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LIVING AND DYING ON THE MARGINS: A JOURNEY INTO THE CULTURE OF
PINK AND BLACK WOMEN'S NARRATIVE ACCOUNTS
OF BREAST CANCER

by

Cleothia Gill

A Thesis
Submitted to the
Faculty of The Graduate College
in partial fulfillment of the
requirements for the
Degree of Master of Art
Department of Anthropology

Western Michigan University
Kalamazoo, Michigan
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Last, but certainly not least, I give thanks to my husband Tony, without whom completion of this thesis would not be possible. His love and unwavering support is my source of inspiration, foundation of strength and peaceful refuge.

Cleothia Gill

DEDICATIONS

This thesis is dedicated to the memory of my grandfather Cleveland Gill, my grandmother Zelma Gill and to my aunt Zelma Ann Kittrell.

LIVING AND DYING ON THE MARGINS: A JOURNEY INTO THE CULTURE OF PINK AND BLACK WOMEN'S NARRATIVE ACCOUNTS OF BREAST CANCER

Cleothia Gill, M.A.

Western Michigan University, 2008

This thesis examines black women's understandings of and experiences with breast cancer through the use of narratives. These narratives offer different positions from which to critically analyze the dominate conceptualization of breast cancer in American society, which is primarily associated with white, middle class, heterosexual women. There is a focus on issues such as breast cancer 'risk', increased mortality rates among black women, dominate discourses and media representations of breast cancer, and mastectomy and body image. African American women's stories are used to 'deconstruct' and reveal how this disease is socially constructed in ways that has profound impact on their lives, particularly as it relates to issues of race, class and gender. There are not only differences in black women's lived experience of this disease, but there are also structural and institutional constraints that inhibit their ability access healthcare institutions and receive equal and quality treatment within the medical encounter. These impediments, as revealed in many narratives, are more likely to increase black women's mortality rates, as well as, significantly impact their 'risk' for developing the disease.

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CHAPTER I

JOURNEY INTO THE WORLD OF BREAST CANCER

“Historically, scientific knowledge has been seen as separate, asocial, universal, and consequently not subjected to the same theoretical or historical deconstruction and unmasking of interests as other types of knowledge” (Fosket, 2000, p.18). Biomedical knowledge, which is derived and aligned with science, has traditionally shared this exempt status, primarily through its reliance on the biomedical model of disease. This model assumes that diseases have specific causes that can be located in the ill person’s body, diseases have the same symptoms and outcome in any social situation and that medicine is a socially neutral science (Lorber, 2000). The traditional conflation of biomedical knowledge with truth and objectivity means that the socially constructed nature of such knowledge is often overlooked, ignored or denied (Fosket, 2000). However, this thesis, through the use of African American women’s narratives, is an attempt to not only understand their conceptualizations and experiences with breast cancer, but it also aims to use these stories as a way to ‘deconstruct’ and reveal how this disease is socially constructed in ways that have profound impact on black women’s lives, particularly as it relates to issues of race, class and gender.¹

These narratives also offer different positions from which to critically analyze the dominate conceptualization of breast cancer in American society. There are not only differences in black women’s lived experiences of this disease, but there are also

¹ While there is no precise definition of deconstruction, this philosophical approach, first put forth by Derrida, “operates in the language of reason by exposing the inherent contradictions in reasonable positions. It seeks to understand the longevity and paradoxes of a text, which is any printed, visual, oral, or auditory product available for reading, viewing or hearing” (Denzin, 1995, p. 52). Thus, in this thesis, I examine the margins of breast cancer discourse, black women’s stories, in order to find the contradictions in issues such as ‘risk’, increased mortality, and breast reconstruction to name a few.

structural and institutional constraints that inhibit their ability to access healthcare and receive equal and quality treatment within the medical encounter. These impediments are more likely to increase black women's mortality rates, as well as, significantly impact their 'risk' for developing the disease. "Rejecting the assumption that an analysis of race means focusing primarily on people of color," (Giroux, 1997, p. 97) this thesis implicates whiteness² as the unmarked category, which breast cancer discourse and culture³ creates within the public consciousness, a disease that is primarily associated with white, middle class, heterosexual women.

It is my intention to show that narratives are a vital source of information because not only are they a fundamental human way of giving meaning to experience (Garro & Mattingly, 2000), but with regards to illness, suffering and pain, narratives are important because they "highlight the fault lines of society" (Klienman, 1992, p. 3). Thus, through narrative, it is possible to examine gender inequalities, racial oppression and other

² "Whiteness refers to a set of locations that are historically, socially, politically, and culturally produced and intrinsically linked to unfolding relations of domination" (Frankenberg, 1993, p. 6). "Whiteness silences itself by pretending that it has no meaning, no particular relation to a cultural privilege that is power-filled. Although, "the silence about whiteness presents it as though it were [sic] not a color; and colors everything else by do doing so," (Eisenstein, 2004, p.59) naming whiteness displaces it from the unmarked, unnamed, status that is itself an effect of its dominance" (Frankenberg, 1993, p. 6).

³ There is indeed a "culture" that surrounds mainstream breast cancer organizing. Using culture as a metaphor for organizations allows groups to be seen as miniature societies with a distinctive social structure, reflected in various patterns of actions, language discourse, laws, roles, ritual, custom, ceremony, norms, folklore, stories, beliefs, myths, etc. (Morgan, Frost, Randy, 1983, p. 18). Barbara Ehrenreich (2002) poignantly describes breast cancer culture in a speech given at a Breast Cancer Action town hall meeting. She revealed that when trying find information about breast cancer, she found a culture that she defined as "pink, femme, frilly, highly commercialized and containing a certain perkiness and relentless cheerfulness" that was counter to any feelings of anger or critical questioning". While, I am in total agreement with these characteristics, I also add that this 'culture of pink' [my emphasis] is also overwhelmingly steeped in whiteness, which is symbolically present in the pink ribbon, "the most ubiquitous sign of breast cancer that confers an instantly recognizable set of meanings and values related to femininity, charity, and white middle class womanhood (King, 2006, p. xxii) and literally in the Race for the Cure, which lacks a sense of diversity in its participants. As chapter five will show, the culture of pink also emphasizes succumbing to conventional biomedical authority and treatments, while subscribing to a philosophy that focuses on positive transformation, survivorship and hope.

practices of power because narrators speak in culturally and historically contingent terms (Riessman, 1993). Black women's narratives and other forms of literature are of particular importance because analyzing these sources requires viewing African American women as whole persons in the full complexity of what it means to be human, instead of the familiar stereotypes that saturate the public domain (Lorde, 1984). Likewise, their stories elucidate that breast cancer extends beyond the realm of science and is influenced by historical, cultural and societal factors that affect the ways in breast cancer is discussed, treated and represented, which in many ways, negatively impacts and marginalizes black women.

The Journey Begins...

On October 29, 2005, I found myself in unfamiliar territory...breast cancer. I entered this place not as a result of my own diagnosis, but through the death of my aunt. Yes, I was aware of the fact that she had breast cancer before her passing, but the disease did not become real for me until I found myself on a plane heading home to her funeral. It had only been a year since she was diagnosed and I guessed that since she had had a mastectomy, was undergoing chemotherapy, and was a woman of deep faith, that eventually she would belong to the group of women generally referred to as 'survivors'. Besides, during our conversations she adamantly reassured me that she was doing fine and with the Lord's grace she would be okay. Needless to say, neither of our hopes or prayers manifested and I found myself trying to make sense of my loss. In hindsight, I question whether her stoical appearance was merely a façade to ease my fears...and maybe her own.

Despite clinical breast exams during yearly physicals and periodic self examination of my breasts, the idea of having breast cancer never seemed a real possibility in my mind because I knew of no one in my family who had the disease. Although I did not understand my 'risk' of getting breast cancer, my educational background in biology allowed me to comprehend the physiological and biological ways in which cancer affected the body. However, 'book knowledge' did not prepare me for the speedy demise of my aunt. I found myself in a sea of sadness and grief. I was angry that despite being a 'compliant patient' and transferring to the 'prestigious' Duke Medical Center, she was dead within a year of diagnosis.

In the midst of my sorrow I felt a sense of guilt at the thought of not being supportive enough. I questioned whether I allowed my aunt the opportunity to truly speak of the physical and emotional aspects of having breast cancer and undergoing treatment. I was ashamed that a part of me did not want to fully hear her story, because I didn't know how to deal with the various emotions she must have felt. It is not that I wanted to silence her feelings, but I was afraid to face my own fear at the thought of losing her. Were my sporadic calls of inquiry enough to let her know that I cared? I had no answers to these questions; and so, I paid homage to her with poetry.

Cleaning

Stage 1

Tired arms reach out to silence the sound of morning
Swollen feet limp to a refreshing shower
Steam, heat, INVISIBLE CHLORINATION
ALUMINUM, GLYCOL PROPYL deodorant keeps me fresh
Time to make a dollar out of fifteen cents
Cleaning...the job of my mother's mother's mother
Scrubbing, rubbing, spreading, bedding
SUPER STRENGTH PROFESSIONAL CLEANERS, two years
Promotion

Head of hotel laundry
Folding, pressing, steaming, cleaning
SUPER STRENGTH PROFESSIONAL CLEANERS, three years
Pain and loss of my dear sweet mother
No time to cry relax or grieve
There's more folding, pressing, steaming, cleaning
SUPER STRENGTH PROFESSIONAL CLEANERS

Stage 2

Why is my body weak tired and worn?
Is it the loss of my dear sweet mother?
Is it the ALUMINUM, GLYCOL PROPYL deodorant that keeps me fresh?
What about the scrubbing, rubbing, spreading, bedding?
SUPER STRENGTH PROFESSIONAL CLEANERS, two years
Or maybe it's the folding pressing steaming cleaning?
SUPER STRENGTH PROFESSIONAL CLEANERS, three years

Stage 3

Lump
Mastectomy, left breast
Chemotherapy port in my chest
Spirit strong
See how I smile when you ask how I feel
Can a woman of faith express fear doubt and pain?
Nauseous disdain at the smell of sick dying bodies
Waiting...
For treatment with radiating substances that don't discriminate
Healthy cells, Cancer cells
Sick and tired tired and sick
They say it's of the inflammatory variety
Rare, fast spreading, difficult to treat
It's all in my genes
But what about...INVISIBLE CHLORINATION, ALUMINUM, GLYCOL PROPYL,
DEODORANT, SCRUBBING, RUBBING, SPREADING, BEDDING, FOLDING,
PRESSING, STEAMING, CLEANING, SUPER STRENGTH PROFESSIONAL
CLEANERS, trying to make a dollar out of fifteen cents?

Stage 4

My sons mourn in silence
My sisters mourn in fear
My niece, how do you mourn?
In silence and in fear
My niece, how do you remember?
Cleaning...the job of my mother's mother's mother
My niece, how do you remember?
How do you overcome the silence and fear?

