they can tell by how I carry myself that I'm not gonna let them do anything to me. If they find something I let them know that I will not do what they say unless they call my sistahs or my family in for the consultation. I just will not, because of the experiences of my one sister with her hysterectomy and the one with my younger brother who died because they told him he had valley fever and what he really had an aneurysm, you know, and that still bothers me.

Several of the women that I interviewed expressed in one way or another their need to share their diagnosis with networks of support as a way to ensure that a less than optimal interaction with a healthcare provider would not occur. This actions was seen as part of their resiliency and advocacy, and that they were "taking care of business," due to the material reality of racial inequality. It also seems that part of self-care is putting the healthcare provider, support staff, or diagnostic technicians "on notice" with respect to the relationships of power within networks of support. This too was described as an important part of "taking care of business."

In an earlier chapter I described the local Black community as "cohesively fragmented" and "resiliently fractured." This does not mean to infer that older Black women are isolated or do not receive or give support to each other, or that they do not operate as a resource for each other and the Black community. On the contrary, the women in my study are part of a local community and culture here in which agency and strategies of resiliency and advocacy are a distinct phenomenon.

As the embodiments of cultural strategies, these factors were also identified in earlier research (Parker et al., 1995) as part of an ethos of Black culture in this setting. Although the original research was conducted among adolescent girls examining body image and self-esteem, these key sociocultural factors emerge from the Black experience used by Black girls to maintain a high sense of self. It is interesting that the strategies appear to be learned at a young age.

#### The Power of "Having a Come to Jesus Talk"

Another important issue, which emerged in the interviews, was the idea of “having a come to Jesus talk” with a healthcare provider. As Williams (1993) notes, the ways in which African Americans "extract material from the biblical canon and shape it to fit into Black life contexts represents a technique of fashioning a biblical tradition relevant to the Black condition" (p.58). Some of the women that I interviewed indicated that while talking to a doctor, they used "having a come to Jesus talk" as a tool for them to verbally "put the healthcare setting on notice." "Having a come to Jesus talk" translated into health self-advocacy. “Come to Jesus talk” was similar to being in a Black Church service and "having a heart to heart talk with Jesus (in-prayer)...like you do when you lay bare your sins before everyone with "no blowing smoke up the you know what." Ms. Bonita offered her working definition of the term because she has used this strategy in healthcare settings:

"Come to Jesus," yeah, well, that's having a real heart to heart with your doctor. It's where you say, "Let me tell you how its gonna be and I'm not willing to take the kind of crap you're dishing out here." It's also a demand for respect and dignity.

"Having a come to Jesus talk" may have a potential benefit for older Black women during preventive screening exams because "assertive behavior encourages physicians to be more thorough in terms of diagnostic testing to determine the spread of the disease" (Krupat, et al., 1999, p. 455). Ms. Cathy describes how she communicates with a new healthcare provider:

They [healthcare providers] start out being a little snappy there and just go blah, blah, blah, and I say "No, not with me," because anytime I get a new doctor, when I first go in I always told him what I was about, and said, "If you don't have time for me then you can't be my doctor. If you don't have time to explain to me what's going on with my body then you're not trying to give me the best service that you possibly can, whether I have the insurance to cover it or not." So I tell them, "just let me be aware of that and then it's my choice if I want you as my doctor or not."

The level of intensity and degree of assertiveness expressed when "having a come to Jesus talk" with a doctor varies in accord with the context of the situation and circumstances in which she finds herself.

Ms. Wiletta shared her experiences with a CAT scan diagnosis of a "kink" in her urethra (she used to work as a X-ray technician and was able to interpret her scan results) and her use of "come to Jesus talk:"

I had to go into my primary care doctor's office and had to have what we Black women call a "come to Jesus talk" with her. I had to let her know that I did not need a triage appointment. I had counted the many tests that this woman had me go to with this pain in me for over one and half years, Colette it was almost 23 tests and I had to call her for results every time. She never called me. Nothing was ever ruled out. The other thing that chapped my hide was that when I had a pain I couldn't make an appointment because she wouldn't make any exceptions and by the time I saw her my pain was gone. So when I went in to have this "come to Jesus talk" with her, I told her "I don't need somebody that's just gonna keep me going to have different exams to rule out whatever it is that you think you're ruling out, I want something definitive." I need you to say, "Okay fine we've done the EKG, we did the Treadmill Test and we know you don't have a heart problem, done, okay. Now we're gonna do an Upper GI and check that, endoscopy and say we checked that and you don't have any lesions and go on to



the next part." So I told her, "I want you to rule it out till you get to what it is cause I am not a hypochondriac and I know something is bothering me." So she says., "Well, I think we can do a CAT scan" I say, "Yes! I have been asking for one of those exams for almost a year." See, one of the things that I do when I go in for x-rays is that I tell them I used to be an x-ray technician so that they know that I am aware of the procedures. Anyway, that's how I saw that "kink" in my urethra [ she detected it before her physician ] I saw it right there when he put it [the film] up on the view cabinet. I saw that my renal pelvis was swollen before the radiologist could say it. Now to me, that's preventive health behavior on my part.

Ms. Wiletta's stated goal was to go through a process of elimination to discern the pain in her groin. In "having a come to Jesus talk" she is exercising control over the encounter with her doctor and the x-ray technician. Similar to other women Ms. Naomi described, "how she got right down to it" with her doctor. Although reluctant at first to tell me about her experience, she finally told me:

I went to my doctor with a female problem recently, and I had to go in there and I had to cuss her out. Is that specific enough for you? I had to actually demand my rights as a patient and tell her my expectations and tell her that when she's talking with me about not feeling well, then let's talk about something that can give me a bigger picture and then you can hone down to smaller things. She did it but I know she didn't like me talking to her that way.

### Speaking Out, Up and Being Heard: Black Women as Change Agents

Keosho Scott (1991) coined the term "habits of surviving" when referring to the shared experiences and practices of agency, advocacy and resiliency utilized among Black women. I use this term in tandem with the sentiments of St. Jean and Feagin (2002) to illustrate how the present is situated in the past and how the past reflects the present among older Black women. Older Black women sustain a sense of being catalysts for change within their community, especially for other Black women. Ms.

Bonita indicated this by her actions when she decided not to cancel our scheduled interview, even though a close friend had suddenly died. She clearly viewed participation in my study as empowering her, and enabling her voice to be heard:

One of the reasons that I am here with you today and didn't change the date is that I think we are impacted by each other [when] we listen to each other. I lost a dear friend on Sunday. We worked in the same office and she was a single mom, had an 11 year old and 20 something year old and they said she had strep three weeks ago. Someone told me that she died because she had the kind of strep that Jim Henson had and it affected her heart, but today I am hearing that it wasn't true. I heard that she was at St. Mary's hospital and was given an unclean needle and went into a coma and died Sunday. So I thought about it hard and decided that talking to you may make a difference for the next woman next time.

Medical attention given to the Black, female body has often been grounded in outright racial bias or the White imaginary of misrecognition and misrepresentations, to the degree that Black women may have adopted "habits of surviving" as part of their health behavior. For example, what Ms. Bonita says about her friend's death references not only the existence of a Black woman's body in the presence of daily repetitions of (perceived) racist realities (a belief that because she was Black, hospital staff did not bother to make sure a needle was sterile). Furthermore, Ms. Bonita's interpretation of these events through the lens of "race" sees this action as an attempt by the health care system to rearrange the reality of this incident to appear as if it was just a hospital error. Hospital errors are on the rise and is noted in the literature as rampant and not only occurs with African Americans (IOM,2002). However, having experience inequities in the quality of care has lent meaning and substance to beliefs about expected inequitable treatment thus further undermining the credibility of the quality of care received and she will tell others about her friend's treatment.

In an earlier chapter I also introduced the term "personal as political"; this term is especially poignant with in this section as an ethnic notion that older Black women have in their representation of a "peoplehood" or ethnic group. As St. Jean & Feagin (2002) note that the bodily actions of Black women in response to everyday racial bias is to fight back. Thus, I view the women in my study as *change agents* because "each instance of present-day racial bias experienced by a member of the group revives the past, and remembrance of painful events by racially subjugated groups and can serve as a catalyst for change" (St. Jean & Feagin, 2002, p.35).

Mistrust, and a fund of knowledge on the past abuses, such as experimentation on the Black female body were part of the narrative voices of older Black women when discussing utilization of mammograms, as Ms. Naomi stated, "We don't trust White people because we remember what happened and know what can happen that might expose you to certain things you don't need to be exposed to, like, I think cancer can also be caused from all that radiation." Thus, Ms. Naomi's observation clearly accentuates what it has meant to be a Black woman, to rely on a health care system that has not always been equitable and a system that has abused Black people.

The power of the fund of knowledge was often evident when the women recalled mothers', a sisters' or a daughters' healthcare encounters or use of voice when talking about their own. Ms. Cathy talks about how she learned to ask questions in healthcare encounters:

My mother's a retired nurse, so she knows a lot of questions to ask that we probably don't know to ask or aren't advised about, and she's done same thing for herself. She's changed physicians a couple times just because she didn't like the treatment she got, and so maybe that's part of why I've changed too. I've heard

my mother say, "Well did you ask them this or did you ask them that?" And if I talk to her about some health issue that I have she'll say "Well, you know they really should be running this kind of test or that kind of test... if they didn't, you need to ask them why." She came down for my breast surgery ... she was asking the doctor all kinds of questions ... I was like, umm, I thought I'd asked all the questions 'cause she was like well, "Why are you doing that?" or "Oh, you need to do that," or "Why do you need to take that much?" ... so it was interesting, just the interaction with my mom has really benefited the healthcare side of things for me, to hear the kinds of questions and answers and issues and stuff like that ...it is of value 'cause it makes a difference [in] how you take care of your own self.

Several participants spoke about using these strategies to support other Black women who were going through hard times. One woman noted: "I have to speak up for them," meaning that she felt she needed to be an advocate for other Black women who won't or can't speak up or ask questions for themselves. Older Black women felt that due to a historical legacy of official as well as de facto racial bias within a rigidly segregated health care system, healthcare providers make use of racial slurs that required them to respond and defend not only themselves but other Black women as well. This is an important observation because it reflects the "webs of consciousness" that were discussed earlier. One woman, Ms. Carla, recalled how she and some of her friends gave support to a female co-worker:

There was this woman I work with and they had found cancer near her throat and she did not have insurance, so she had let it go because they could not afford for her to go. But she finally went into the hospital and they did the surgery. At one point we did have a heated discussion with a White nurse, about getting her more blankets and one of the nurses told my sister that she thought I was getting ready to go "ghetto" on her. Now for her to make that statement out loud about Blacks to a Black is wrong, honestly. So we saw this right? All of us, we physically took shifts staying with her at the hospital to make sure she got good care. Now that's when you really feel your Blackness cause you don't know what to blame for this going on so long. Could they have helped her out sooner or was it because she was Black and poor, or just Black?

Many of the women in my study have learned that, regardless of their position or status in our society, they will most likely be the target of racial bias, and therefore, they must construct the means to deal with or to mediate these occurrences, as a Black subject.