Tell the story...or invest in pink?

By Cleothia Gill

After writing this poem I also paid tribute to my aunt by learning more about breast cancer. I not only wanted to better understand my 'risk' for the disease, but I also wanted to read and find solace in literary works by and/or about African Americans with breast cancer. As I began my search, I soon realized that despite the varied organizations, an abundance of scientific literature, self-help manuals and personal accounts of women's experiences, the dominant conceptualization of breast cancer is as a disease that primarily affects white, middle class heterosexual women. For example, the predominate images in magazines, on websites, and in photos of the popular event, The Race for the Cure, are that of smiling white women dressed in pink. Not surprisingly, I felt alienated as a black woman due to the dearth of representations and discussions of how breast cancer impacts African American women's lives.

Several questions began to formulate about the connection between cancer and black breasts. For example, what is the dominate narrative that surrounds breast cancer and how does it impact and/or create the images generally associated with this disease? What are the explanations for increased mortality rates among black women and what exactly do doctors and scientists mean when they refer to breast cancer in African Americans as 'aggressive' and 'hard to treat'? What are the connections between race, gender, class and breast cancer and what impact do they have on black women? Finally, what do African American women's narratives or literary works reveal about their experiences with this disease?

In an attempt to answer these questions, I searched for African American women's stories and narratives about breast cancer. This search generated a variety of works such as, fiction, essays, memoir, biomythology⁴, poetry, and edited works that consist of collected interviews by African American researchers who also suffer from breast cancer⁵. What follows is a qualitative examination of 86 accounts from women of diverse backgrounds and ages, which not only reveals black women's experiences with and conceptualizations of breast cancer, but also provides a platform from which to critically analysis dominant breast cancer ideology. These stories were analyzed and categorized based on recurring themes that will be revealed in the 'chapter breakdown' that soon follows.

Scope of Study: Theoretical Insights

Race, Class and Health Inequalities

The issues raised in this thesis speak to broader medical, anthropological and sociological concerns as they relate to the interconnections between class, race, gender and disease. Socioeconomic status (SES), which refers to the position of the individual in a system of ranked statuses based on criteria that include occupation, income, and education, (Dressler, 2000) along with social inequality, is an issue of concern with regards to healthcare. It is widely acknowledged that being able to receive appropriate

⁴ This is a term coined by Audre Lorde with her book *Zami: A New Spelling of My Name*, (1982) which is a fictionalized account of her life as a young girl to young adult. It is a blend of autobiography, fiction, and mythology.

⁵ While this latter source raises the issue of utilizing the results of interviews that stem from previous research, conducted by persons with their own set of questions for analysis, I propose that these works do not present a problem with my thesis because it still holds valuable information and insight into black women's experience with breast cancer. More importantly, due to scant research into the existential experience of black breast cancer sufferers these stories provide information from black women's perspective, rather than what is generally discussed in the media, which has a more scientific focus.

care is important when dealing with a medical condition such as breast cancer and consequently those who lack health coverage or access to quality medical treatment are at a disadvantage. These disadvantages are further exacerbated in Black Americans who experience significant levels of inequality concerning health in that, “African Americans suffer by comparison with every indicator of morbidity, mortality and access to health care” (Dressler, 1993, p. 325). In fact, numerous studies indicate that minority individuals not only experience worse disease outcomes, but they also experience differences in the delivery of health, both diagnostic and therapeutic (Alarcron, 2001).

However, “access to medical treatment is not simply about being uninsured. It is a class-and color-based phenomenon (Becker, 2004, p. 259). Racial inequalities, such as discrimination in jobs, education, and housing, within the broader American society also have an indirect impact on African American health. For example, even when African Americans make the same or more money when compared to whites they still live in racially segregated communities and as a result, while poor nonwhite women do not have access to health care because of lack of money, middle class women of color also do not have access to health care because they live in segregated communities where there is a lack of services (Bayne-Smith, 1996). In addition, William Dressler (2000), in studying heart disease among African Americans, suggests that failed expectations in social status or achievement, which may also be related to structural and institutionalized racial inequality, creates stressful conditions that contribute to increased health risk. Thus, being subjected to discriminatory attitudes and practices, as well as having access to quality health care, are factors that impact overall health and well-being.

Gender and the Social Construction of Disease

This thesis also raises concerns about the socially constructed nature of science, medical knowledge and disease and challenges the objective stance of biomedicine that reduces the experience of pain and illness to etiological mechanisms and biological processes that are measured in “objective” and “natural terms” (Good & Good, 1993; Honkasalo, 2001). According to Lantz and Booth (1998), “public discussions about illness and disease are particularly powerful vehicles for communicating ideas or fears about a society or social change more generally. In exploring how illness is socially constructed we are investigating how social forces shape our understanding of and actions towards health, illness and healing” (p.909). Although, the social constructionist approach entails examining the social aspects of biomedicine and the development of medical knowledge and practices, it does not necessarily call into question the reality of disease or illness states and bodily experiences; rather it emphasizes that these states and experiences are known and interpreted via social activity and therefore should be examined using cultural and social analysis (Lupton, 1994)⁶.

As such, gender is significant in exploring how disease is socially constructed. As a social phenomenon, it is one of the most important statuses in any society. Gender impacts illness and/or disease through economic circumstances, work and family responsibilities, lifestyle choices and through social interactions with family, other intimates, and health professionals (Lorber, 2000). Gender is also one of the most

⁶ Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability. Illness is the lived experience of monitoring bodily processes. While, disease is what the practitioner creates in the recasting of illness in terms of theories of disorder. It is also what practitioners have been trained to see through the theoretical lenses of their particular form of practice (Kleinman, 1988).

significant factors in transforming physical bodies into social bodies⁷ (Douglas, 1996, Lorber, 2000). The interplay between illness, gender and bodies not only reveal the socially constructed nature of scientific knowledge, but it also indicates that this interconnectedness influences how scientists and physicians explain the cause of various diseases. This is particularly evident when looking at scientific beliefs regarding the origins and proliferation of breast tumors. For instance, the prevailing idea during the 19th century in most scientific circles was that the uterus, and later the ovaries, were dominant organs in women, controlling not only physical health but mood and behavior as well (Olson, 2002). As such, many physicians looked toward the ovaries for an explanation of breast cancer's origins.

Not surprisingly, this view persists in modern times as suggested by Zillah Eisenstein (2001) who argues, that “constructs of femininity imagines the female body as one and the same with breasts and its ovaries. As a result, estrogen, a female hormone produced largely by the ovaries and viewed as the substance that makes women different from men, is primarily evoked and scrutinized in the biogenetic construction and explanation of breast cancer” (p. 121). More specifically, in this view estrogen is the primary agent that contributes to tumor formation. However, given all the focus on estrogen, only one to two-thirds of all breast tumors have estrogen receptors and depend

⁷In *Natural Symbols*, a classic work dealing with the anthropology of the body, Mary Douglas (1996) argued that the human body is always treated as an image of society and ideas about the body corresponds closely to ideas about society. The physical experience of the body, always modified by the social categories through which it is known, sustains a particular view of society (p.74). What this means with regards to breast cancer is that the meanings associated with women's bodies and breasts profoundly influence how this disease is conceptualized within biomedicine and the general public.

on estrogen for growth.⁸ Thus, to say that breast cancer is socially constructed means that cultural assumptions and biases about women's bodies influence our knowledge, perceptions, and experiences of breast cancer in this society (Kasper, 2000).

Power and Discourse

Finally, I address the issue of power as it relates not only to the effects of discourse but also to the lasting power inherent in the construction of black bodies as deviant and pathological, which oftentimes reveals itself in the medical encounter between patients and doctors and in scientific explanations of disease in African Americans. Foucault (1978) suggests that power operates to impose identities on its subjects and it is in discourse that power and knowledge are joined together. He states "power is not something that is acquired, seized, or shared, something that one holds on to or allows to slip away; power is exercised from innumerable points in the interplay of non-egalitarian mobile relations" (Foucault, 1978, p.94). Thus, power is not necessarily localized. It operates through a series of relations. Power is efficacious because it is not an oppressive force that weighs on people; rather it is able to gain access to the bodies of individuals, their acts and attitudes and modes of everyday behavior (Foucault, 1978).

Simply put, within breast cancer discourse, those in power, doctors, breast cancer organizations, and pharmaceutical corporations, create and transmit knowledge that is viewed as 'real' and 'true' in society. As a result, they are able to influence the ways in which women understand and experience breast cancer. For example, doctors and

⁸ Unfortunately, "the importance placed on estrogen as contributing to tumor growth not only influences research ideas and naturalizes it as a hormonal explanation of breast cancer, but it also negatively impacts black women because it limits inquiry into non-estrogen receptor breast disease" (Eisenstein, 2001, p. 113).

scientists created the notion of 'risk', whereby individuals must show responsibility for their health through changes in diet, exercise and abstaining from certain lifestyle activities such as drinking and smoking. The culture of pink reinforces this notion through organized education and support groups, while pharmaceutical corporations and detection companies not only create drugs and technologies to help prevent breast cancer 'risks', but they also provide financial support through sponsorship at organizational events, such as the Race for the Cure. The relationship between doctors, breast cancer organizations, and drug companies substantiate Foucault's (1978) suggestion that "power relations are both intentional and non-subjective...there is no power that is exercised without a series of aims and objectives (p. 94-95).⁹

These dominant discourses of breast cancer are powerful because they are able to make invisible the fact that they are just one among many, and to include different discourses would then create a variety of femininities associated with the disease and offer alternative ways of being and ways of doing femininity(Kotthoff & Wodak, 1997)¹⁰. Although this construction of breast cancer is steeped in whiteness, it reflects

⁹ It is important to note that power is also effective because it is closely related to hegemony. Hegemony refers to the fact that the dominant classes exert their power both directly through the state and indirectly by cultural ideas, values, attitudes and beliefs, which are ideologies (Lawner, 1974; Gibson, 1998). Ideologies, which obscure relations of power and domination and prevent people from grasping their situation in the world, helps make hegemony effective because it contributes to 'commonsense' knowledge (Gibson, 1998). According to Gibson, "commonsense, is ideology at its most powerful and productive. It is at this point at which particular systems of meaning (ways of seeing and being) are taken to be universally true. Knowledge that is historically constructed and tied to particular interests and social groups is viewed as natural and non political—as just the way things are" (Gibson, 1998, p. 145). This is important because hegemony is consensual operating through the commonsense of everyday, whereby medicine does not act on people coercively but rather through the subtle transformation of everyday knowledge and practice concerning the body (Scheper-Hughes, 1992). More specifically, people go the doctor, and I add follow the idea of 'risk' and other suggestions of breast cancer discourse, not because doctors have thrust their views on them, but they agree to go because they share these views (Scheper-Hughes, 1992).

¹⁰ Sojourner Truth's "Ain't I a Woman" speaks to this notion of different femininities. This speech expresses what feminist theorists still argue today: that the category of woman is entirely constructed, but not evenly. 'Unlike women of color, white woman have the 'privilege' of 'forgetting' or not noticing the operations of race and possess many socially sanctioned opportunities for doing so. In asking "Ain't I a

that the discourses of identity articulated by majority populations are likely to be univocal and monologic because it is relatively easy for dominant groups to express and confirm their shared identity publicly, which partly explains the neglect of women of color and lesbians (Riggins, 1997). More specifically, dominant discourse raises one message above all others and in doing so, it silences alternative views and diverse voices. Not surprisingly, the discourse of breast cancer does not reflect reality like mirrors; instead they are artifacts of language through which the very reality they purport to reflect is constructed (Riggins, 1997). However, because “discourse can be both a stumbling block, a point of resistance and a starting point for an opposing strategy” (Foucault, 1978, p. 101) black women’s narratives, despite their marginalization, offer powerful platforms of resistance.

Chapter Breakdown

Chapter two provides a historical overview about how breast cancer emerged from a private experience into public awareness and discusses how the disease became associated primarily with white, middle class, heterosexual women. It also examines how the historical construction of black women’s bodies contributes to their exclusion in breast cancer imagery, which may contribute to African American women’s subsequent feelings of alienation. Chapter three discusses the concept of breast cancer ‘risk’ and how mainstream discourses focus on individual behavior as the cause of increased ‘risk’, while black women implicate the environment. Chapter four explores why black women have increased mortality rates. In chapter five I examine how breast cancer discourse and

Woman” Truth queries the roles of race and class in gender arrangements, but her question opens possibilities for other differences among women to deconstruct the category of woman” (Conboy, Medina, & Stanbury, 1997, p. 4).

the culture of pink promote the idea of 'returning to normalcy' after breast cancer treatment by encouraging women to get breast reconstruction, encourage women to view the disease as a positive transformative experience, and focus on being a survivor. Finally, in the conclusion I not only tie all these ideas together but I discuss briefly, what I have learned about my 'risk' for breast cancer.

CHAPTER II

COMING OUT: THE EMERGENCE OF BREAST CANCER IN THE PUBLIC ARENA

Cancer, a disease associated with (upper) middle class life, affluence, and excess, has been viewed as the “dread” disease because of its unknown etiology and unsuccessful attempts at treatment and survival. As a result, cancer was not only feared, but people were demoralized and treated as infectious carriers (Sontag, 1977). Unfortunately, cancer patients not only found themselves shunned by relatives and friends, but they were also lied to by their physicians. Cancer was a death sentence. It was felt to be “obscene in the original meaning of the word: ill-omened, abominable, and repugnant to the senses” (Sontag, 1977, p. 9).

Cancer, the “demonic pregnancy” harboring a “fetus with its own will” was notorious for attacking parts of the body, such as the colon, bladder, rectum, breast, cervix, prostate, and testicles, all of which evoked feelings of shame in its sufferers because it implied something about the “person” who had it (Sontag, 1977, p. 13-17). These sentiments were further exacerbated with metaphors and descriptions that conceptualized cancer as a disease that “crippled” vitality, “shriveled” the patient, and “deadened” desire (Sontag, 1977). It was a painful disease that “consumed” the body, brought death in “stages” and mutilated or amputated various parts (Sontag, 1977). It is of no surprise when considering these pessimistic attitudes towards cancer that this was a disease suffered in shame and in private. Even in the face of better treatment options that improved survival rates, cancer, and more specifically breast cancer, remained marginalized in American society during the 19th and early to mid 20th centuries. This

marginalization of breast cancer occurred because women's breasts occupy contradictory and ambiguous positions. Breasts are not symbolic of one idea; rather, they are assigned various meanings that are constantly in flux.

In America, women's breasts are the "crown jewels of femininity" (Yalom, 1997, p.3)¹¹. Historically, and in some contemporary instances, women's breasts symbolized their role in the family through the association with the suckling of babes, defined the occupational status of females within the privacy of the home, as opposed to the public life of men, and they were, and are, the source of sexual desire for lovers and husbands. However, Ellen Leopold (1999) suggests that the iconic power of the breasts, "reminded a woman to put the needs of others before her own. Any pleasure a woman might take in her own body or her own life was deemed to be inconsequential to the culture, a secondary effect, derived for the pleasure she gave to others. What did matter was the preservation of family life and inescapably breast cancer put this at risk" (p. 31). Thus, breast cancer not only endangered the bodies and lives of women, but it also threatened their families.

Ironically, many of these meanings attributed to women's breasts render them contradictory emblems in American society. Historically, tensions have always existed around women's breasts. For instance, when the good breast model is in ascendance, the accent falls on its power to nourish infants or the entire political and/or religious community and when the bad vision dominates, the breast is an agent of enticement and

¹¹ The breast in representing femininity is simultaneously implicated in whiteness. The female body, despite its racial identity and multiplicity of colors, exists as a fantasized icon. The fantasy parades despite the many ways that reality negates it. Variety is displaced by singularity; colors become white. And, the white body becomes the universalized abstraction: thin, large breasted, small waisted, [sic] with blond hair (Eisenstein, 2001, p. 141).

aggression (Yalom, 1997). Iris Young (2003), in *Breasted Experience: The look and the feeling*, also suggests that breasts are controversial because of the nipples, which are “indecent no no’s for they show the breasts to be active independent zones of sensitivity and eroticism. Breasts shatter the border between motherhood and sexuality” (p.160)¹². On a personal level Carolyn Lattier (1998) in, *The Women’s Perspective on an American Obsession*, proposes that for many women it is strange living with breasts because they are viewed as sexual organs, and unlike other genitalia, they are judged and commented on in public.

When analyzing breast cancer the symbolism and meanings of women’s breasts are important because they are a potentially contradictory sign of femininity. On the one hand, they symbolize motherhood, central to women’s traditional identity, and the other, female eroticism, the key to sexual attractiveness. Thus, cancer of the breast threatens to damage the popular images that reflect cultural beliefs about the ideal roles for women, the perfect feminine body and it is a danger to society at large (Lantz & Booth, 1998). As a result, cultural preoccupations about breast cancer are contradictory and serve as extremely powerful metaphors for social disorder (Lantz & Booth, 1998). These metaphors of disruption unfortunately relegated any discussion of breast cancer to the margins of society. However, changes in cultural attitudes towards women’s breasts slowly allowed breast cancer, as a subject of interest and concern, to emerge in public consciousness.

¹² It is not my intent to suggest that all women relate to their breasts in the same ways. While some women may find pleasure and eroticism in their breasts others may not. The view presented typically represents patriarchal explanations and ideas about women’s bodies. In addition, the erotic nature of women’s breasts may also be attractive to lesbians.

Advertising, the ASCC and the WFA

In 1904 E. S. Judd of the Mayo Clinic wrote, “The point I wish to emphasize . . . is that the surgeon can provide a definite cure in the majority of cases where the patients present themselves for treatment on the appearance of the first symptoms” (Olson, 2002, p. 68). Judd’s statement rested on the premise, which was influenced by William Halsted who invented the Halsted radical mastectomy, that since breast cancer was a localized disease, early detection and prompt surgical treatment cured cancer in the initial stages of growth.¹³ This sentiment was further reflected in 1910 when many Western nations began public health campaigns to control cancer and lower mortality by primarily promoting early detection and radical mastectomy (Leopold, 1999). These health campaigns represent the first step toward the demystification of breast cancer; and in the United States this took the form of the American Society for the Control of Cancer (ASCC), precursor to the American Cancer Society, which was created in 1945.

In the 1920’s the ASCC, consisting primarily of surgeons, not only wanted to sell women the idea of surgery as the primary treatment and cure for breast cancer, but they also put forth a message that stressed the importance of early detection (Leopold, 1999; Olson, 2002; Knopf-Newman, 2004). In many regards, women who ignored this message were implicitly implicated in their own demise should it occur. For example one pamphlet distributed by the ASCC read as follows:

How a wise woman won the battle against cancer. She had faith in her physician. He had confidence in his power. Lose no time . . . Medical cancer cures are all bogus. Barring the use of radium or similar means for the small affairs of the skin, surgical operation is the only cure for cancer (Olson, 2002, p. 68).

¹³ Chapter three discusses the idea of cancer being a ‘localized disease’, while chapter five addresses the Halsted radical mastectomy, which was an extremely disfiguring mastectomy operation.

However, despite the promotion of early detection, doctors recognized they had to overcome women's fears of mutilating surgery, which was increasingly raised through consumer advertising.

Advertising was important because it raised women's doubts about their bodies and sexuality. This was reflected in the proliferation of products aimed at women such as Listerine to control bad breath and douches and deodorant to eliminate body odor (Leopold, 1999). In addition, changes in fashion made women more bust conscious and consumer marketing aimed at the breast created a standard of perfection that most women could not meet.¹⁴ Thus, bringing breasts within the scope of consumer culture heightened a woman's sense of her body as inherently defective. Due to the idea that beautiful breasts were considered healthy, many women feared and abhorred the thought of breast cancer (Leopold, 1999). They had to make a choice between social survival, which declared the presentation of an intact body, and their physical survival, which demanded the mutilation of the body (Leopold, 1999). Realizing the importance of advertising, the ASCC decided to have women carry the message of early detection through the creation of the Women's Field Army (WFA) during the late 1920's.

The WFA was important in bringing breast cancer to public awareness and attention through their media campaigns that sought to educate women about the disease. Donning tan uniforms, as shown in figure 1, these women leafleted, broadcasted, and delivered the message of early detection while simultaneously raising money to help finance the ASCC and administer the first cancer prevention clinics (Leopold, 1999; Olson, 2002; Knopf Newman, 2004). In addition to organizing lectures, exhibitions

¹⁴ This standard is very much still prevalent today. However, as will be shown shortly many women turned to breast enlargement in order to achieve the 'perfect' breasts.

Figure 1: Image of the Women's Field Army Uniform. Reprinted by the permission of American Cancer Society, Inc. from www.cancer.org. All rights reserved.



and delivering millions of brochures, the Women's Field Army at the 1939 World's Fair, also exhibited a life size translucent model of "Cancer Woman." This model demonstrated electronically, beginning with a single spot of light in the breast, the progressive growth and spread of a tumor through the lymph nodes of the armpit, neck, to the lungs and breasts (Leopold, 1999 p. 167).