Many women said that they solicited second opinions from the relationships forged within networks of support, such as a member of the community who works in the health field or even the local pharmacist . Many of the women stressed the need to follow up advice from a healthcare encounter through these types of relationships. For example, pharmacists at local grocery stores were mentioned by many of the women as trusted sources of information (whether they were White or Black), primarily because they were not seen as healthcare providers in the traditional sense . "I developed a relationship with my pharmacist...they have this book which is like their Bible...that the doctor won't let you look at, but they [the pharmacists] will show it to you if you ask them." Another woman described how she found out about the relationship between her hormone replacement therapy (HRT) and a recent acne outbreak, as a side effect of the medication that her healthcare provider had not warned her about:

The pharmacist is taking on the role of what the doctors should be doing to explain things. I thought, here I am almost 60 years old and getting acne. The pharmacist showed me what was in the hormone replacement therapy that I was taking and how that was related to my acne and so now I am doing a cleansing. I found out all kinds of things that my doctor should have told me.

This is the type of agency that make the personal political in the sense of advocacy and resiliency, because the pharmacist is part of the body politic and becomes an ad hoc

contributor to the funds of knowledge, as an adjunct advisor and a trusted source of information and referral.

#### GUMBO RECIPES FOR ASPECTS OF BEHAVIOR: AN ANALYSIS

Gumbo as a context for health behavior references the agency of older Black women, cultural difference, “race” and perceptions, expectations and beliefs and experiences within the health care system. The narratives of the women in this chapter suggested that the ethos of Black womanist culture may provide "cues to action" that are "socially emergent and co-created "as a function of having a Black identity" (Hecht, et al., 1993, p.82). As a key ingredient of an ethnic gumbo collective social memory becomes part of the tool-kit for liberation and references accumulated knowledge as a fund from which to extract meaning, and has served to instruct these women across the lifecourse on their use of bodily praxis as a form of power. The roux of this gumbo arises from the confluence of perceptions, expectations, experiences, and beliefs, about "race" and cultures.

#### Culture

It is within culture and the ethos of "being" Black that the Black and female body is provided with a sense, a reference and a voice for its Black consciousness as part of the mind-body-spirit continuum. Several women have spoken about their feelings of powerlessness and vulnerability earlier, however in this section women spoke about the different types of power that they access and utilize within relationships-- relationships

with God, with the self, within their culture and through their networks of support in laying claim to an identity of their own making and meaning, and then acting on the basis of that identity as praxis. Spirituality was discussed as part of an all-pervasive "energy" that is the source, sustainer, and "essence" that is known in an extrasensory fashion i.e., consciousness (Myers, 1987). Older Black women have created tools for liberation not as the practice of unrelated, fragmented and aimless beliefs, but as a bodily action that significantly intertwines a whole culture, in this case the culture of Black people and the quest of Blacks for survival and advancement. I suggest that it is the interface between the concepts of "being" Black, and the world that is experienced through that female body, which are construction sites where embodiment places these women intersubjectively within these contexts. Thus, I am in agreement with Hall (1986) who observes that this process may be the framing of all competing definitions of reality within range. I believe that older Black women may live in a world of multiple realities. Several women indicated that they have been able to "transcend and transform" their experiences of oppression through what I have termed a mind-body-spirit continuum that affirms personal and community relationships of agency through advocacy, and resiliency.

Among the women in my study there was a reality of beliefs, perceptions and expectations, which were things that Black women knew or suspected as a result of "being" Black, like Ms. Darla's experience when she was refused care. Another reality can be called agreement reality, with a focus on things that they consider to be real because others have told them that they are real, like the sharing of experiences through

womanist talk like "when you sit down, you talk about it and you got gumbo." Thus, within the ethos of Black womanist culture, a gathering of consciousness as self awareness and social memory becomes not merely a set of ideas; rather, it is the handing down of whole sociocultural environments and prescriptions of how these women should deal with living in a racial democracy that eventually become habitual. We also heard evidence of how their preventive health behavior has been and is still very much affected by the perceptions, expectations, and beliefs about "race" and "being" Black. Hence, even though each woman in my study had utilized mammograms and pap exams during the two years in which these interviews took place, we must remember that many aspects of their culture have formed a connection from the past through the present to the future, constructing an ethos through which these older Black women may filter and interpret their experiences, create and / or limit their choices in their future decisions to seek care. The framing of realities also brings alternative accesses to power within womanist talk and perspectives of thought, that is, as agency these use advocacy and resiliency in multiple and complex ways.

Particularly, it was the use of womanist "talk" that emerged as a tool of liberation and agency that seems to be ever present in the lives of older Black women as factors that often supported agency for themselves or on the behalf of other Black women. The use of "talk" was central to the construction of their behavior in many areas only one of which happened to be healthcare settings. According to Shotter (1989); "our self talk is constituted for us very largely by the already established ways in which we must talk in our attempts to account for ourselves and for [our experience]" (p.141). Several women



spoke about how their access to relationships of power through the agency of talk with their networks of support that results of in a sort of spiritual-cultural “mindfulness.” For example, “having a come to Jesus” talk was a component of a cultural practice used with their doctors in letting their treatment expectations be known, in asking questions, demanding further tests and in getting second opinions. These elements must be fully explored and understood as they are located within the contexts of much larger and more subtly expressed expectations of perceived White references to their identity as by-products of "race" and/or to older Black women’s interpretations of Black womanist ethos, culture and behavior.

Language and behavior are part of cultural differences and how these women made sense of other people and verbal and non-verbal cues underlie their perceptions, judgments, and interactions with others. As social transactions of cultural difference these encounters may influence decisions of doctors on patterns of care such as referrals, treatment options, and diagnostic tests. And may also impact individual patterns of health behavior among older Black women, such as compliance, self-care, and self-decision making. Intercultural and responsive communication are part of body politics that may influence the construction of health promoting relationships among older Black women. For example, giving and receiving information was part of constructing a fund of knowledge that helped women learn more about other women's experiences with healthcare providers, and evaluate and learn more about an individual healthcare provider's background. According to Thomson (1990), reality is reflected in the use of verbal and non-verbal cues; for example, in language: "words are labels for what we

sense; they record what is already there..." (p. 103). And most of us know the old adage, "actions speak louder than words," this means that our actions, as non-verbal cues, convey a lot more than what we say, however, most of us are not even aware of the meaning of our actions. The actions of healthcare providers were shared through "talk" with other Blacks and other women. I suggest the relevancy of understanding these perspectives with respect to health behavior of older Black women may rest in the fact that collective re-memories of older Black women are not merely enabling or predisposing factors; rather, they often become sharper and larger every time an experience of mistreatment, feelings of mistrust, or racial bias occurs (or is perceived to have occurred) and subsequently shared.

### Race and Performance

Older Black women are the creators and carriers of a rich cultural tradition with a sense of Black particularity i.e., "race" that has not been constructed outside of the notion of a national identity, i.e., African American, and a sense of the survival of a collective unity drawn from a common beginning thus their health behavior be viewed as a holistic cultural gumbo. There was an almost palpable sense of people-hood expressed in the narratives among these women, a sense and a reference to the reproduction and transformation of the significance of "being" Black through tremendous effort and resiliency. Older Black women clearly referenced the functions and limitations of trust / mistrust and cultural difference with respect to beliefs about "race" as part of their behavior in healthcare settings. In their narratives women referenced their mistrust and

being hyper-vigilant as a response of self-advocacy that has been both internally and externally constructed across a life course of “being” Black and female. It is in this manner that I interpreted this behavior as representing certain aspects of *performance* or *fronts*. Goffman (1959) suggests that we all use “fronts” to define others and ourselves. These are “social masks” used in the performative aspects of our interactions with each other. However, I suggest that misinterpretation or miscommunication of those “fronts” may occur when they are tied to actual practices based on beliefs about “racial” difference. These in turn may create anger, confusion, frustration, and engender further mistrust among older Black women due to a lack of culturally appropriate health knowledge / the non-use of culturally responsive verbal and non-verbal cues by support staff or healthcare providers. In healthcare settings, for example, if neither actor in this “racial” masquerade is able to access or offer culturally appropriate responses to the other, “being” Black and having a “race” may become signs and signifiers by default, caught in a tautology both informed by and reproducing “racialized truths” that are communicated or expressed through these interactions. Agency and advocacy are part of applied practice in their interactions with healthcare providers that focuses on their communication within these settings, and the purpose of the encounter. The health behaviors that become meaningful to an older Black woman are based on her history, her culture, and her perceptions, expectations, and experiences as a Black individual in a racist society.

“Being” Black and female as an identity for many of the women in my study was inextricably bound to the values, traditions, and rituals of a Black people who are

engaged in agency, resistance and resiliency expressed in the statement “we are, therefore I am” (Stack, 1975). The cultural reality of sickness and healing as noted by Hahn (1990) who, borrowing from Berger and Luckmann (1966), is "constructed" by the culture of a society. Clearly, the women in my study felt that experiences of mistreatment due to perceived racial bias can be overcome through faith, the use of a womanist voice, networks of support, self-advocacy, and resiliency. For example, "having a come to Jesus talk" was seen as necessary when interacting with healthcare providers for protection of Black bodies, psyches and as a protection to a woman's spiritual self. Scheper- Hughes & Lock (1987) have pointed out we must conceptualize our notions of the body within political, social, cultural, and individual spheres of influence, we must understand that each person's body is implicated in all of these different areas and thus in one way or another expresses them by its condition.

In sum, their behaviors in healthcare encounters that were shared in narratives seemed to be part of not only their individual and but also communal makeups, as part of their psyches, as a "mindset" engaged in referencing or expressing ideas of agency as in "taking care of business" for all Black women. As an ethos developed over many generations of African American women, their agency is commonly rendered as an oppositional stance as a consequence of their history as Black people. The Black experience has provided them with a fund of knowledge that encourages the development of self-affirming responses. Consequently for many of these women the ingredients of their cultural gumbo seem to have always been "racial" identity, culture and survival.

## VII: CONCLUSION

Health Behaviors among older Black women may be the result of enduring sociocultural recipes. Findings from this research elucidate experiences, perceptions, and expectations of the health care system from the perspectives of older Black women. In this ethnography, women shared their insights when interacting with doctors, diagnostic technicians, and office staff over their lifecourse. Older Black women viewed screening programs within the context of contemporary racial bias, mistrust and skepticism in the health care system and the larger society.

Narrative data indicates that when it comes to timely diagnosis and optimal treatment, older Black women in Arizona believe that they are disproportionately faced with many poor health conditions as a result of inequitable treatment. They also felt that breast and cervical cancer were preventable, or at least controllable, if access to services and treatment was optimal. The statement that "recipes run in families, not illnesses" means that it is important to recognize that, despite differences among the older Black women in this study in levels of education, income, and knowledge about preventive healthcare, many common perceptions and issues arose as the nature of a Black experience.

### Collective Sociocultural Memory as a Fund of Knowledge

Older Black women noted that experiences of being unfairly treated in doctor-patient relationships were commonly transmitted between women and passed down in intergenerational transmission. As noted by Freedman (1998), "among African

Americans stories of injustice within healthcare settings go back generations" (p.944). Consequently, the narratives of these women were rooted in the larger ecosociocultural environments of health risk, "being" Black, "race," and the health care system, but are also informed by their membership in this ethnic group, as active participants in the cultural dynamics of "being" Black, and a belief of "what we all know" by which their experiences have become part of an often shared fund of knowledge. In this dissertation I use the oft-repeated phrase "what we all know" to describe the sharing of information, methods of thinking and learning, and practical skills related to a Black community's everyday life. At the core of my use of this concept is the notion of Black culture as a dynamic entity--not simply a collection of Afrocentric foods, clothes, and holidays, but a community comprised of social, physical, spiritual, and economic resources to make one's way in the world, as noted by Mitchell and Feagin (1995):

This store of knowledge not only includes strategies for working against [racial bias]...but also encompasses positive role models and happy family circumstances that buttress self-esteem and an ability to thrive under adversity. From the beginning of enslavement by European Americans, African American women have played a critical role in the development of a strong and lasting oppositional culture. (P.65-86)

For example, these women told and re-told stories about themselves and other Black women, often situating and connecting their individual experiences within those experiences of other Black women and broader ecosociocultural contexts that relate to screening measures and preventive healthcare.