Despite the importance of the WFA in creating open and public discussions about breast cancer, the members were very conservative and reinforced sexist perceptions about women's roles, duties and responsibilities to the family (Leopold, 1999). This was primarily reflected in their support of a pamphlet from the American Society for the Control of Cancer entitled, "*What every woman should know about cancer*", which stated that "women should have medical exams every year; make sure a copy of the pamphlet was distributed to every woman in her club; have a qualified speaker give a lecture on cancer at least once a year; and protect the members of her family and if attacked, provide the best immediate medical attention" (Leopold, 1999 p. 162, Knopf-Newman,

2004)¹⁵. However, the audience that the ASCC and the WFA primarily targeted was the white affluent middle class elite¹⁶. This is evidenced in the mentioning of “women’s clubs”, encouraging women to seek the ‘best’ medical treatment, which would be unaffordable for poor women and minorities, and apparent in the fact that in order to be a member of the WFA, women had to pay a one dollar fee (Leopold, 1999, Knopf-Newman, 2004).

Accompanying the community educational networks of the Women’s Field Army in the 1930s and 1940s were an increasing number of women’s narratives about breast cancer printed in women’s magazines. Although such reports first emerged during the 1910s, these types of stories focusing on breast cancer appeared with increased frequency during the same moment that the women’s field army gained momentum (Leopold, 1999; Knopf-Newman, 2004). However, being primarily printed in health oriented publications, these narratives also spoke to a white elite audience. These stories scarcely mentioned the pain and suffering associated with breast cancer; but instead they stressed the importance of early detection and seeking immediate help from doctors (Leopold, 1999). Nevertheless, the significance of the WFA in helping breast cancer emerge into public conscious cannot be ignored. Their campaigns, along with the ASCC, were important because they provided some of the first venues to discuss a disease that was overwhelmingly viewed as taboo.

¹⁵ Although Leopold (1999) offers no exact explanation of ‘attacked’, in my opinion this refers to women encouraging other female members of their family to seek help if breast cancer is suspected.

¹⁶ Despite this limited audience, the translation of the pamphlet into various languages was indication that this information may have trickled down to poorer women and other ethnic groups such as from employer to employee or between mistress and servant (Leopold).

War, Playboy and the Women's Movement

Beginning in the 18th century women's breasts began to take on political significance, whereby women were asked to serve national and international interests by breast feeding in order to increase the national birth rate, reduce infant mortality, and to regenerate society (Yalom, 1997). In addition, during times of war and revolution, women have been encouraged to pad their breasts for the soldier boys or uncover them as symbols of freedom (Yalom, 1997). Americans specifically used images of female breasts during World War One to move American youth to defend Europeans lest their own women be next in line. For example in a 1917 enlistment poster the victim is shown with uncovered breasts as a sign of feminine vulnerability not strength, whereby males would be encouraged to protect them by enlisting in the war (Yalom, 1997 p. 130). Looking at these photos was a reminder to men of the values that war destroys: love, intimacy, and nurturance. As such, these images further relegated women's place to the private sphere.

However, the association of breast with domesticity began to change during and after World War Two, which ushered in "the American breast fetish" (Yalom, 1997) that consisted of "in your face bosoms" appearing on the noses of bomber planes and within the distribution of millions of pin-ups to the G.I.'s through magazines, such as *Esquire* and *Yank*, in order to "raise the morale" of U.S. troops" (Yalom, 1997 Leopold, 1999).¹⁷ This increased fascination with women's breasts was further influenced by the circulation of Hugh Hefner's magazine *Playboy*. James Olson (2002) suggests that Marilyn

¹⁷ It is important to note that in WWII women were less likely to be viewed as vulnerable since they were working in many bomb factories during this time. In fact, those working were seen as actively doing their duty for the country, which could also extend to providing sexual entertainment in a more public way than previously before.

Monroe's 1953 placement as the centerfold of Playboy made women's breasts the physical icons of American popular culture, while creating and reinforcing new cultural expectations that large breasts were beautiful and sexy and American women needed them. Thus, due to the increased popularity of Playboy, women's breasts were no longer something to hide in public, but became emblems of beauty and sexuality that many women sought to achieve. More specifically, Playboy not only increased the association of women's breasts with the fetish, but it also made them commodities used to sell every commercial product imaginable.¹⁸

Ironically, Playboy's increased sexualization of women's breasts had two major impacts on breast cancer. First, it allowed women's breasts to be openly discussed and second, it influenced many surgeons to adopt breast conserving techniques, such as lumpectomy, instead of relying solely on the Halsted radical mastectomy (Olson, 2002). This practice was slow to occur in the United States unlike in European nations because surgeons in the U.S. were overwhelmingly male and it was only until men fully established the importance of women's breasts, primarily as sexual objects of pleasure, that doctors were willing to use less mutilating surgeries (Olson, 2002).¹⁹

In the late 1960's the "bra burning" protests for women's liberation contrasted drastically with the increased proliferation of women's bodies in Playboy and other

¹⁸ This idea of having the "perfect" breasts and their ability to "please" men generated by Playboy was not that different from advertisements during the early part of the 20th century. However, what was different was the almost total disassociation in the public arena of breasts with nurturance and domesticity; rather what emerged was an extensive objectification and sexualization of women's bodies. It was no longer shameful to show one's breasts. In fact, during this time many women sought to get breast enlargements in order to be more appealing.

¹⁹ I am not suggesting that it was only during the 20th century that women's breasts took on sexual connotations. What I am proposing is that the late 20th century marked an almost permanent association in the public consciousness of breasts with sexual pleasure. In addition, although post-World War II reintroduced conservative and disempowering expectations for women, it did not change the increased sexualization of women's bodies and breasts.

pornographic magazines. Fighting for the right to make decisions about one's own body, feminists sought female liberation in the midst of the increased sexualization and objectification of women. Although the early women's movement did not successfully address breast cancer and fully bring it into public debate, it laid the ground work and influenced later breast cancer sufferers, to openly address issues they considered important to women (Knopf-Newman, 2004).²⁰ Nevertheless, breast cancer during the sixties was still a private affair and it was not until the early seventies that breast cancer would fully emerge from the closet of shame.

Celebrity Confessions

Celebrity confessions of cancer also helped bring the disease to the forefront of public awareness because public figures in American culture are excused for violating conventional societal norms and "pushing the envelope" when discussing taboo issues. The celebrity announcements of Shirley Temple Black, Betty Ford, Happy Rockefeller, and Rose Kushner in the 1970's poignantly illustrate the role of celebrity in the buttressing of breast cancer into the public realm. Shirley Temple Black, who as a famous child star won the heart of America, was the first major celebrity to come forth to discuss her breast cancer experience.

Although her story first appeared in 1972 in a tiny California newspaper, it was soon picked up by radio, television and other newspapers and reported throughout the country (Olson, 2002). This was a momentous occasion in American society because breast cancer, despite the changing cultural climate about the meanings of women's

²⁰ It is important to note that one of the reasons, that breast cancer was not officially addressed by feminist in the 60's and 70's was that they were primarily concerned with reproductive rights. Because women active in this early woman's movement was young and healthy they did not think much of breast cancer because it was generally associated with older women (Leopold, 1999).

breasts and increased survival rates, was still relegated to the margins and vehemently viewed as the “dread” disease²¹. Nonetheless, in spite of the ostracizing nature of this disease Shirley Temple Black’s willingness to discuss her experience opened the door to a public platform on breast cancer.

Two years later, in 1974, Betty Ford’s and Happy Rockefeller’s breast cancer announcements further propelled the disease into the public. These two confessions were significant because they allowed for national and worldwide coverage of breast cancer, in which Ford was featured on the cover of Newsweek in an issue that discussed four surgical options for breast cancer; thereby in effect making her a national symbol and spokeswoman for the disease (Knopf-Newman, 2004). Ford’s announcement was also important because it encouraged women to get mammograms and introduced the first breast cancer activist who caused significant changes in treatment...Rose Kushner.

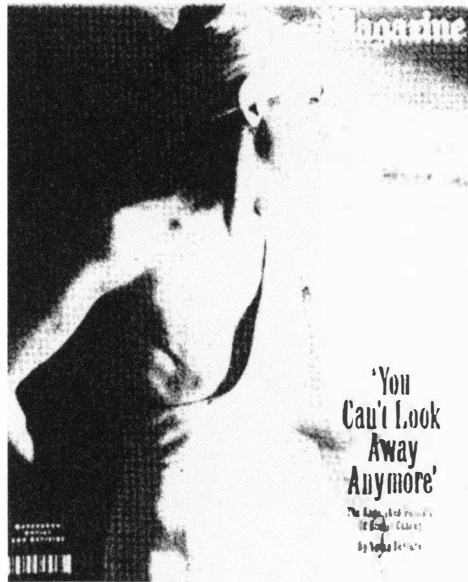
Kushner is widely known for criticizing the Halsted Radical Mastectomy and advocating the role of the informed patient in the experience of breast cancer with her book entitled, *Breast Cancer: A Personal and Investigative Report* (Knopf-Newman, 2004). In transforming her experience into a public platform, Kushner challenged, and ended, the one step practice whereby women went in for a biopsy and upon awakening and without consultation had had a mastectomy (Leopold, 1999; Knopf-Newman, 2004). She successfully argued that there was enough time for a two step procedure in which women could have time to explore other options and “separating biopsy from mastectomy gives women a voice in controlling their own destinies” [italics hers] (Leopold, 1999 p. 235). Ironically this sentiment had already been suggested by Black who was quoted as saying:

²¹ In many ways even in society today cancer is still viewed as the “dread” disease.

I wouldn't have it that way. I find . . . distasteful the prospects of waking up and finding that someone else had made a decision and taken an action in which I, lying quite inert on the operating table, had had no voice . . . I signed papers that agreed only to an excisional [sic] biopsyThe doctor can make the incision; I'll make the decision (Olson, 2002, p. 127).

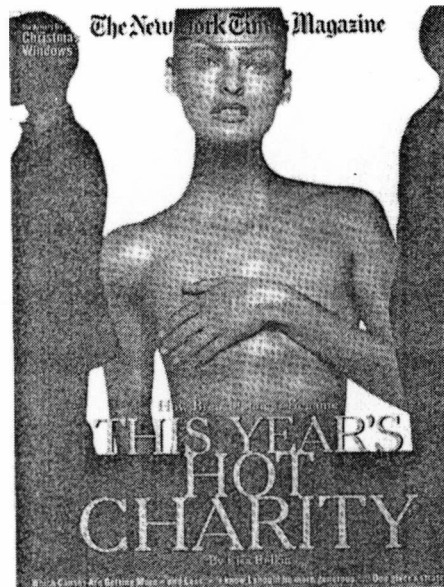
With breast cancer at the forefront of public debate, the disease appeared in various segments of American popular culture. For example, in the late 80's and 90's, magazines, newspapers, documentaries, and TV shows, such as CBS' "Young and the Restless", openly discussed breast cancer with featured episodes and interviews that further demystified it. Images of the post-mastectomy body also appeared in public for the first time on the cover of the New York Times Magazine in August 1993 (Figure 2).

Figure 2: First image of a mastectomy to appear in a public periodical. Taken from the cover of the New York Times Magazine August 1993.