Black women have long recognized the importance of sociocultural memory in sharing cultural knowledge. Yet until very recently only a few, mostly other Black women--their daughters, sisters, mothers--heard their voices or were able to make sense

out of these experiences. In this manner the women in my study may be seen as creating what Henry Louis Gates (1987) refers to as a "radical black subjectivity and identity outside of [the] hegemonic prescriptions [of race]" (p. 29). Thus, collective re-memories are vital components of a kind of "social mind" that is carried by each woman, and those memories may be utilized to compare a racist encounter in the present with responses to racist encounters in the past (St. Jean & Feagin, 1998). As Ms. Juanita noted when talking about the advocacy with which Black women will share their perceptions and experiences of mistreatment by other Blacks "it's our way...it's getting the knowledge out there about a service ...and it can also undermine that service, like 'that doctor don't go to him, he's not gonna hear you'...[it's] advice...[it's] educational." Thus as a fund of knowledge, this information sharing (as subjugated knowledge) has been constructed by these women. Their "way" is what makes the personal political because these experiences are explicit, tangible, and have been executed at the site of their individual Black bodies, and that's how this knowledge becomes part of a "social mind."

Older Black women also felt that little has changed in the health care system in regards to the delivery of care to African Americans. As a result, women noted that it was important to continue to keep a collective sociocultural memory alive through the use of "talk" as a way of sharing their fund of knowledge with other women reminding the other's of specific "recipes" for behavior. My participants not only talked to each other about their healthcare experiences, but also spoke more broadly about perceived injustices. As one participant noted "we do talk and we will tell when one of us is mistreated."

One of the cultural practices that emerged from interviews was adopting a "hyper-vigilant" stance before going to the doctor as part of self-preparation and self-advocacy. Women described an "earned" mistrust of the health care system indicating their expectation that they would not be treated in the same manner as a White woman. Being "hyper-vigilant" meant that Black women were sometimes seen as overly aggressive and confrontational by doctors and nurses, behaviors that might have paradoxically altered their healthcare. Thus, as social transactions these interactions

"may adversely affect the quality of care received...because the [healthcare] provider is obviously the more powerful actor in clinical encounters," giving rise to unintentional health consequences for the older Black woman (Smedley et al., 2002, p.3).

Quite a few women noted that healthcare providers just don't "get it" when it comes to interacting with Black women. "Not getting it" meant that healthcare providers did not have the ability, knowledge, understanding, or cultural awareness of the significance of their patients "being" Black and female, thus their inability to convey a respect for the Black female body, particularly in preventive screening encounters, such as mammograms and pap exams. Many of the participants in my study noted that non-verbal cues, such as a lack of eye contact, a lack or hesitation of physical touch, "facial movements, twitches and lip curls," and verbal cues such as the tone or speed of speaking all signaled disrespect by provider's and support staff.

One way to demand respect within healthcare settings was in "speaking out" or "acting up" on one's behalf. One of these strategies was called "having a come to Jesus talk" (getting yourself ready to deal with "those" people) and seems also have been used to demand further tests, or to insist on second opinions and referrals from reluctant



doctors. Several women said that because they had experienced discrimination in healthcare settings they would not hesitate to use of an assertive tone of voice with a doctor to ensure that they got proper care. As a result, Black women felt that they were often viewed as confrontational and having “an attitude” by health care professionals whom misinterpreted their communicative style as being aggressive or angry.

Although African Americans are often said to have fatalistic beliefs such as attributing God's will for them to have a particular illness, the women that I interviewed expressed fears of being mistreated or abused at the hands of Whites if diagnosed with the disease like breast or cervical cancer because that could prove fatal. The older Black women in my study expressed fears of being treated like "guinea pigs," especially when going for mammograms and pap exams. These fears were perceived threats to the individual Black body, which were then translated by women as "being" guinea pigs as a whole. One of the women in my study defined fear of the unknown as a "Black" Pandora's Box. Several participants also included their beliefs of being "treated" differently and mistreatment expectations as part of their fears and fatalistic attitudes about breast and cervical cancer prevention. Ms. Juanita contextualized the significance of having a Black body with fear of the unknown tying these together as ideas about being mistreated, when she noted, "I've heard women say if they get breast cancer they believe that they will probably die anyway because they were told that because our skin was so dark that we had to have a different kind of treatment.” Understanding and acknowledging the significance of these fears and their implications for preventive

follow-up treatment may enable the development of more culturally sensitive diagnostic and treatment protocols for older Black women.

### "Race" Matters

In some instances, as with "race" ----the color of the body is what essentializes many of the lived experiences of an older Black woman-- then it is probable that this is how she interprets the world, thereby enabling her (as a social body) to act, and the very nature of these actions will depend a great deal on her perceptions, expectations, experiences, and how she extracts meanings or makes sense of that world. As individuals, racial identity became significant at the site of their Black body. Older Black women spoke articulately and in-depth about experiences of racial bias, as histories, memories and collective knowledge, i.e. ethnic notions that were conveyed as questions, intuitions, revisions, and categories of the mind that often served to reconstitute their Blackness and femaleness. Several women have described and given clear and concise example of the kinds of difference that "race" has made in their lives, emphasizing various ecosociocultural factors with respect to "being" Black and female that may actually help healthcare providers address inequities in their health status.

Several women felt they were being racially profiled because illnesses were being racialized as predisposing variables to their Blackness in healthcare encounters especially when given "high" risk information by doctors. In addition, these older Black women noted that "not getting an offer of a referral for further tests" and even "the amount of time that it took to be called in for their exam (especially when they had made an appointment for the exam or health problem weeks ahead of time)," were other factors in

their understandings of racial bias. Women in my study felt that doctor's too easily used "race" as a stand-in for expectations of poor health outcomes among Blacks rather than looking at other mitigating factors.

The women in this study by no means wanted to confine themselves to their own personal histories; rather, they drew consciously or unconsciously on moments of a retaliatory and discriminatory past. The contemporary meanings of racial difference were interwoven in their narratives with actual past practices that were based on racial difference. Many women vividly recalled the movement of their civil and human rights from a position based on the "social heritage of slavery, discrimination and insult" (DuBois, 1986, p.819), to separate but equal doctrines, and the widely held beliefs of inferiority that led to Blacks boycotting in Montgomery (1955), marching on Washington (1963), and gaining Civil Rights (1964) and Voting Rights (1965).

Many of the issues raised by the older Black women in this study are the consequence of re-memories that indicated how "race" and "being" Black has been expressed or considered within the contexts of culture, ethos, and behavior in relation to their interactions with Whites across the lifecourse, and more specifically within healthcare encounters and healthcare settings. In sum, the narratives of the women in this study seem to suggest this summary of findings: (1.) that "being" Black and having a "racial" identity are often significant at the site of Black women's bodies. (2.) The authority of their own and of other women's lived experiences, legitimize their expectations and perceptions of the health care system and encounters with healthcare providers as part of a "racial" democracy. In this sense, I believe that one of the

consequences of living in a "racial" democracy is that perceptions of White superiority and Black inferiority are reinforced because there is little opportunity for open dialogs to occur among Blacks and Whites on ideas about "race." Consequently, there is very little chance for either party to unlearn those inherited perceptions, expectations and biases, or to learn culturally responsive ways to communicate, thereby encouraging the optimal access, utilization, and delivery of healthcare.

### Study Limitations

Several limitations of the present study should be noted. First, the sample size was small and thus may not be representative of older Black women in other regions of the United States. In addition, I did not attend clinics with my participants nor was I able to objectively determine the actual quality of the doctor / patient interaction. Thus the data may have been inaccurately represented by my participants. Importantly, because so much information is shared among these women, study participants may have been reporting on others behavior or may have interpreted their own experiences with healthcare provider's in light of other women's stories and experiences with doctors. In addition, the time frame of the study (18 -24 months) was relatively short and therefore important factors regarding healthcare follow up may have been missed.

#### IMPLICATIONS OF SUMMARY OF FINDINGS

At present, a paucity of data on healthcare seeking behavior among older Black women has hampered efforts to make preventive messages and available healthcare services more culturally appropriate for the needs of this population. Little is known about how patients' expectations and perceptions of care affect patterns of use for preventive and curative services. Thus, research that is sensitive to the determinants of health promotion and disease prevention among older Black women is needed, including research on how they access and utilize healthcare. The interviewing process has generated important data on health behaviors among a small local population, which can broaden our understanding of women's lived experiences.

Findings from this research also elucidate racial and health disparities among older Black women. For example, the ambiguity that is associated with a clinical encounter is often perceived as bias among older Black women. Therefore, a comprehensive engagement with and acknowledgement of the significance of "being" in a Black body; "race," patterns of health behavior, and the perceptions and expectations of the type of healthcare service that will be given by healthcare providers may go a long way toward enhancing compliance. How can trust and rapport be established among older Black women in the health arena? Clearly, it is beyond the scope of healthcare providers to address alone. Black women should be brought together with healthcare providers to allow them to dialogue about women's experiences and felt needs regarding preventive health. It is only through on going dialogues that trust can begin to be reestablished.

From an anthropological perspective, the sociocultural contexts of the existing funds of knowledge that are generationally situated within the larger Black population must also be taken into consideration when designing preventive healthcare intervention and promotion programs if they are to adequately communicate and meet the needs of the communities they serve. Healthy People 2010, in its mission to eliminate racial and ethnic disparities in health by the year 2010, has identified several leading health indicators which reflect major public health concerns in the United States. Among them are educational community-based programs, access to quality health services, and health communication. Therefore, a contextual awareness of the perspectives of older Black women and of the cultural ethos of Blacks in relation to the health care system could inform healthcare providers' culturally responsive knowledge base on patterns of health behavior among older Black women. This requires that healthcare providers must first accept the existence and the sustainability of cultural difference and "ethnic notions," such as, skepticism, perceptions, expectations, and beliefs about the health care system, particularly in the area of preventive care diagnostics and treatment of the Black body.

Therefore, the most prominent requirement needed for the delivery of optimal preventive healthcare to older Black women and African Americans in general will be the ability of those in the healthcare setting to expand their cultural capacity and develop culturally responsive communication skill sets. Older Black women in Arizona have the capacity to operate as change agents in the areas of health promotion and prevention. Capacity building can be a powerful asset for health promotion, prevention, and care, as it would have the full commitment of its constituents, and promotion of wellness and

prevention of disease are powerful community tools for improving health status. This type of change will effect how well a Black woman ages, how well she copes with life's challenges, and how well she will survive a serious illness.

## **APPENDICES**

Appendix A- African American Community/Population Density - City of Tucson  
Urban Planning and Design, 2004

Appendix B - Key Informant Interview Guide

Appendix C - Recruitment Flyers

Appendix D - Pre-Screener Tool

Appendix E- Sample Interview Guide

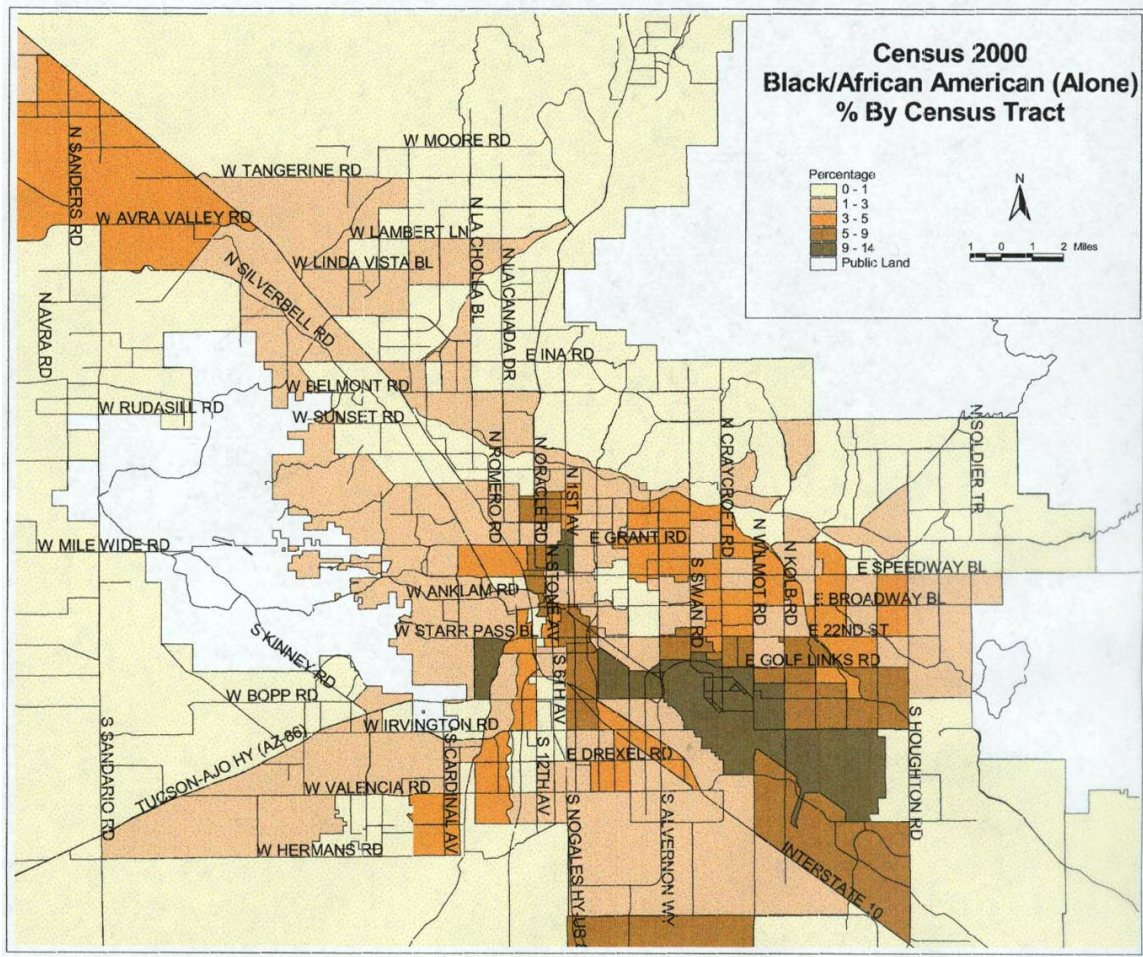
Appendix F- Small Group Discussion Guide

Appendix G-Healthcare Providers Interview Guide

Appendix H- Black Womens Health Conference Questionnaire



# Appendix A- African American Community/Population Density - City of Tucson Urban Planning and Design, 2004



## Appendix B - Key Informant Interview Guide

This study will focus on the many factors that impact older African American women, specifically how these factors may influence these women's health beliefs and preventative health care seeking behavior.

You have been chosen because of your proactive involvement in the African American community in Tucson and because I believe that you will offer an insightful and informative perspective on the subject of this study.

The available literature suggests that health beliefs and behaviors are determined by a number of factors, including the availability and accessibility of health care, education, trust, and faith in the quality of health care delivery systems. Researchers also suggest that for African Americans, information and understandings of health care also result from and are most prominently considered when they come about through a system of shared beliefs, values, customs, and behaviors that are culturally transmitted from generation to generation through learning about African American culture.

You have been identified as one of the key individuals for me to speak with in order for me to learn first hand about these factors that may influence older Black women and their health care access and utilization behavior.

I would like for us to go through this interview in four phases with questions at each stage, but please feel free to interrupt me with anything that you think is important, in any stage, remember I am trying to learn from you.

---

The first few questions that I will ask are to get to know a little more about you, then I would like you to focus on the general social, cultural and physical environments of Tucson as they affect the Black population here. The second set of questions that I will ask, I would like you to focus on Black women generally. In the third and final set of questions, I would like you to focus on your own personal beliefs, attitudes and behaviors.

**Our interview today, will be anonymous and confidential. With your permission, I will be taping our interview. This interview should probably take from an hour half to two hours..**

---

(Begin) Semi-Unstructured Interview

### Introduction

- Q1** Tell me a little bit about yourself?
- Q2** How many members are in your family?
- Q3** Did you go to school here? Or How did you happen to come to Tucson?
- Q4** What is your highest level of education?
- Q1a In our pre-screening questionnaire, you said you were:**
- Q1b** Employed ----What kind of work do you do?
- Q1c** Retired ----What kind of work did you do?
- Q1d** Unemployed ----What kind of work are you looking for?
- Q2** Who would be considered the key income person in your household?
- Q3** What organizations in the community are you or have you been involved in?

**DV: Predisposing (distal) -----cultural and physical environment ; cultural perception of illness; policies focus here on the general social, cultural and physical environments of Tucson as they affect the Black population.**

**Q1** Tell me what you know about the history of the Black community in Tucson?

I understand that in the physical environment of Tucson, the Black population is more spread out and may have been historically concentrated, in neighborhoods, like , Sugar Hill, South Park and A Mountain, and more recently the Eastside. Unlike other cities of its size there seems to be no core concentrated Black neighborhood, where a social, economic, cultural and political community would be created, maintained and accessed.

Yet in spite of the physical environment here, there seems to be a very resilient, proactive, and shared Black community that has a strong social, economic, cultural and political base citywide.

**Q2a** How do you think this Tucson Black community thrives and creates a cultural environment for itself?

**Q2b** In your opinion does this community have a social support network?

**Q2c** What are some of the community social support networks? How are they supported?

**Q3** How do new Black people to Tucson find out about the cultural environment, when they are looking for the physical environment of a Black neighborhood?

**Q4** How is information shared among the Black community already here ?

**Q5** What are some of the functions of social support networks in the Black community of Tucson?

**Q6** What is your perception of Black community connectedness in Tucson today?

**Q7** Black people have been in the Southwest for over 500 years and specifically in area that is now called Tucson, since 1500. I read that a Black man, named, Estevan, came to this area with the first Spanish. Yet in preparing for this research, most of the preventative health care programs and previous study done in Tucson have primarily focused on American Indians and Mexican Americans, there was very little information on Black people.

**\*Why do you think this is case?**

**Q8a** Tell me what you have heard about treatment of Blacks in health care settings in Tucson ?

**Q8b** What do you think about what you have heard?

**Q9** A persons race and racism have also been raised as an issues that impact Black people when they interact with healthcare delivery systems.

**\*Tell me what you think about that?**

**Q10** To what extent do you think the social support networks in the Tucson Black community influence the individual members of the Black population here?

**Q11** Trust in the health care delivery system has been raised as an issue that may influence Blacks in accessing and using preventative healthcare.

**\*Tell me what you think**

---

**DV: Enabling (intermediate)** ----- for BW (40 and older)--- service accessibility, cost, family organization, social support, cultural attitudes, beliefs, cultural health behaviors. focus here on Black women (40 and older) generally.

- Q1** What do you think the health practices are for Black women, who are 40 and older?
- Q2** What role do you think perceived racism plays in an these Black women's health related behavior?
- Q3** What role do you think her social support networks plays in her health behavior?
- Q4** What else do you think affects whether or not this Black woman goes for a preventative exam?
- Q5** Do you think BW who are 40 and older see pse as:  
necessary for good health or not necessary for good health?
- Q6** Do you these BW self-exam their breasts regularly ?
- Q7** Do you think these women get regular annual physicals to detect diabetes and hbp?
- Q8** In your opinion, what role does the cost of a screening exam or a physical have in the preventative health behavior of Black women? What role does time play?
- Q9** What have you heard women in this age group say about preventative health care exams, such as mammograms, and pap smears?
- Q10** Could this influence another women's decision to access or not access preventative health care?
- Q11** I've heard that body size and racial tension are two of the many factors that may affect a Black woman's decision to go for a screening exam.  
What do you think about that?
- Q12a** Do you think that Black women's experiences with preventative healthcare are shared with her social support network, and specifically shared with the females in these networks?
- Q12b** What impact or influence do you think this has ?
- Q13** Research suggests that for many African American women in this age bracket, personal experiences and a knowledge of the history of medical abuse on Blacks have resulted in a lack of trust and confidence in the health care system.  
\*Tell me what you think about that?
- 
- Q14** A person's race and the practice of racism have also been raised as an issues that influence the access and utilization of healthcare delivery systems.  
  
\*Tell me what you think about that?
- 
- Q15** Preventative health care delivery systems often say that they design preventative health care promotion messages for specific racial and gender groups, for example, hbp campaigns among Blacks.  
\*Tell me about some of the preventive health care information that you have either seen or heard that focuses on preventative healthcare for Black women in this age group?
- Q16** Do you think information about preventative health care services is shared through the social support networks of Black women in this age group?
-

**DV: Enabling (intermediate) (Continued)**

- Q17** How successful do you think preventative health messages are with these women? Would you say that they are very successful, somewhat successful or not successful at all?
- Q18** How could the way that these are marketed be made more culturally competent for Black women 40 and older?
- Q19** How could doctors, nurses and other health care practitioners be trained to appropriately interact with populations that are different from themselves?
- Q20** In your opinion, what needs to be in Tucson to offer better healthcare information and services to Black women?
- Q21** Some research says that over 2/3<sup>rd</sup>s of Black women, 40 and older still are not taking advantage of mammograms and other preventive services.

**What do you think the reasons are? (use list after response)****Q21a List of reasons**

The cost of the exam  
 Long waiting times  
 Transportation problems  
 Lack of referral by their physicians  
 Inattention while talking with the health care personnel  
 Lack of knowledge about the availability of services  
 Racism  
 Lack of Trust in health care services  
 The Shared past experiences of other Black women.  
 A belief that such services are not needed  
 Confusing clinic or hospital atmospheres  
 Wearing clinic robes that don't cover the body  
 Cultural insensitivity of health care practitioners, providers, staff

**DV: Service Factors (proximate)-----** health care delivery, personal beliefs, attitudes and personal health behaviors. **focus here on your own personal beliefs, attitudes and behaviors.**

- Q1** Tell me your personal definition of health?
- Q2** deleted
- Q3** What is your personal health care regimen? Do you exercise? Do you practice preventative health care?
- Q4** Where do you get your information about available health care services?
- Q5a** How are decisions made about your own personal health care?
- Q5b** Do you consult your personal social support network?