And by December 1996 (Figure 3) it was apparent that breast cancer was increasingly becoming *the* [my emphasis] charity to be involved with. Nevertheless, the most important contemporary development in the history of breast cancer was the creation of

Figure 3: Early images associated with breast cancer. Taken from the cover of The New York Times Magazine December 1996.



various organizations established to raise awareness and money for breast cancer research.

Many of these organizations continued with the message first promoted by the ASCC, which was early prevention and treatment via surgery. One of the most successful organizations to emerge was the Susan Komen Foundation, which was founded in 1982 based on a promise by Nancy Brinker to her dying sister that she would do everything she could to end breast cancer (King, 2006). Not only has the Komen foundation raised vast sums of money for research and increased women's awareness and understanding of breast cancer, but it is also responsible for turning the disease into a marketable product with which consumers, corporations, and politicians are eager to associate (King, 2006). Breast cancer was easier to support because not only did it affect white middle class women, but it also did not carry the stigma that other diseases evoked, such as AIDS, which is strongly related to issues of morality, sexual lifestyle practices, and poverty.

Two significant symbols of the breast cancer movement emerged because of the Komen foundation, the pink ribbon and the event known as the Race for the Cure. The pink ribbon is important because it is the most readily recognizable symbol of breast cancer awareness. It is also used to help raise money when it is placed on various items for purchase by consumers. The significance of the Race for the Cure is that it allows for and creates connections between breast cancer survivors on a local and national level, as well as bringing widespread media coverage and corporate sponsorship (King, 2006).

In addition, through these races, which are conducted similarly regardless of size or location, a sense of shared identity is created among sufferers and the message of survivorship and hope is widely disseminated. This message is significant because in referring to themselves as survivors, breast cancer is reconfigured from a stigmatized disease and individual tragedy best dealt with privately and in isolation to a neglected epidemic worthy of public debate (King, 2006). The race for the cure is also important because it encourages a sense of activism, whereby participating in the race is an enriching and affirming experience in which the survivor emerges as a beacon of hope and courage, further eliminating the shame previously associated with breast cancer (King, 2006).²²

Despite the plethora of awareness, monies, and increased education raised by mainstream breast cancer organizations, they, similar to the WFA, continue to support a narrow view of breast cancer that subtly blames women for their disease if they do not follow all of the prescribed treatments. The 'culture of pink' is also less critical about the

²²The strength and optimism of breast cancer survivors alongside research money generated by institutions and consumer oriented philanthropy, has profound implications for how breast cancer is experienced by those who have the disease, how it is approached by the biomedical community who research and treat it and how it is understood in the culture as a whole (King, 2006, p. x).

role of the environment in contributing to breast cancer; and without question, there is support and promotion of conventional methods of treatment. These organizations, like their forbears, continue to speak primarily to a white middle class audience which is evident through the lack of diversity at The Race for the Cure.²³

However, there are activist and feminist organizations such as Breast Cancer Action (BCA) and Breast Cancer Fund (BCF), which put forth critical messages about holding corporations accountable for polluting the environment, which they see as the primary cause of cancer. Instead of putting forth the image that all survivors can return to a life of normalcy and the once happy state prior to the disease, these organizations attempt to not only raise awareness about breast cancer, but they also want to decrease the sexualization of women's bodies and breasts that continue to impact women's experience with the disease. For example, in 2000 the BCF put forth a campaign that wanted to address both the issue of breast cancer and the sexualization of women's breasts and bodies. Similar to the New York Times Magazine cover in 1993, the BCF used images of the post-mastectomy body as the focus of their campaign entitled "Obsessed with Breasts" (BCF 2000).²⁴ When placing these images 'Victoria's Secret' (Figure 4) and 'Obsessed with Breast' (Figure 5) at bus shelters, they were met with outrage and condemnation. For example, in the following quote from San Francisco's largest bus shelter company, Outdoor Systems, director Lew Lillian states, "In good conscience we just couldn't let these ads through. They're just too tough. You can't force people to look at rough stuff like this. They are very shocking" (Curiel, 2000, ¶ 7).

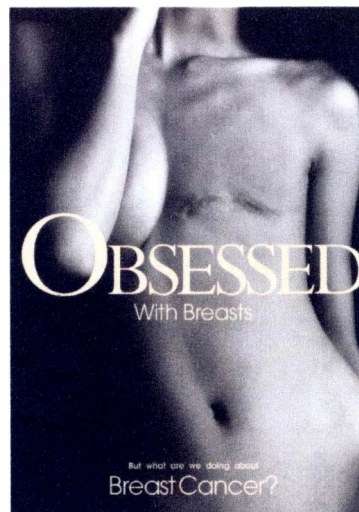
²³ It is important to note that similar to membership in the WFA, women pay an entrance fee to participate in the Race for the Cure. This in my view influences 'who' is able to attend such events (King, 2006).

²⁴ These images were created by placing an image of the founder of BCF mastectomy scar over that of 'young beautiful models to address both the issue of sexualization and breast cancer.

Figure 4: Victoria's Secret. Image taken from the Breast Cancer Fund's *Obsessed with Breasts* campaign. www.breastcancerfund.org. Photographer: Heward Jue.



Figure 5: Obsessed with Breasts. Image taken from the Breast Cancer Fund's *Obsessed with Breasts* campaign. www.breastcancerfund.org. Photographer: Heward Jue.



Unfortunately, what this response reveals is that in spite of the tremendous gains made in bringing breast cancer into the forefront, the general public is still uncomfortable about this disease, particularly with the revelation of the real mutilation that occurs to women bodies. The media would rather, and does, present this disease with happy, smiling faces of triumph instead of discussing the pain and suffering accompanying

breast cancer. It is easier to 'see pink' than acknowledge the millions of one or no breasted women affected by this disease, Thus, certain aspects of breast cancer, those things that indicate we have lost and/or losing 'the war against cancer' is still relegated to the realm of private experience, especially when addressing disfigurement and the emotional trauma suffered. For Black women this is worse, because they have been marginalized within the dominant historical narrative of breast cancer and as many black women's accounts suggest, they continue to feel a sense of alienation within current breast cancer culture, which focuses exclusively on white, middle class, heterosexual women.

Other Narratives of Breast Cancer

"Public health problems such as the breast cancer epidemic are like all other social problems in that they are constructed through a process of collective definition, primarily by individuals or groups making public assertions of grievances or claims about putative conditions" (Lantz & Booth, 1998, p. 909). Rather than being a reflection of an objective state of affairs, a social problem exists in terms of how it is defined in society and represented in social discourse (Lantz & Booth, 1998). Thus far, the 'official' narrative of breast cancer has revealed that much of the current understanding of this disease as a social phenomenon, personal crisis, and advocacy of activism comes from the analysis of predominately white, middle class women (Anglin, 2006).²⁵

The question that arises is how and why these representations have become dominant and how these hegemonic images exert control over everyday life and practices associated with health and illness (Lock, 2001). More simply put, how did breast cancer become predominantly associated with white women and what impact does this have on

²⁵ There is also an age component to this whereby; most of the women are believed to be post menopause.

African American breast cancer sufferers? Although there were many factors that speak to the first part of the question Ellen Leopold (1999) suggests that the defining moment that sealed the impression that breast cancer was a 'white heterosexual disease' was the announcement by First Lady Betty Ford, whose post-mastectomy white, middle class body became synonymous with breast cancer. Not surprisingly, this association persisted in later years as evidenced by a 1998 study that investigated how breast cancer was represented in the media and in articles. This study indicated that the predominant message presented was that breast cancer is an important disease because it strikes young, white, women in the prime of their lives, often taking them away from productive careers and families (Lantz & Booth, 1998, p. 914).

However, the statistical truth hidden beneath this perception was that although fewer black women were diagnosed with breast cancer, mortality rates for African American women were and remain significantly higher than those for white women (Knopf-Newman, 2004, p. 82). Despite the importance of Ford's and Kushner's confessions, they did not adequately address the ways in which race, sexuality, and socioeconomic class affect interactions in the medical sphere. As many critiques of the women's liberation movement articulate, mainstream feminist perspectives often elides and/or silences the concerns of women of color, poor women, and lesbians in ways that contribute to tangible inequities in medical practices and mortality rates (Knopf-Newman, p.107-108)²⁶. "It is not enough for organizations to advocate on issues affecting underserved women because a breast cancer movement that actually reflects the diversity

²⁶ Ironically, despite the BCF's attempt to raise breast cancer awareness their post-mastectomy images continues to proliferate the notion that we should be concerned about breast cancer because it attacks of "young white women".

of those who are affected by breast cancer must represent the entire range of issues that affect all women” (Anglin, 2006, p. 315).

This specific image of breast cancer was further perpetuated as a result of the lack of coverage within the broader American media of black women’s breast cancer stories. For instance, in 1976 Minnie Riperton, a famous soul singer, revealed to Flip Wilson, who was hosting *The Tonight Show* for Johnny Carson, that she had undergone a mastectomy due to breast cancer (Olson, 2002).²⁷ Particularizing her story for black women with the help of *Ebony* magazine, Riperton conveyed the same message as Ford but to people in the black community who needed to see themselves represented in this narrative about caring for one’s body and one’s health (Knopf Newman, 2004). Obviously breast cancer cannot erase differences with respect to race, class, or sexuality. However, nearly all the standard reporting for the time, focused on an unnamed, middle class white audience. Although black periodicals like *Ebony* also used Ford’s announcement as a way to teach its female readers about breast cancer, the mainstream press refrained from widely covering Minnie Riperton’s breast cancer story two years later (Knopf Newman, 2004).²⁸

²⁷ It is surprising that not much is known about Riperton’s story because from 1978 to 1979 she became the national spokesperson for the American Cancer Society (Olson 2002). The neglect to provide widespread coverage to Riperton’s story is merely one example of several African American female celebrities that were ‘overlooked’ in the broader media. Another neglected figure was Audre Lorde. Lorde, who described herself as a black, lesbian, feminist poet was important in addressing breast cancer from a more critical perspective, many of which were embraced by more activist organizations. Her ideas will be covered throughout this thesis.

²⁸ I propose that while magazines and media outlets geared toward African American audiences are important in disseminating knowledge, many of these require extra money for subscriptions. Thus, many Black Americans, like any other American, still rely heavily on mainstream media. As such, although these stories are covered in the black press, there is still no guarantee that they will reach various segments of the African American community, who may not know about or can afford these sources.

This lack of inclusion of black women's stories and or images in main-stream media and the limited diversity in many breast cancer organizations have a profound impact on black women's lived experience with breast cancer. Many of the narratives analyzed spoke of feelings of alienation with regards to imagery or expressed a profound need to find African American women to share their experiences:

Catherine Harvey: I opted to have immediate reconstructive surgery. I was very disappointed because when they showed me all of the tapes of what it would be like, they had no African American women as models. I have keloid skin, and I felt I did not have a very accurate picture of what it was going to look like (Dunnavant, 1995, p. 129).