**In our pre-screening interview, you told me that you have utilized preventative health care, either in the form of mammograms, and/or pap exams:**

- Q6** How do you know when its time to go for a preventative screening exam?
- Q7** Tell me about your personal experience at your most recent preventative exam: what kind of exam was it? how did you feel you were treated through out the entire process ? (from making the appointment, upon arrival, during check in, in the waiting area, the exam and delivery of results)

---

**DV: Service Factors** (proximate) (Continued)

- Q8** What have you heard either your community or personal social support network say about preventative screening exams?
- Q9** What have you heard in general about health care delivery of service?
- Q10** What have you heard said about how Black people are treated in health care settings?
- Q11** Does what you've heard influence your decision to utilize these services?
- Q12** Keep in mind the definition that I have given for social support networks, does your personal social support come mainly from males, females or both?
- Q13** Tell me about some of your own personal experiences with any area of healthcare? what kind of setting was it?(doctors ofc, clinic) ? how did you feel you were treated through out the entire process ? (from making the appointment, upon arrival, during check in, in the waiting area, the exam and delivery of results)
- Q14** In a recent study, African-Americans surveyed believed that they received lower quality health-care than Whites. When asked about direct personal experience with racism in health-care settings, some of the Blacks responded that they, a family member or friend had been treated unfairly specifically because of their race. Over one-half of African Americans surveyed believed that Blacks with heart disease are less likely than Whites with heart disease to get specialized medical procedures and surgery. They also believed that Blacks were less likely than Whites to get the newest medicines and treatments for HIV/AIDS.
- \*What do you think about that?
- Q15** What is your personal belief regarding this idea?
- Q16** What do you think needs to be done about the training of doctors, health practitioners and support staff when dealing with someone of a different race than they are?
- Q17** As a Black women, tell me what is the value of hearing about other BW's experiences?
- 

**End of Interview**

As one of the key individuals interviewed first, the information that you have given me is crucial to an understanding of the roles that cultural difference plays in preventative health behavior.

- Q1** Do you have any questions for me?
- Q2** May I contact you later for clarification anything that you may have said?

Thank you for sharing your time and perspectives with me.

---

## Appendix C - Recruitment Flyers

Flyer #1

### **Health disparities and inequalities are most apparent among minority female populations, especially African American women. Please take a moment and fill out the Health Survey**

**Fact:** African Americans have proportionally older adults than any other racial/ethnic minority group and women outnumber men. By the year 2030, one in four older Americans will be a member of a racial/ethnic sub-population group (AOA, 2000). Race/ethnicity can be perceived as a fundamental measure of exposure to health risks. Reasons for health disparities include inadequately targeted prevention messages, and cultural differences between the health care system and the population served.

**Fact:** Specifically, the poorer health experienced by Black women reflects a cumulative effect of inadequate health care across the life span. Life Expectancy is lower overall for Black women. Black women have higher rates of Hypertension than White and Hispanic women increasing their risk of stroke and heart disease. Diabetes is sixty percent more common in African American women compared to White women. Kidney Disease disproportionately affects Black women, often as a complication of high blood pressure or diabetes. Breast Cancer, although more prevalent among White women, is more likely to lead to death when it affects Black women. Moreover, Black women with Breast, Uterine and Cervical Cancer die more often than White women with these diseases because over two-thirds are still not taking advantage of preventative screening exams (Hunter et al., 1993; McCarthy et al., 1998).

**Fact:** A complex challenge, which faces researchers, is to understand the basis for health care disparities, and to determine why disparities are apparent in some, but not other disease categories and service types. Little is known about how other factors such as patient or practitioner preferences, perceptions, or biases affect patterns of care, service delivery, access and utilization. Restricted access to quality medical care results from a range of both perceived and actual barriers (Dresser, 1993; Kleinman, 1996; Hahn, 1990, Institutes of Medicine (IOM), 2002).

**Fact:** Recent research has indicated that often times the health status of the Black woman as part of the overall African American population is affected by whether the health care services that are offered are culturally appropriate, are available and accessible and how this population (IOM 2002) utilizes health care.

**Fact:** Today research is being conducted in the Tucson and Phoenix Arizona areas, with the overall objective being to strengthen culturally responsive and culturally appropriate health prevention, promotion, and intervention that is user friendly and non-discriminatory. The specific goals of this research are to establish culturally responsive linkages between the healthcare systems, healthcare practitioners and older Black women to improve access for and foster appropriate use of the healthcare system. Specifically the utilization of preventative screening exams, and the improvement, availability and dissemination of health related information offered to older Black women in the Tucson and Phoenix area.

Flyer #2

## **Women, Race & Health: Where is your voice?**

**Healthy People 2010 has a specific focus on eliminating, and not merely reducing, racial and ethnic disparities in health among minority populations, especially women by the year 2010!!!.**

### **Did you know that?**

- Of the 140,000 Black people who die each year, about 60,000 of those deaths need not have occurred! This means that those 60,000 Blacks, whose life expectancy was cut short, died needlessly due to causes that would not have killed them had their health-care been equal to that of Whites!
- Health disparities are most apparent and closely associated among minority female populations, especially Black women. Life expectancy is lower overall for Black women. In addition, Black women are 3 times more likely to die while pregnant than White women.
- Black women have higher rates of hypertension than White and Hispanic women increasing their risk of stroke and heart disease. Diabetes is sixty percent more common in African American women compared to White women. Kidney disease disproportionately affects African American women, often as a complication of high blood pressure or diabetes.
- Breast cancer, although more prevalent in White women, is more likely to lead to death when it affects African American women. Moreover, Black women with uterine and cervical cancer die more often than White women with these diseases. A recent study found that the actual tumor cells in African American women grow more rapidly, leading to cancers that are more aggressive at an earlier age.
- The physician or health care provider may be unable to respond to a patient's personal needs because of perceived racial differences.

**We would very much like to listen to what you have to say. If you are interested in having your voice heard in the research and discussion on this topic please give us the following information and we will contact you for an interview:**

Name: \_\_\_\_\_ Age \_\_\_\_\_

Address: \_\_\_\_\_

Email: \_\_\_\_\_ Telephone Number: \_\_\_\_\_

**Contact:** Colette Marie Sims, Ph.D.c., Anthropology

Teaching Faculty, Africana Studies

621-9173

[culturedoctor@msn.com](mailto:culturedoctor@msn.com) or [csims@u.arizona.edu](mailto:csims@u.arizona.edu)



## Appendix D - Pre-Screener Tool

### Prescreening Questionnaire

#### Demographics:

Date of Birth: \_\_\_\_\_

How long have you lived in Tucson ? \_\_\_\_\_years

Are you employed? \_\_\_\_\_Yes \_\_\_\_\_No

If yes, where do you work?\_\_\_\_\_

Do you have health insurance? \_\_\_\_\_yes \_\_\_\_\_No

**Health:** How would you describe your health status ?

Excellent                      Good                      Fair                      Poor

Have you ever been diagnosed with a serious illness?

If yes, what was it?

When was that?

#### Preventative Exams Frequency:

Have you ever had a mammogram?                      Yes                      No

When was the last time you had a mammogram?

Were you referred for any further tests or treatment? Yes No

Did you go? Yes No

Have you ever had a pap smear?                      Yes No

When was the last time you had a pap smear?(within the last year; within the past two years; within the past three years, never)

Were you referred for any further tests or treatment? Yes No

Did you go? Yes No

Have you ever felt discriminated against in a health setting (doctor's office, clinic, hospital) ?

\_\_\_\_\_yes \_\_\_\_\_no

May we contact you for an interview? \_\_\_\_\_yes \_\_\_\_\_no

## Appendix E- Sample Interview Guide

I am trying to understand how AA women are utilizing health care services and the issues that they face when they go to different kinds of health care practitioners. I'll be asking you a lot of questions today, and I just want your opinion, there are no right or wrong answers to any of my questions. I'm just beginning my study, so please tell me if you don't understand my questions or you think I should be asking about something else.

I would like for us to go through this interview in phases with questions at each stage, **but please feel free to interrupt me with anything that you think is important, in any stage, remember I am trying to learn from you.**

Our interview today, will be anonymous and confidential. Nothing that you tell me will be revealed with your name, so you can be as honest and open as you like. I am really trying to understand your experience. With your permission, I will be taping our interview. This interview should probably take about an hour half to two hours.

---

### **A: Background**

How long have you been living here in Tucson?

Where did you grow up?

How many years of school did you attend?

How many people are living in your house? (ages) Are s/he working now?

You said you were.....(Refer to Screening Questionnaire)

Employed ----What kind of work do you do? How long have you been working there?

Retired ----What kind of work did you do? How long have you been retired?

Unemployed ---- Are you looking for work? (if unemployed, are you getting any kind of gov't support?)

Who would be considered the key income person in your household?

### **B: Health Access & Utilization**

How is health care changing over time? What is getting better; what is getting worse?

What is your personal definition of Health?

How has your past experience with the health care system affected how you act nowadays?

(Ask about quality of care, interactions, how and if they were profiled)

Where do you get your information about available health care services for women?

If I asked you to think about your stress level on a scale of 1 – 5 with 5 being a very high level, how would you rate your self?

Why?

What affects your decision about who to go see about a particular health concern? (is it economics, insurance, past experience, advice from ...)

Do you ask other Black women?

Do you ask your family?

How important is it to check other information before you do what a practitioners has told you to do?

Do you question a doctor's advice? Do you question a doctor's prescription?

How does the treatment by a practitioner influence how you act as a patient?

Are there times when you more readily volunteer information? When you withhold information? When is that?

When do you question a practitioner?

Do you ever (have you ever) demanded a test or have you gone for a second opinion?

Do you think getting information early is important or does it just open up a Pandora's box?

**B: Health Access & Utilization** (Continued)

What do you think about comparative statistics that say that African American women are at higher risk for hypertension or diabetes, etc...

How does past experience with HC practitioners' influence trust (in doctor, in system as a whole)?

On the phone you told me you had/did not have health insurance \_\_\_\_\_ (Refer to Screening Questionnaire)

Is that private, public health or government health insurance?

Do you see the same health care provider?

Have you avoided going to a doctor because you're concerned about losing your insurance or having your premium go up?

If your insurance changes (because of a job shift), how does that influence how you seek care?

What actions do you take for your personal health?

Do you exercise?

Do you watch what you eat?

Are you concerned about any particular health issue (high blood pressure, cholesterol, diabetes, cancer, etc.)??

How do you view your risk for getting these .....?

If you are worried about having a health issue.... Do you treat it quickly or do you have a wait and see attitude?

Are you ever concerned about the cure being worse than the illness in terms of changing one's quality of life?

When was the last time you had a full physical? \_\_\_\_\_

Have you had a bone mineral density test? \_\_\_\_\_

Have you had a colonoscopy? \_\_\_\_\_

Do you have a family history of any of the following illnesses: Ovarian Cancer \_\_\_\_\_ (if Yes)

Who? \_\_\_\_\_

HBP \_\_\_\_\_ (if Yes) Who? \_\_\_\_\_ Breast cancer \_\_\_\_\_ (if Yes) Who? \_\_\_\_\_

Diabetes \_\_\_\_\_ (if Yes) Who? \_\_\_\_\_

How does having a friend or family member who has one of these problems influence your own sense of risk?

Are you more likely to question things if you have a family history?

How do you respond to how risk information is given to you (information on diabetes, breast cancer, hypertension, cervical cancer )?

How is this type of information given to you?

Is there anything you are doing to try to prevent getting these illnesses ?

**My next sets of questions are about tests that you may have taken.**

**Mammogram**

You told me on the phone that you had a mammogram. (or not). Refer to Screening Questionnaire)

How long ago was that?

Where did you go? What kind of setting was it ?( a doctors ofc, a clinic or a hospital)?

**B: Health Access & Utilization** (Continued)

What made you decide to get that test?

How did you know where to go?

Do you remember what the results were?

Did you get a referral? If so, did you go...

On a 1 to 5 scale with 5 being the highest, how was your experience getting this test?

Why?

How did you feel the doctor, nurse, and support staff treated you ?

Were you listened to and most importantly were you questioned addressed?

Would you go back to the same provider, health care setting?

Did the health care provider explain the procedure to your satisfaction?

(If not) Why have you decided not to since \_\_\_\_\_(Refer to Screening Questionnaire)

What have you heard from other Black women about mammograms?

Does what you've heard influence your decision to get one?

---

**PAP Smear Exams**

You told me on the phone that you had a routine Pap smear. (or not). (Refer to Screening Questionnaire)

How long ago was that?

Where did you go? What kind of setting was it ?( a doctors ofc, a clinic or a hospital)?

What made you decide to get that test?

How did you know where to go?

Do you remember what the results were?

Did you get a referral? If so, did you go...

On a 1 to 5 scale with 5 being the highest, how was your experience getting this test?

Why?

How did you feel the doctor, nurse, and support staff treated you ?

Were you listened to and most importantly were you questioned addressed?

Would you go back to the same provider, health care setting?

**(If not)** Why have you decided not to since \_\_\_\_\_ (Refer to Screening Questionnaire) then go to alternative exam exp./

What have you heard from other Black women about pap smears?

Does what you've heard influence your decision to an exam?

---

What role do you think cost plays in getting, What role do you think time plays in getting: What role do you think being treated differently because of your race plays in going for these exams?

A regular physical?

A mammogram ?

A routine pap exam?

➤ **(Refer to Screening Questionnaire: if neither had a pap or a mammo then ask)**

**B: Health Access & Utilization** (Continued)

I would like to ask some questions about some of your personal experiences with health care providers I would like you to think about the entire experience (from making the appointment – when you arrived- during the check in - in the waiting area – during the exam - delivery of results, and any follow-up)

---

How long ago was that?

Where did you go? What kind of setting was it? (A doctors ofc, a clinic or a hospital)?

What made you decide to go?

How did you know where to go?

Do you remember what the results were?

Did you get a referral? If so, did you go...

On a 1 to 5 scale with 5 being the highest, how was your experience getting this test?

Why?

How did you feel the doctor, nurse, and support staff treated you ?

Were you listened to and most importantly were you questioned addressed?

Would you go back to the same provider, health care setting?

---

**C: My next set of questions are about Family & Networks of Support**

As a Black women, tell me what is the value of hearing about other BW's experiences?

Does your social support come from mainly females, males or both?

Who do you consider part of your social support network?

Do you ask your social support network about their health experiences?

Do you share your experiences with them?

How do others in your family or social support network treat you when you're diagnosed with something or told you're at risk?

Do they treat you differently, give you advice, etc?

Do you have any family members or friends who use a label like "hypertension" to influence what's happening around you (saying things like "don't upset me, I have hypertension...")

How are young people today changing because of what they see happening with older people?

Are there differences in the health information that you would give your children then what you would give to other people in your support network?

Are the messages to kids from parents changing at all (increased concern with having a healthy diet, exercising...?)

Do you see that young people are more concerned about being healthy than elders are?

Is there any generational difference that you see when it comes to health (more interest in diagnostic testing among the younger generation, etc)What have you heard about the treatment of Black people in health care?

---

**D: My next set of questions are about the Black Community**

What do you think is important for other people to learn, know and understand about Black culture and a Black community?

What groups in the Tucson community are you or have you been involved in?

How do you think the Tucson Black community thrives and creates a cultural environment for itself?

How do new Black people to Tucson find out about the Black community (as a cultural environment) here, when they are often looking for the physical environment of a Black neighborhood?

**D: My next set of questions are about the Black Community** (Continued )

Is information about health care discussed in the community? If so, how—what is word of mouth information in the community??

How is information shared among the Black community members already here ?

In your opinion, does the Black community in Tucson have a social support network? (if yes, ask the following)

What are some of the community social support networks?

How are they supported?

Do the social support networks here influence members of the Black community?

What do you think some of the functions of social support are as a network in the Black community Tucson?

What is your perception of Black community connectedness in Tucson today?

**E: Cultural Competency Vignettes'**

When you go to a health care provider, do you feel you are being stereotyped when you walk in the door?

Sometimes I have heard women say that they had to have a *Come to Jesus* talk with her doctor?

Do you know what that is?

Have you ever had to have this kind of talk with any health care provider?

What is word of mouth information in the Black community?

Research suggests that for many Black women, 40 and older a knowledge of the history of medical abuses on Blacks such as the Tuskegee experiments, the involuntary sterilization's on young black women and a belief that numerous other atrocities have occurred have resulted in the lack of trust and confidence in the health care system. **Tell me what you think about that?**

In a recent study, African-Americans surveyed believed that they received lower quality health-care than Whites, some of the Blacks responded that they or someone that they knew had been treated unfairly specifically because of their race. **Tell me what do you think about that?**

Health care promotion and prevention say that they advertise the availability of health care services through pamphlets, commercials, and flyers. They say that they target specific information for different race and age groups. Can you **tell me** about some of the health care information that you have either seen or heard that focuses on the health care for Black women in this age group?

Some research says that over 2/3<sup>rd</sup>s of Black women, 40 and older still are not taking advantage of mammograms and other preventive services. **What do you think the reasons are?** (after they list reasons do insert of reasons)

The health care practitioner ( such as the doctor, the nurse or their support staff) may be unable to respond to many of the patients that they care for..... because of their own personal bias and the impact that this bias may have on their professional behavior when treating patients.

**Tell me what you think about that?**

What do you think needs to be done about the training of doctors, health providers and support staff when dealing with someone of a different race than they are?

**End of Interview**

The information that you have given me is crucial to an understanding of the roles that cultural difference plays in preventative health behavior. Do you have any questions for me? May I contact you later for clarification anything that you may have said? May I re-interview in 6 months?



- Black community in Tucson & Health Care

Ask if there are any questions or concerns then **Ask first question**

---

**Our first topic for discussion is Health Care Access and Util which includes Preventative and Health Behaviors:** The first questions I want to ask you are about preventive exams like mammograms, pap smears. In your responses, think about your own personal experience as well as those of other AA women you know.

Some research says that over 2/3<sup>rd</sup>s of Black women, 40 and older still are not taking advantage of mammograms and other preventive services.

***What do you think the reasons are?***

(after they list reasons do insert of reasons from Q21 Key Informant Guide )

---

- Do you think Black women who are 40 and older consider screening tests like mammograms & pap exams as important?
- Is that something that's talked about among the women that you know?
- Do you know many women who have taken them?
- From your experience, where do you think Black women obtain their information about these health care services?
- How would you think that being treated differently because of your race influence someone going for preventive screening exams?
- How do you think past experiences of Black women with health care systems have affected how they act nowadays?
- Do you think that women who are Black receive the same quality of care as other women?
- Are the interactions with the doctor, and the staff different? How?
- Do you think that Black women are racially profiled or stereotyped by the health care provider and staff when they go for a health care visit?
- If yes, What are some of those stereotypes?

**For those of you who may have had preventative exam, when you went for your most recent preventative screening exam, whether mammogram or pap smear:**

- What made you decide to get that test?
  - How did you feel the doctor, nurse, and support staff treated you ?
  - Were you listened to and most importantly were your questions addressed?
  - Do you plan to get another exam next year?
  - If Black women are worried about having a health issue, do they treat it quickly or have a wait and see attitude? Why?
  - Do you think this affects their attitude toward preventive care?
- 

Some research has found that Life Expectancy is lower overall for Black women. Black women have higher rates of Hypertension than White and Hispanic women increasing their risk of stroke and heart disease. Diabetes is 60% more common in African American women as compared to White women. Kidney Disease disproportionately affects Black women, often as a complication of high blood pressure or diabetes and Breast Cancer, although more prevalent among White women, is more likely to lead to death when it affects Black women.



- Have you heard those statistics? What do you think about them? Why do you think this is the case? (is genetic; is it lifestyle; is it lack of access to preventive care...)

I have heard other Black women referred to as legends in their own minds....always doing for everybody and making sure everyone else is taken care of before ourselves, because we have had to do it all...most of the time.....

- What role do you think this idea plays in us accessing and utilizing health care systems....?
- Do you think older AA women are less likely to take care of themselves because they've always taken care of others? Is this unique to AA women or do you think it is true of women in general?

---

#### **Networks of Support & Funds of knowledge:**

- Who do you consider part of your networks of support when it comes to health issues?
- Do you ask the people in your networks of support about their health experiences?
- Do you share your experiences with them?
- What have you heard from your social networks of support about the treatment of Blacks in health care settings?

---

#### **Trust and Care**

- How does the treatment by a practitioner influence how you act as a patient?
- What do you think is appropriate and inappropriate to discuss with your health care provider/practitioner?
- *Would you feel more comfortable discussing and asking questions if the health care provider was Black? Why?*
- Do you question a doctor's advice or just accept it? Do you question a doctor's prescription?
- Is there a particular time that you can recall when do you question a practitioner?
- What happened?
- How important is it to check other information before you do what a practitioners has told you to do?
- Who do you discuss it with? Is your support network part of the discussion?

---

**In the interviews, sometimes I would hear women say that they had to have a "Come to Jesus talk" with their doctor in order to be heard, get care etc.**

- Do you know what that is?
- Have you ever had to have this kind of talk with any health care provider?

---

Research suggests that for many Black women, 40 and older a knowledge of the history of medical abuse on Blacks such as the Tuskegee experiments, the involuntary sterilization's on young black women and belief that numerous other atrocities have occurred have resulted in the lack of trust and confidence in the health care system.

**Tell me what you think about that?**

---

In a recent study, African-Americans surveyed believed that they received a lower quality of health-care than Whites, some of the Blacks responded that they or someone that they knew had been treated unfairly specifically because of their race.

**Tell me what do you think about that?**

Health care promotion and prevention say that they advertise the availability of health care services through pamphlets, TV commercials, and flyers. They say that they target specific information for different race and age groups.

---

**Can you tell me about some of the health care information that you have either seen or heard that focuses on the health care for Black women?**

The health care practitioner ( such as the doctor, the nurse or their support staff) may be unable to respond to many of the patients that they care for..... because of their own personal bias and the impact that this bias may have on their professional behavior when treating patients.

**Tell me what you think about that?**

What do you think needs to be done about the training of doctors, health providers and support staff when dealing with someone of a different race than they are?

**The Black community in Tucson**

From your experience living in Tucson, Is information about health care discussed in the community?  
Where?

What is meant by word of mouth information in the Black Community?

What do you think is important for others, specifically doctors, nurse, healthcare providers. to learn, know and understand about Black culture and a Black community?

Thank you for spending your afternoon or morning with me.

## Appendix G-Healthcare Providers Interview Guide

I am trying to understand how AA women aged 40 and older are utilizing health care services and the issues that they face when they go to different kinds of health care practitioners. I'll be asking you a lot of questions today, and I just want your opinion, there are no right or wrong answers to any of my questions. I'm just beginning my study, so please tell me if you don't understand my questions or you think I should be asking about something else.