Lois Smith-Williams: Even after I finally did accept it, I still thought that silence was golden. I wasn't going to tell anybody about my surgery. After all, I had never known anyone who had her breast removed. Of course, I had heard of Happy Rockefeller, Nancy Reagan and Betty Ford, but I didn't know them. They were people that you read about in the newspapers and you see on television. Besides, they weren't African American (Dunnavant, 1995, p.197).

Denise: I wanted to hear from other African American women my age about their successful treatments, so he gave me the names of African American support groups to contact. I was surprised to see how many there were considering I had never seen any ads or TV coverage with women of color associated with breast cancer. I had only seen or heard about support groups for White women (Stanford, 2005, p. 155).

Wilma Carroll: When I had my surgery, I was the only Black woman around. So, I knew there was a need that was not being fulfilled. I knew there had to be other women who felt like me and who didn't want to feel like they were the only ones out there. As a result, I eventually started a branch of the Sisters Network in the Long Island area (Dunnavant, 1995, p. 142).

Karin: My understanding of the unique African American experience with cancer first occurred when I set out to locate a support group. I attended a support group meeting of one well-known cancer-focused organization but could not identify with the women in the group. Most of them were White, over fifty, and had children. I was relatively young, single, and African American. In addition to the demographic differences, I soon discovered that my prognosis was different. Because I am an African American female, my chances for survival were less than those of my White counterparts...I found a very supportive and spiritually uplifting group "Rise Sister Rise" whose members were all African American women battling breast cancer. These women, or might I say "these sistas,"

understood my circumstances from the moment I walked in the door (Stanford, 1995, p. 10).

Addressing this issue of inclusion is important for several reasons. First, if black women feel alienated then they are less likely to feel that their experiences and circumstances are important to those advocating for early detection and increased awareness for the disease. As a result, they may not engage in breast screening or clinical trials, which may contribute to poor survival. I also suggest that to disregard the concerns of women of color ignores the fact that they are dying at disproportionate numbers, thereby, increasing the levels of mistrust of the medical community. The absence of black female bodies used to educate about breast cancer indicates that there remains deep racial ideas pervasive in this society, even among those who seemingly advocate justice for women. Many of these ideas are connected to and are a direct result of the historical construction of the black female body, which also helps explain why images of black women, and their overall lived experience with breast cancer, is relegated to the margins in discussions of this disease.

Race, Medicine, and Marginalization of the Black Female Body

Not only does the dominant narrative conceptualize breast cancer as a white woman's disease, it also discusses women's breasts as if they all hold the same meaning. Yes, black women's bodies and breasts are viewed as feminine, nurturing and sexual, but the long legacy of slavery and scientific racism also imbues them with different meanings. It is this history that also has helped relegate black women to the margins within discussions of breast cancer.²⁹ Beverly Guy-Sheftall (2002) profoundly addresses

²⁹ I would add that although there has been increased discussion about black women, these talks primarily discuss the "whys" of increased mortality in black women. While this is profoundly needed, it is equally

the stigmatizing affects of slavery on black women's bodies that render their meanings different from white women by suggesting that, "the female body in the West is not a unitary sign. Rather it is like a coin and on one side it is white and on the other, not-white or prototypically, black. The two bodies cannot be separated, nor can one body be understood in isolation from the other. White is what woman is; not-white (and the stereotypes not-white gather in) is what she had better not be" (p. 14).

Throughout the 19th century and well into the 20th, the conventional public wisdom, buttressed by elaborate, pseudo-scientific articles in the medical literature, was that there were biologically and genetically distinct human races and that African Americans, along with southern and eastern Europeans, Chinese, and any darker skinned immigrants of other nationalities, were biologically and intellectually inferior, more susceptible to disease and implicitly a threat to the health of the body politic (Geiger, 2006, p. 263). Historically, this negative construction of black bodies, primarily as diseased and dirty, has made them targets for a variety of moral panics surrounding health and disease (Comaroff, 1993, Burke, 1996). Much of the history of race and medicine began at the colonial encounter and unfortunately for blacks in America carried over and continued through and beyond slavery.

Jean Comaroff (1993) suggests that the development of British colonialism in Africa as a cultural enterprise was inseparable from the rise of biomedicine as a science, which primarily meant that images of cleanliness, appearance, and beauty were increasingly used in the 19th century to define social hierarchy and difference (Burke, 1996, p. 18). While there was little knowledge about bacteriology, there was a persistent

important to treat black women as whole human beings and pay attention to their existential experience with this disease as well.

association of the African body, with noxious organisms, disease, degradation, and contagion that threatened to invade the inviolable world of white order (Comaroff, 1993, Burke, 1996). The racialized science in the latter half of the 19th and early 20th centuries and its creation of the black female body was primarily fueled by travel narratives and the exhibition of Sarah Bartman, the Hottentot Venus.

First, early European travelers' narrative accounts of the black female body, situated African women and those in the Diaspora in a position oppositional to white women in which the former was a symbol of bestiality, lasciviousness, and sexual deviance, while the latter represented purity, chastity, and ideal femininity. Morgan (2002) suggests that "early modern English, literature and material culture was fully involved with a gendered racial discourse committed to constructing stable categories of whiteness and blackness" (p. 38). "While we know that black women's buttocks were used to describe their sexuality, travelogue descriptions of their breasts were also important and in order to properly understand the history of American attitudes about the black female form, we must begin with a close look at how both blackness and femaleness figured within the European imagination" (Wallace-Sanders, 2002, p. 6).

Writer's descriptions such as those by Richard Ligon, William Towron, and De Marres, during the 16th to 18th centuries created a space for racial difference by disallowing black female bodies to embody 'proper' female space, because of the extreme association of their bodies with monstrous beastliness and difference (Morgan, 2002). Such accounts were stated as follows:

Ligon: Black women's breasts hang down below their navels so when they stoop at their common work or weeding, they hang almost to the ground, that at a distance you would think they had six legs (Morgan, 2002, p. 38).

De Marees: When [the child] is two or three months old, the mother ties the childe with a peece of cloth at her backe....When they crieth to sucke, the mother casteth one of her dugs backward over her shoulder, and so the child suckes it as it hangs (**Morgan, 2002, p. 52**).

These examples not only show that black women's bodies were deemed drastically different from those of white women, but it also points to the creation of the stereotype, which according to Sander Gilman (1985), centered on the black body as an image of disease and pathology in the general Western imagination. Gilman (1985) further states that "we all create images of things we fear or glorify. These images never remain an abstraction: we understand them as real-world entities. We assign them labels that serve to set them apart from ourselves. We create stereotypes" (p. 15). Unfortunately the ultimate stereotype that helped seal black women as the antithesis of white woman was accomplished in the 19th century with the exhibition and dissection of Sarah Bartman.

In the 19th century the antithesis of European sexual mores and beauty was established based on the sexual parts of Bartman, who served as the central image for the black female, and Georges Cuvier, who performed Bartman's dissection, went as far to say that Sarah's body served as the master text on black female sexuality for Europe's scientific community³⁰ (Gilman, 1985; Sharpley-Whiting, 1999). However, unlike white women the black female body, according to Buffon the French naturalist, represented a lascivious apeline hypersexuality (Gilman, 1985). Overall, racial science and colonial exhibitions greatly influenced the general Western imagination of black bodies in which images of disease and pathology were powerful, both expanding and elaborating the

³⁰ Cuvier was not the only one conducting scientific investigations on black female bodies; in fact Marion Sims, who performed unanesthetized surgeries on the genitalia of black female slaves in the 1840's, made significant inroads into the field of gynecology from this practice (Washington, 2006).

existing preoccupations with the sensual, physical, and bodily nature of subordinate peoples (Timothy Burke, 1996).

American slavery also helped to define black women's bodies. "On the auction block, their bodies were exposed, handled, even poked to determine their strength and capacity for childbearing. One auctioneer introduced a slave woman this way, "Show you neck Betsey. There's a breast for you; good for a round dozen before she's done child-bearing" (Beverly Guy-Sheftall, 2002, p. 24). This remark shows that slave women were victims of their reproductive capacity, since they were encouraged and forced to breed like animals. Black women were the South's perpetual wet nurses (Figure 6), providing from their breasts milk for black and white babies alike; thus the exploitation of black women's bodies, vaginas, uteruses, breasts, and also their muscles, set them apart from white women, which was the mark of their vulnerability (Guy-Sheftall, 2002).

Figure 6: Breastfeeding. ©Copyright 1989 Benetton Group S.P.A.- Photo: Oliviero Toscani.



Unlike white women, during the era of slavery, black women's bodies were unprotected female flesh and occupied abnormal gendered positions.³¹ Black women's femininity had no sacredness in slavery, but instead there was an open exchange of female bodies in the raw; the enslaved woman was dispossessed, standing outside the established symbolism of white gender (Eisenstein, 2004). Consequently under these circumstances they were considered subhuman. While one can certainly say that American society has come a ways from this type of thinking, I argue that this history, although unspoken, is still etched in the bodies of African American women. White America is uncomfortable with the black female form because it is not only a reminder of a tumultuous period of American history, but in my opinion it remains the antithesis of white women and therefore, is still deemed 'polluting' 'dangerous' and 'hypersexual'.

These sentiments were clearly expressed during the 2006 Superbowl halftime show in which Justin Timberlake revealed Janet Jackson's breast by pulling on a piece of her costume. However, in the public mind, Janet was in fact solely to blame for this 'indecent' event, whereby she faced hateful ridicule and banishment from MTV. There was no discussion about Justin Timberlake's role in this fiasco. In fact, he immediately disappeared from any discussion of the event. It was as if Janet had in fact, pulled the cloth off by herself. Once again, like many of the rapes inflicted upon numerous slave women by white men, it was Janet Jackson's 'hypersexual' body that led and enticed Justin Timberlake to commit an unspeakable act for which he was not to blame, while simultaneously 'endangering' the minds of youthful viewers with 'polluting' images of

³¹ The fact the black women performed work both belonging to men and women clearly set them apart from white women, which further separated them from the 'ideal' femininity that women possessed. While their bodies were gendered according to their reproductive functions, their 'muscle' was also used to perform laboring work in the fields.

deviant sexuality during a family occasion.³² Thus, the historical lived experience and construction of black women's bodies not only marginalizes them within society and media representations of breast cancer, but African American women's bodies, and more so their 'uncontrolled behaviors' are also a 'danger' to their own well being, which is implicated in breast cancer 'risk' factors.

³² African American women still today feel themselves standing on the auction block, with exposed bodies for sale to be exploited. Their history of shame and exposure and nakedness has given them a complicated dread of their own female flesh, which may also explain why there is a lack of images of black women's bodies after mastectomy (hooks, 1999). In addition, the lack of images of black women speaks to the fact that because "everyone in this culture, including black folks, are so accustomed to seeing black female bodies depicted as licentious, immoral, and consumed by hedonistic desire and monstrous longing for power" (hooks, 1999, p. 73) there is no way black women can be associated with the 'soft', 'innocent' and feminine identity of the 'average' breast cancer sufferer.