I would like for us to go through this interview in phases with questions at each stage, **but please feel free to interrupt me with anything that you think is important, in any stage, remember I am trying to learn from you.**

---

**Our interview today, will be anonymous and confidential. Nothing that you tell me will be revealed with your name, so you can be as honest and open as you like. With your permission, I will be taping our interview. This interview should probably take about an hour.**

A: Background

How long have you been living here in Tucson?

What is your current position? How many years of school did you attend?

How do you see your role in the public health arena ?

How long have you been working at the health field?

Have you ever worked with the African American population in a :

health practice setting \_\_\_\_\_ health education setting \_\_\_\_\_  
 health promotion/prevention \_\_\_\_\_ delivery of health service \_\_\_\_\_ health policy/administration \_\_\_\_\_

(After each yes ask).....Tell me a little bit about that.

### **B: Experiences and Observations:**

From your observations or experiences do African Americans seem to interact differently than other ethnic groups with health care systems?

From your observations or your experiences do African Americans have different health concerns than other groups? (If yes) How do they differ?

From your experiences or observations, what are the most common health problems among African Americans?

Do you find that Blacks are at a higher risk for some diseases? Why do you think this is the case?

### **B: Interactions with OBW**

Have you ever worked with African American women in a:

health practice setting \_\_\_\_\_ health education setting \_\_\_\_\_ health promotion/prevention \_\_\_\_\_  
 delivery of health service \_\_\_\_\_ health policy/administration \_\_\_\_\_

**(If yes then ask.....If none of these then go right to Health Culture and Perception Questions)**

---

**If practice/ promo/prevention/health education ask:****HAUB**

Do you see many Black as patients or participants in prevention initiatives, here? About how many a month?

From your observation or experience do Black women seem to interact differently than women of other ethnic groups with the health care system?

Do you find them more or less compliant in terms of referrals, and followup?

How effective do you think preventive healthcare information is for Black women ages 40 and up ?

Do Black women ask many questions about screening exams (paps, mammograms, etc.)?

What have you heard Black women say about screening exams, such as pap, mammograms and physicals?

Has it been your experience that Black women are more vocal in their interactions with healthcare practitioners or in health promotion/prevention situations than other women? Can you think of any examples of this?

Some research says that over 2/3<sup>rd</sup>s of Black women, 40 and older still are not taking advantage of mammograms and other preventive services. What do you think the reasons are for this?

**Also use Q21 sheet here**

**If a service delivery system/policy and administration ask:****HAUB**

Do you see many African American women as clients, or as patients, here? About how many a month?

From your observation or experience do Black women seem to interact differently than women of other ethnic groups with the health care system?

Do you find them more or less compliant in terms of referrals, and followup?

How effective do you think preventive healthcare information is for Black women ages 40 and up ?

Do Black women ask many questions about screening exams (paps, mammograms, etc.)?

What have you heard Black women say about screening exams, such as pap, mammograms and physicals?

Has it been your experience that Black women are more vocal in their interactions with a healthcare service delivery system/policy and administration than other women? Can you think of any examples of this?

Some research says that over 2/3<sup>rd</sup>s of Black women, 40 and older still are not taking advantage of mammograms and other preventive services. What do you think the reasons are for this? **Also use Q21 sheet here**

**C: Health Culture & Perception**

Research suggests that for many Black women, 40 and older a knowledge of the history of medical abuses on Blacks such as the Tuskegee experiments, the involuntary sterilization's on young black women and a belief

that numerous other atrocities have occurred and continue to occur have resulted in the lack of trust and confidence in the health care system.

**Tell me what you think about that?**

Do you think that healthcare practitioners are aware and sensitive to the importance of trust and confidence among older African American women? \_\_\_\_yes \_\_\_\_no

Do you think that healthcare promotion/prevention is aware and sensitive to the importance of trust and confidence among older African American women? \_\_\_\_yes \_\_\_\_no

Do you think that healthcare educators are aware and sensitive to the importance of trust and confidence among older African American women? \_\_\_\_yes \_\_\_\_no

Do you think that healthcare administration and policy is sensitive to the importance of trust and confidence among older African American women? \_\_\_\_yes \_\_\_\_no

**(After each response whether response was yes or no.....ask .....Why do you think that is the case?)**

---

Do you think that the current literature provided by health care about preventative screening exams for breast, cervical, ovarian cancer, hbp and diabetes is culturally relevant to African American women and their concerns?

What do you think are some of the stereotypes about African Americans and their interactions with health care delivery systems (in hc/prevention settings or with policy/ administration) ? Are you aware of different stereotypes for Black women?

Do you think that practitioners change how they interact with a patient because of their age or their race?

In a recent study, African-Americans surveyed believed that they received a lower quality of health-care than

Whites, some of the Blacks responded that they or someone that they knew had been treated unfairly specifically because of their race.

**Tell me what you think about that?**

Do you think that health practioners or support staff influence one another with regard to perceptions about the minority populations that they treat, such as, African Americans?

What do you think needs to be done about the training of doctors, health providers and support staff when dealing with someone of a different race than they are?

Have you and your colleagues participated in cultural competency training workshops?

Tell me how this training has been useful for you in interactions with African Americans?

---

**End of Interview**

The information that you have given me is crucial to an understanding of the roles that cultural difference plays in preventative health behavior.

Do you have any questions for me? May I contact you later for clarification anything that you may have said?

Thank you for sharing your time and perspectives with me.

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## Appendix H- Black Womens Health Conference Questionnaire

### Shortened Version

BWTF Conference: Tools to Build a Healthier You

Please take a moment and fill out this brief survey and turn it back in today. Thanks!

Date of Birth: \_\_\_\_\_ How long have you lived in Tucson? \_\_\_\_\_ Years

Are you employed? Yes \_\_\_ No\_\_\_ If yes, where do you work? \_\_\_\_\_

Do you have health insurance? Yes \_\_\_\_\_ No \_\_\_\_\_

General Health: How would you describe your health status?

Excellent \_\_\_ Good \_\_\_\_\_ Fair \_\_\_\_\_ Poor \_\_\_\_\_

Have you ever been diagnosed with a serious illness? Yes \_\_\_\_\_

No \_\_\_\_\_

If yes, what was it? \_\_\_\_\_

When was that? \_\_\_\_\_

Mammograms: Have you had a mammogram? Yes \_\_\_\_\_ No \_\_\_\_\_

When was the last time you had a mammogram? \_\_\_\_\_

Were you referred for any further tests or treatment? Yes \_\_\_\_\_ No \_\_\_\_\_

Did you go? Yes \_\_\_\_\_ No \_\_\_\_\_

Pap Exams: Have you had a pap smear exam? Yes \_\_\_\_\_ No \_\_\_\_\_

If Yes, when was the last time you had a pap smear?

within the last year \_\_\_\_\_ within the past two years \_\_\_\_\_ within the past three years \_\_\_\_\_

Were you referred for any further tests or treatment? Yes \_\_\_\_\_ No \_\_\_\_\_

Did you go? Yes \_\_\_\_\_ No \_\_\_\_\_

Physical Exams: Have you had a physical? Yes \_\_\_\_\_ No \_\_\_\_\_

If Yes, when was that? \_\_\_\_\_

Were you referred for any further tests or treatment? Yes \_\_\_\_\_ No \_\_\_\_\_

Did you go? Yes \_\_\_\_\_ No \_\_\_\_\_

Now, Please think about your most recent preventative health exam (mammogram, pap smear, physical, etc.). On a scale of 1 to 5, with 5 being the most positive, and 1 being the least positive, how would you rate your experience?

Quality of Health care received \_\_\_\_\_ Were your questions answered? \_\_\_\_\_

Were you listened to? \_\_\_\_\_

Cultural sensitivity of the health care practitioner \_\_\_\_\_ What type of exam was

it? \_\_\_\_\_ If you gave a low rating to any of the questions above, please explain \_\_\_\_\_

A. Have you ever felt discriminated against in a health setting or clinical encounter (a doctor's office, clinic, etc) or that the doctor, the nurse or support staff treated you differently because of your race?  
Yes\_\_\_\_ No \_\_\_\_\_

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B. Have you ever felt like you were being stereotyped when you walked in the door of a health care setting (doctor's office, clinic, etc)? Yes\_\_\_ No\_\_\_

If you are interested in having, your voice heard in discussions on Black women and health, I would very much like to listen to what you have to say. Please provide the following information and I will contact you for an interview.

---

Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
Telephone Number \_\_\_\_\_ Email: \_\_\_\_\_

Contact: Colette Marie Sims, Ph.D.c., Department of Anthropology,  
Teaching Faculty, Africana Studies  
520-621-9173 or (520) 571-9081 [culturedoctor@msn.com](mailto:culturedoctor@msn.com) or [csims@u.arizona.edu](mailto:csims@u.arizona.edu)

## ENDNOTES

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<sup>i</sup> Accordingly, since one of the areas of focus in my study is on the patterns of health behavior to detect these specific diseases, the chosen definition of "older" for this specific population seemed appropriate. Throughout this study the use of the term older Black women or older African American women is interchangeable and both indicate women over 40 years of age. Furthermore, a review of the gerontological and health care literature offered a wide a variety of different ages used to define the term "older," including being at 65 or over (the current eligibility age for Medicare) and being over the age of 45, 50, 55, or 65 depending on the data source and rationale (Markides & Lee, 1990; Koop, 1991; Gale & Erickson, 1997; Tilley et al., 2003 and Brown & Topcu, 2003). Additionally, an analysis of the demographic data collected among the fifty older Black women in the interviews conducted beginning in late 2002 indicated that their average age is 55, with the oldest participant at the time of the interview being 95 years of age thus meaning of this term is reflected within the ages of my population.

<sup>ii</sup> The term multiple ecologies is used in this dissertation to broaden the arena in which the dynamics of the agent (history, tradition, Being Black, culture) operate in relationships between the host organism (African Americans) and the environment (ecosociocultural).

<sup>iii</sup> An ecosociocultural context / perspective / framework is where, "race" is seen as in a primarily reflecting the intersections of biological, cultural, socioeconomic, political and legal determinants, as well as the practices of racial bias that affects not only health behavior but also the optimal delivery of healthcare. According to Malinowski, (1923,1935) definitions of context are to be viewed as "embracing all aspects of cultural life, social and physical environment" and may also include "specific speech events" (in Briggs, 1988:12). The "context of [socio] cultural reality" refers to the "activities, interests, moral and aesthetic values that may be correlated to the "context of situations" which refers to the "purpose, aim and direction of accompanying activities"(Malinowski, 1935, p 21 -24).

<sup>iv</sup> "Being Black" is used both as a noun and a verb. As a noun I use the term to refer to an articulation of a person, and a description of a culture, or a piece of culture. As a verb "being" Black also means in the state of being "racialized" as to describe the status or response of or to a person who is "racially" identified as Black or African American.



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<sup>v</sup>Racial democracy is a term coined by the Brazilian sociologist Gilberto Freyre in the early 20th century. In Brazil this theory refers to a history of extended miscegenation which has created a cultural *mélange* in which all races are equally valued. However, nothing is farther from the truth, especially in contemporary America. Although extended miscegenation has occurred creating a cultural *mélange* of many shades of Blackness only those populations who are invisible, e.g. non-raced are equally valued. Thus the use of this term in my study is from the expanded theoretical perspectives of racial formation theory (Goldberg, 1997; Cornell & Hartmann, 1998; Hutchinson, 1997) and is used to discuss the struggle for African American human rights in America who reside in a republic founded on the promise of full access to a democratic process that has yet to be fulfilled.