CHAPTER III

SCIENCE, RISK AND A FOCUS ON INDIVIDUAL BEHAVIOR

Despite the contemporary belief that breast cancer is a result of modern living, the oldest description of cancer, although this term was not used, was discovered on the Edwin Smith Papyrus in Egypt dating back to 1600BC, which described tumors and ulcers of the breast (Leopold, 1999; ACS, 2002). It was not until Hippocrates, considered by many to be the ‘father’ of western medicine, that the word ‘cancer’ was used as a common medical term. This enduring description emerged because according to Hippocrates, cancer had the appearance of black bile and tumors seemed to have tentacles, like the legs of a crab reaching out and grasping for normal tissues (Olson, 2002)³³. He called these tumors *karkinos*, which eventually evolved into the word *carcinoma*, the medical term for malignant tumors developing in epithelial cells³⁴ (Olson, 2002).

Hippocrates’ humoral theory perpetuated the view that cancer was a systemic disease whereby black bile was not confined to the tumor, but instead was systemic and flowing throughout the body (Olson, 2002). Physicians such as 2nd century Clarissimus Galen and 7th century Paul of Aegina, took this premise a step further by arguing that cancer not only spread throughout the body, but it was particularly prevalent in the female uterus and breasts (Olson, 2002). However, in the 19th century physicians rejected systemic explanations of cancer because in finding blocked lymph nodes and vessels,

³³ Hippocrates’ association of cancer to black bile rested primarily on the humoral theory of disease, which suggested that health was determined by the balance of the body’s four humors, blood, phlegm, yellow bile, and black bile (ACS 2002).

³⁴ Epithelial cells form tissues that line the cavities and surfaces of structures throughout the body. They also form tissue that comprises various glands.

they speculated that cancer of the breast was a local disease and if confined to a single site before spreading, it could be treated (Olson, 2002).

Due to increased scientific and technological advancements, cancer, which has both local and systemic characteristics, is now understood to be a disease where the natural regulators that control cell apoptosis or cell death malfunction and the growth rate exceeds the rate at which cells die (Komen, 2007). These unregulated cells accumulate into a mass of extra tissue called a tumor, which may eventually travel to other parts of the body where they begin to grow and replace normal tissue. This spread of cancer cells is then called metastasis (Komen, 2007). Therefore, considering the ways in which cancer operates, breast cancer is a disease where uncontrolled cell growth originates in breast tissue.

There are two types of breast cancer, invasive and in situ. The more serious of the two, invasive breast cancer, develops when cancerous cells form inside the lobules or mammary ducts and break out into the surrounding breast tissue.³⁵ This in turn provides an opportunity for cancer to spread to lymph nodes and in advanced stages to other organs (Komen, 2007). In situ breast cancer cells grow inside the lobules (lobular carcinoma) or milk ducts (ductal carcinoma). These cells have not spread to the surrounding tissue or beyond and are considered precancerous because they have not developed the ability to metastasize (Komen, 2007).

Although neither ancient nor contemporary doctors know the precise cause of cancer, scientist now identify several 'risk' factors that may determine if a woman is likely to develop the disease. In fact, "'risk' is probably one of the most familiar and

³⁵ Lobules are the milk producing glands of the breast and the ducts refer to the tubes that carry milk to the nipples.

commonly used terms in discussions about breast cancer prevention. Women, doctors, government officials and others talk about whether someone is at either high or low risk of developing this disease, how the risk of getting breast cancer can be reduced and what the risks of certain forms of prevention are” (Simpson, 2000, p.131). Although having a risk factor does not guarantee that a woman will develop breast cancer, the medical community, similar to the early detection campaigns of the ASCC and WFA, suggests that if a woman thinks she is at risk she should seek help immediately, generally by getting a mammogram or a clinical breast exam. The most frequently discussed ‘risk’ factors are as follows:

- **Family History**
Women whose mothers, grandmothers or sisters have had breast cancer are two to three times more likely to develop breast cancer. However, 85% of women with breast cancer have no family history of the disease.
- **First childbirth**
The risks are higher among women who have never had (and breast fed) a baby or whose first childbirth occurred after the age of thirty.
- **Menstrual history**
Early first period (before age 11) and late menopause (after age 52) both increase risk.
- **Diet**
High-fat, low-fiber diet increases risk. Risk also increases with higher weight.
- **Age**
Risk increases with age. This disease is rare in women under the age of thirty. Women over fifty make up 77% of breast cancer cases.
- **Alcohol and Tobacco Use**
Women who consume two to five alcoholic drinks a day have a higher risk of breast cancer than do non-drinkers.
- **Genetic Alterations**
Specific alterations in certain genes, such as those in the breast cancer genes (BRCA1 or BRCA2), make women more susceptible to breast cancer.

- **Hormone Replacement Therapy**
Recent evidence suggests that menopausal women who have long-term exposure (greater than 10 years) to hormone replacement therapy (HRT) may have a slightly increased risk of breast cancer.
- **Socioeconomic Factors**
In the United States, white women from upper-socioeconomic classes living in urban areas are more at risk for breast cancer than other women, for reasons researchers do not yet understand.

Physical Changes that may indicate breast cancer include:

- Breast Pain
- Nipple discharge/tenderness
- Change in shape or size of breast
- Irritated, red, scaly or swollen skin on the breasts, nipple or areolas

While these 'risks' seemingly apply to all women, lesbians and African Americans must pay attention to additional factors.

Lesbians

It is not known whether lesbians get more breast cancer when compared to heterosexual women, but as a group they have higher incidence of certain risk factors linked to breast cancer.

- Never having a child
- Obesity (30% more obese when compared to 20% for all other women)
- Smoking
- Alcohol Use
- Less likely to perform self breast exams
- Less likely to have health insurance because many business do not offer partner benefits
- Irregular use of mammography and other health care services
- Highly educated

Additional risk factors for African Americans

Due to the incomplete understanding of risk factor exposures in African American women, many researchers raise doubts regarding the ability to accurately predict breast cancer risk in black women via the established tools utilized for white women (Newman, 2005). This sentiment is further expressed from the National Cancer Institute, which recently changed its risk calculator to better suit African Americans because the previous calculator, based on studies of breast cancer in white women, underestimated 'risk' for black women 45 and older and overestimated 'risk' for younger African American women (Boyd, 2007). Thus, it is important for black women to understand other variables that may contribute to increased risk or early onset disease. Among these are:

- Younger ages at menarche have been found in black women.
- Physical Inactivity
- Inadequate intake of micronutrients
- BRCA-related breast cancers in African Americans have been identified.
- Postmenopausal obesity is an established risk factor for breast cancer because of the higher circulating estrogen levels and black women were 80% overweight and 40% obese.
- African American women tend to be less susceptible to osteoporosis and have greater radial bone densities. This increases breast cancer risk because bone density is a surrogate marker of estrogen levels (Newman, 2005).
- Early onset of breast cancer may be due to the higher prevalence of early childbearing that is observed among African American compared to white women. Multiparity, (repeated pregnancies) increases breast cancer risk prior to the age of 45, but is protective against breast cancer risk after age 45 (Newman, 2005).

Risk—Reading Between the Lines

When we begin to look at the risk factors associated with breast cancer it is hard not to be confused. There are so many factors to consider that they seemingly wander are

all over the place. In some instances they are also contradictory, especially with regards to black women. For example, consider the following two risks:

- **First childbirth:** The risks are higher among women who have never had (and breastfed) a baby or whose first childbirth occurred after the age of thirty.
- Early onset of breast cancer may be due to the higher prevalence of early childbearing that is observed among African American compared to white women.

How is it possible that both late and early childbirth increases black women's risk for breast cancer? Or, instead of listing "inadequate intake of micronutrients" as a risk factor, why not simply state that poverty increases one's risk? It is of no surprise that several women's narratives displayed shock that they were diagnosed with breast cancer because they didn't have *any* risk factors:

Karin: I was an African American woman in my mid thirties. I was practically a vegetarian; I exercised regularly; I didn't smoke; and was not aware of any family history of cancer. There was no way I could have cancer (Stanford, 2005, p. 4).

Kat: I was diagnosed with breast cancer in September of 2000. Shock does not even come close to the feeling I had after being told that my lump was a malignant mixed tumor. I was someone who regularly fasted, ate well, and took supplements. I considered myself generally, healthy (Stanford, 2005, p. 58).

Tina: She is from Zaire and when she found a lump and contacted the oncologist he stated she was under stress and to ignore it, but I could not ignore it. Nobody listened to my concerns because I did not fit the profile of someone who would get cancer, I am athletic I do not smoke and drink only occasionally. I eat healthy meals and I am not overweight. In addition, I am under 40 years of age with three kids. The only positive factor was indeed the stress that almost everybody experiences here in the U.S (Stanford, 2005 p. 91).

These inconsistencies, besides revealing that doctors have only the faintest idea about what really increases a women's risk for breast cancer, indicate two things, 1) when dealing with 'risk' there is a fine line between scientific 'facts' and cultural beliefs about gender roles and 2) there is more emphasis on individual behaviors rather than discussing

factors such as carcinogenic substances in our environment that may increase a women's risk for breast cancer.

Gender is a significant factor to consider when exploring this disease because it affects illness through economic circumstances, work, family responsibilities, and lifestyle choices (Lorber, 2000). Gender roles and relations, especially changes in women's social position, are "issues of widespread public and private anxiety due to the increase in women's power and autonomy relative to men, trends toward decreased fertility, increased age at first marriage, increased rates of divorce, increased numbers of people who never marry and increased participation in the labor force by women" (Lantz & Booth, 1998, p. 910)³⁶. Exploring how women are portrayed in breast cancer discourse, particularly as it relates to 'risk', reveals that they are viewed as victims of their own behavior and that women's lifestyles are not only damaging to the social order, but also to themselves. For example, the woman who fails to avoid smoking, participate in exercising, or limit alcohol usage, things that run counter with the idea of what a 'traditional woman' should be, may be looked upon as being responsible for her own sickness. Thus, victim blaming is inherent in the idea of 'risk'.³⁷

As such, women are the cause of their own breast cancer via modern living and advancement in society, which suggests that the lack of performing gendered roles has

³⁶ It is important to note that gender, in conjunction with the socially constructed categories of race, ethnicity, class, and sexual orientation, creates different risks and protections for physical illnesses, produces different behavior when ill, elicits different responses in health care personnel, affects the social worth of patients, and influences priorities of treatment, research, and financing (Lorber, 2000, p.3).