<sup>vi</sup> Networks of Support can be defined as aid, guidance, assistance, and helpful information exchanged through social relationships and interpersonal transactions with friends, family, extended-kin, and other groups. Networks of support often operate over time, from one generation to the next. Culture is one aspect of a network of support, and culture is defined as a people who share a common history, place of origin, language, food preferences, spirituality, health beliefs, and values that bring about a sense of self-awareness of being a member of this ethnic group.

<sup>vii</sup> I use the term re-memory to reference the questions, intuitions and revisions as memories of the older Black women shared in this study that weaves into and out of the present, the past, individual streams of consciousness, as side stories that are memorable or re-called without losing the thread of thought, or the common story that unites their experiences into a cohesive, meaningful whole. This term is useful when discussing the perceptions, expectations and beliefs that are constructed from the shared experiences, expectations, and beliefs of generations of Black women. This term is used from the work of Toni Morrison *Playing in the Dark: Whiteness and the Literary Imagination*, 1992; *Beloved*, 1987. For further discussion see Hamilton, Cynthia S. "Revisions, Re-memories and Exorcisms Toni Morrison and the Slave Narrative." *Journal of American studies* 30.3 (1996): 429.

<sup>viii</sup> With respect to the term "what we all know," and its significance when discussing perceptions and beliefs among older Black women and healthcare encounters these are to be understood as definitions of context. Definitions inform the importance of our understanding of the explicit and implicit definitions of context with respect to performance and the interactional environment of a healthcare setting, encounter between an older Black woman and predominately White healthcare service delivery.

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<sup>ix</sup> I will use the term Black and White as a proper noun in recognition of specific cultural groups. To that end, I have chosen to capitalize the B and the W. Throughout this dissertation the terms Black and African American will be used interchangeably. According to US Census (2000) data, what is now known as the Black population encompasses many different kinds of people. For example, since 1970 sizable numbers of African and African Caribbean immigrants have become part of this group.

"Who is Black?" has long been that a Black is any person with any known African Black ancestry, (Myrdal, 1944:113-18; Berry and Tischler, 1978:97-98; Williamson, 1980:1-2). According to U.S. Census (2000) data, what is now known as the Black population encompasses many different kinds of people. For example, since 1970 sizable numbers of African and African Caribbean immigrants have also become part of this group. For discussion on the interchangeable use of the term Blacks with African Americans see Kimberle William Crenshaw 's article Race, Reform, and Retrenchment: Transformation and Legitimization in Antidiscrimination Law, Harvard Law Review 101, no.7 (May1988): 1332.

<sup>x</sup> SEER is the Surveillance, Epidemiology and End Results Data Program. SEER is a set of geographically defined, population based central cancer registries in the United States, operated by local nonprofit organizations under contract to the National Cancer Institute [NCI]. Registry data are submitted electronically without personal identifiers to the NCI on a biannual basis, and the NCI makes the data available to the public for scientific research. With respect to "racial" difference It is interesting to note that some of the researchers utilize the same source of data e.g. the Surveillance, Epidemiology, and End Results [SEER] program of the National Cancer Institute, studies conducted by the National Cancer Institute and population data collected by the US Census Bureau.

<sup>xi</sup> A genetic model is where "race" is seen as primarily reflecting "biological homogeneity," e.g., Black/White differences in health as genetically pre-determined (Williams, 2002)

<sup>xii</sup> Four isoforms control the amount of estrogen that reaches a cell; some are protective and some feed the growth of tumors. Normal breast tissue contains a mix of each isoform this is to keep the estrogen that interacts with the cell in balance. Cancer changes the mix of isoforms and the balance of estrogen that comes into the cells (Professional Guide to Diseases, 2002).

<sup>xiii</sup> Socioeconomic position [SEP] expands the concept of socioeconomic status [SES ],e.g., income, education, insurance status to also consider the (eco)sociocultural environment created through the "racial" positioning of African Americans through social, cultural, economic, systemic and structural hegemonies e.g. segregation, discrimination and racism that often ascribes, impacts or determines [SES],which in turn

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impacts, determines the health status and well being of the racialized population (Krieger, 1997; Williams & Collins, 2001).

<sup>xiv</sup> Hirschfeld's (1997) discussion of "race as a category of the mind and/or a category of power" specifically notes that identity by "race" is part our social fabric as a category of the mind among Whites and African Americans. Being pre-disposed to be on the receiving end of various acts of racial bias, such as, discrimination, segregation or physical attack is often part of an socialized, and culturally shared "unquestioned belief" due to the racial status of "being" Black in U.S. society. In other words, as a category of the mind and as category of the power of potential for it to occur -- racial bias may be "out of sight but it is never out of mind" of Blacks (defined by EVP, 2002).

<sup>xv</sup> The ethos of Black womanist culture may provide "cues to action" that are "socially emergent and co-created "as a function of having a Black identity" (Hecht, et al., 1993, p.82)

<sup>xvi</sup> Phillida Salmon (1985) notes that racist or sexist attitudes are given expression in the refusal to recognize the person within the Black skin, the female body. Within this perspective individual women are further diminished – reduced to the "typification of a social category". Thus the term gendered racial bias is used in my dissertation to define the larger set of racial codes tied to gender that are used by healthcare providers, the health care system and health care research and practice in the United States. For example, the "Black aggressive tumor" discourse in breast cancer research is an effective way to code and reference biological, pre-disposed inferiority of the Black woman's body. Foucault ( 1980, 1979) notes that the body is (a significant] site for struggles over power.

<sup>xvii</sup> Theoretically, "race" is believed to typically involve more or less readily identifiable physical differences, and ethnicity often has corresponded with cultural differences-- patterns of language or accents, modes of dress, behaviors--that make ethnic boundaries easy to establish and observe. e.g. racial formation see Omi & Winant, 1994.

<sup>xviii</sup> The "one drop rule," is this nations taken for granted definition of Blacks Both Blacks and Whites generally accept that. According to Davis (2002) "reflects the long experience with slavery and later with Jim Crow segregation...the 'one-drop rule,' means that a single drop of 'black blood' makes a person black. It is also known as the 'one black ancestor rule,' some courts have called it the 'traceable amount rule,' ( p.5). Anthropologist call it the 'hypo-descent rule,' (Harris, 1964:56) meaning that racially mixed people are assigned the status of the subordinate group.

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<sup>xix</sup> With respect to the use of the term "ethnic notions" similar in meaning with "what we all know" these terms are also interchangeable within this study and refer to culturally constructed "unquestioned beliefs"(VS, 2005) as unembellished truths within the fund of knowledge about certain things as conventional wisdom about "being" Black when interacting with some Whites.

<sup>xx</sup> The use of the term "womanist" as applied to theory and practice (see Terborg-Penn, 1983;Walker, 1983; Parks, et al., 1996). Particularly when I refer to sociocultural beliefs and values of the women in this study, as active participants within the ethos of Black culture. and to their insights that seem to reflect a "personal standard of womanhood developed without undue dependence on either sexist societal norms or the anti-ethical positions of [feminism]" (Carter & Parks, 1996, p 491). Womanist talk is the term I have given to the communicative behavior of those older Black women who use their "voice" as part of advocacy and resiliency, and this term is also applicable in understanding the use of "having a come to Jesus talk" with a healthcare provider.

<sup>xxi</sup> The ultimate trope of difference is a term similar in definition to defining "race" as the ultimate "trope of kinship" when used by Gates (1986). I use these terms interchangeably because they embody a radical Black subjectivity. Also see Gilroy (1994) in theorizing Black nationalism and communication where he defines the "trope of the family" as representations of Blackness that are ideal, imaginary and pastoral through a symbolic projection of "race" as kinship (pp. 192-207). Also see Dubois "trope of a veil" discussions.

<sup>xxii</sup> The term ethos refers to the thoughts, feelings "beliefs, attitudes and characteristics of an individual or a group" (Webster, 2005, p. 481) that "pertain to health and imply or refer to behavior" (Elder, et al., 1994, p.48). The term and definition of ethos and behavior are being understood in my dissertation as to refer to those societal and cultural patterns in which racial bias may act both as a barrier to the use of preventive healthcare and as a contributor to poor health status among older Black women.

<sup>xxiii</sup> Embedded refers to a lack of ethnographic data from older Black women and their insights on how the meaning of "being" Black and having a "race" has spawned stereotypes, created assumptions among healthcare providers and older Black women that can have negative consequences on health and well being. The term "embedded" refers to the idea that for the older Black woman and the providers that they interact with, living in a racially conflicted society they may routinely use 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> hand experiences, knowledge, expectations, perceptions, and beliefs related to health care and the Black body because these notions are often firmly established as part of "what we all know"

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<sup>xxiv</sup> The term culturally deemed geographic sites is a perspective from cultural geography and refers to aspects of geography that relate to different cultures, with an emphasis on cultural origins and movement and the cultural characteristics of regions (e.g., language, religion, ethnicity, politics, historical development, agricultural methods, settlement patterns, and quality of life). There is a strong relationship between cultural geography, anthropology, and archaeology.

<sup>xxv</sup> Prior to the Civil Rights Act of 1964, due to racist real-estate covenants, redlining, and other discriminatory practices, non-white peoples were almost never afforded the same opportunities to move into middle class neighborhoods, even when they may have been economically able to do so. "White flight" is a colloquial term for the demographic trend of white people, generally but not always upper and middle class, moving from increasingly and predominantly non-white areas. Whites often moved from urban cores to nearby suburbs or even to new locales entirely. In some cases, upper and middle-class blacks immediately organized and sustained former middle-class enclaves abandoned by whites. (Wikipedia, 2006)

<sup>xxvi</sup> Righteous skepticism as a form of hyper-vigilance is part of mistrust and is used to protect from or to be prepared for racial bias. Healthy paranoid are part of this type of skepticism as conditioned responses and are the result of having to construct a mechanism, a cognitive strategy that operates to prepare and to protect the Black body from assault. African Americans understand that having a "racial" identity means that racism/discrimination may be "out of sight but it is never out of mind" (defined by EVP, 2002; Wiggins, 2005).

<sup>xxvii</sup> The terms sense and reference are used to coalesce the ideas of a sign, such as "race" and a signifier, such as "being" Black with respect to understanding the impact of these identifiers.

<sup>xxviii</sup> Referring to Blacks as Nigra's in 1960's medical training curriculum is interesting because almost 20 years later the use of these kinds of racial slur were still being uttered, for example, a former Governor, of the state of Arizona, Evan Mecham in issuing the order to rescind the observance of Martin Luther King, Jr's . birthday as a state holiday insisted in his State of the State Address that his contemporary use of the slave term "pickaninies" in referring to African American children was not only acceptable but also entirely appropriate.

<sup>xxix</sup> The construction of an identity in every age and every society, Said maintains, involves establishing opposites and "Others." I use the term "interpretive community" as my understanding of how this happens because "the development and maintenance of every culture requires the existence of another different and competing *alter ego*."

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<sup>xxx</sup> I used the term "reigning registers" as defined by me (1996) in referring to the Black community, family and networks of support that "tell it like it is." Word of mouth as a tool is what facilitates the construction of "reigning registers" among Black women and is used to access and share information and how Blacks stay informed in a small setting, where there is no newspaper, or media outlets that specifically focus on the members of that community.

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