³⁷ Although this research does not allow a full discussion of victim blaming ideologies it is important to note that blaming the victim reinforces political objectives that call for less social programs. It also assumes that individuals alone can control their health destiny without consideration of their economic capacity to do so or the availability or accessibility of health services (Bayne-Smith, 1996). Victim blaming ideologies suggest that if individuals adopt "appropriate" life styles, they can essentially avoid disease all together (Crawford, 1977).

led to unhealthy bodies (Lantz & Booth, 1998).³⁸ Ironically, the vast majority of US women at all ages have at least one of the risk factors associated with breast cancer and the message is clear, that “there is a tradeoff for the modern American woman. She may have come a long way, but there is something unhealthy or unnatural about her choices. She has increased her chances of developing a life-threatening disease that is essentially female and strikes a part of the body that is very much equated with being a woman. By desiring more autonomy and greater choices in their lives, especially reproductive choices, modern young women are threatening the social order” (Lantz, 1998, p.916).

These ideas are not new but in fact were suggested by the early campaigns against breast cancer. The idea that women were to blame for their health appeared in 1947 in an article in the journal of the American Medical Association. It insisted that “failure to reduce cancer mortality is not due to inadequate therapeutic measures...but to the prolonged delay between the time when the patient has first symptoms and the time when definitive treatment begins” (Leopold, 1999 p. 172.) What this statement suggested was that medical science had done its part and if women do not take advantage of this treatment it was their fault. Prior to this article the Women’s Field Army also supported sexist notions that blamed women for not conforming to gender roles by not countering a 1935 medical report that declared “Cancer of the breast is the penalty for failing to bear and ...nurse children” (Knopf-Newman, 2004, p.18).

In fact, the protagonist in Patricia Haley’s (2002) *No Regrets* shows that oftentimes women self-inflict blame upon themselves for getting breast cancer:

³⁸ Except stating that lesbian are less likely to have health insurance because they cannot receive partner benefits, lack of health insurance is not listed as a ‘risk’ for all women.

I didn't think much about breast cancer nor is there any reason to. My family didn't have a history of cancer. My mother didn't have breast cancer, and neither of my grandmothers had it before they died either. I didn't do self-exams and didn't get a mammogram. I was too young to even think about it. I was planning to get one when I turned forty. I never got the chance. I ended up getting cancer at thirty-five. Karen got choked up. If only I'd been more in tune with my body. If I had checked my breasts monthly like they recommended, I wouldn't be going through this again and again and now again. When will this stop (Haley, 2002, p. 113).

What this example shows is that there is an increased emphasis on being personally responsible for one's health. Engrained within the minds of women is the notion that they should be intuitively aware of their bodies and vigilant in seeking and partaking of preventive measures against breast cancer. Thus, women are not only blamed for getting breast cancer because they do not occupy 'proper' gender roles as it relates to taking care of the family, but they are also implicated for failing to meet the mandate that women must take care of and 'maintain their bodies at all costs.

Environmental 'Risk'

Thus far, the discussion of 'risk' primarily focuses on changing individual behaviors. Women are encouraged to stop smoking, drinking, and engage in exercise. However, when there is a shift from emphasizing individual responsibility and victim blaming, to a focus on the environments in which group of individuals live and work, there is significant indication that the environment is a possible source of risk (Simpson, 2000; Brody & Rudel, 2003). In fact, laboratory studies indicate that mammary carcinogens, in the form of synthetic chemicals and environmental pollutants, are in common commercial products and are ubiquitous factors in women's daily lives, particularly those living in industrial societies (Brody & Rudel, 2003). Audre Lorde

(1982) addresses the fact that many of these chemicals are found in jobs commonly held by minorities:

Keystone Electronics was a small factory that had a government contract to process and deliver quartz crystals used in radio and radar machinery. These crystals were ground, refined, and classified, according to how heavy an electrical charge they carried. It was dirty work. The two floors of the plant rang with the whine of huge cutting and refining machines. Mud was all over everything, cemented by the heavy oil that the diamond grit blades were mounted in. The air was heavy and acrid with the sickly fumes of carbon tetrachloride used to clean the crystals. It was offensive to every sense, too cold, and too hot, gritty, noisy, ugly, sticky, stinking, and dangerous. The cutting crew was composed of Puerto Ricans because the local people (white) would not work under such conditions. Women read the crystals on a variety of X-ray machines or washed the thousands and thousands of crystals processed daily in huge vats of carbon tetrachloride. All the help in the plant, with the exception of the foreman and forewoman were Black or Puerto Rican. Nobody mentioned that carbon Tet destroys the liver and causes cancer of the kidneys. Nobody mentioned that the X ray machines when used unshielded, delivered doses of constant low radiation, but Keystone hired Black women and didn't fire them after 3 weeks and even let them join the union (Lorde, 1982, p.125-126).

Although this is a fictional account it holds many truths regarding the notion that one's race and class oftentimes determine what type of work is available, meaning, that poor women of color are more likely to work in toxic environments. Similarly, they are also at increased 'risk' of living in environmentally racist neighborhoods.³⁹ Take the example of Bayview Hunters Point. This primarily African American district in the corner of San Francisco bears a heavy burden of toxic waste sites and hazardous materials. It has the second highest age adjusted rates of breast cancer among all districts in San Francisco and twice the number of breast cancer cases among women under fifty (Fishman, 2000). Despite the increasing evidence that pollutants in the environment and our daily use and exposure to carcinogenic substances contribute to breast cancer

³⁹ "Environmental racism is a form of discrimination that expresses both class and white/Anglo racial privilege. Laws and zoning codes are enforced in racially and economically discriminatory ways. Poor communities disproportionately populated by people of color are the most directly affected by wasted landfills, chemical factories, and lead smelters" (Eisenstein, 2001, p. 87-88).

incidence, mainstream discourses are reluctant to acknowledge the potential threat of substances such as various cleaning agents, pesticides, cosmetics, and shampoos.

However, Bernice McFadden (2004) speaks briefly about increased 'risk' due to cosmetics with the protagonist Camilla in *Camilla's Roses*:

Camilla grew up worrying about pressed hair, getting a relaxer and training bra...by her sixteenth birthday she knows that Clorox only burns the skin and does not bleach it... A couple a hundred jars of fade cream. She supposed she had it coming. And why wouldn't God take from her what she had treasured most. Her breasts. The part of her she had made perfect first by making them white. It had been her magic armor protecting her from the plights of being born black. Life had moved along smoothly when she started applying the cream to her breasts and had only gotten better with each piece of anatomy she included. By the time she met Bryant, her whole body was four shades lighter than she was eons ahead of where her foremothers had been at her age (McFadden, 2004, p.133, 145, 179).

This passage speaks to the fact that many African Americans use various cosmetics and fade creams that are potentially damaging to their health. While this study does not cover identity, many African, Caribbean, and African American women, for a variety of reasons, use skin bleaching creams, dyes, and perms many of which may increase breast cancer 'risk'. In fact, all women, irrespective of color are at risk when using cosmetics and shampoos due to lack of FDA approval. However none of these things are discussed as breast cancer risk factors in mainstream discourse. More specifically, for many black women, the use of these substances are related to the fact that they are 'at risk' of subscribing to and trying to achieve European standards of beauty. This also relates back to the historical construction of black female bodies whereby 'dark' skin and 'coarse' hair are not desirable characteristics of beauty. Thus,

many black women use various cosmetics to 'change' these features in order to be more 'appealing'.⁴⁰

Unfortunately, achieving 'proper' standards of beauty through the use of carcinogenic substances not only increases black women's 'risk', but living in segregated environments that lack quality and healthy foods are also factors that influence whether one is more likely to develop this disease. For instance, the emphasis on eating a healthier diet to decrease risk may not apply to poor women living in urban areas, such as Detroit. Over a half million Detroit residents live in 'food deserts' due to the closing of chain grocery stores because of presumed high cost of operation in 'crime ridden' areas. Food deserts are "areas of relative exclusion where people experience physical and economic barriers to accessing healthy food" (Green Options, 2007 ¶ 2). The food venues in these areas offer little fresh and healthy food, but instead they specialize in alcohol, money orders, cigarettes, lottery tickets, and other non-food products (LaSalle Bank, 2007). In addition, much of the food offered consists of junk food, candy or expired meat (Smith & Hurst, 2007). Those who have transportation, time, and the economic means have to travel large distances to get fresh produce (Smith & Hurst, 2007, LaSalle Bank, 2007). Thus, the suggestion to eat a better diet is not feasible or available for many poor inner city residents. Bordieu's concept of the habitus also helps to explain why focusing on changing individual behaviors is not the best way to decrease breast cancer risk among women.

⁴⁰ Since there is a lot of diversity among black women, this is not to say that all black women who perm their hair or use fade creams to lighten blemishes are trying to subscribe to European standards of beauty. But I do think there is a pervasive belief within the black community that black women must look a 'certain' way or be a 'particular' shade/color to be considered desirable and beautiful.

According to Bourdieu (1977), the habitus pertains to an acquired system of generative dispositions which is objectively adjusted to the particular conditions in which it is constituted...the habitus creates dispositions and generative principles that are embodied in the ways people think, feel, act and classify their social world and location in it (p. 72). What this means is that class plays an important, but subconscious role in determining how people think about their lives, how they hold their bodies, gestures and it even influences 'taste'. For example, while a rich man may reach for caviar, a farmer for fresh vegetables, and a poor urban child may take delight in a bag of chips, these preferences are in fact influenced by the habitus, which is established according to one's class.

The habitus equally applies to the other 'lifestyle' factors indicated within the discourse of 'risk', such as alcohol use, smoking, and the frequency with which one visits a physician. To suggest that people change these behaviors may not be as simple as doctors think since Bourdieu (1977) suggests that these dispositions are beyond the grasp of consciousness and cannot be voluntarily transformed.⁴¹ Nonetheless, I propose that with an increase in economic resources, equal access to healthcare and allowing patients inclusion in treatment plans, people can choose to change these behaviors. However, I must stress that I do not agree that change solely rests on the individual, rather substantial changes must occur in the historical, social, environmental, and economic factors that negatively impacts health. Regrettably, the continual negligence to address these issues in American society persists and contributes to the increased mortality rates found among African American women.

⁴¹ Although I had some understanding of the habitus, Simon Williams' *Medicine and the Body* (2003) inspired and influenced the linkage between the habitus and health.

CHAPTER IV

POPULAR DISCOURSES OF INCREASED MORTALITY

The American Cancer Society (ACS) suggests that in 2002 there were 2.3 million women in the United States with a history of breast cancer alive, which included those who were cancer free or undergoing treatment. More specifically, in 2006 there were, 212,920 new cases of invasive breast cancer, 61,980 in situ cases and from both cases combined, it is estimated that approximately 41,430 women a year will die from breast cancer (ACS 2005).⁴² Among African American women it is estimated that 19,420 new cases are expected to occur. In fact when compared to other cancers such as lung (13.2%), colon (13.3%) and ovarian cancer (2.5%), breast cancer is the most commonly diagnosed cancer in black women at 27% (ACS 2005-2006).

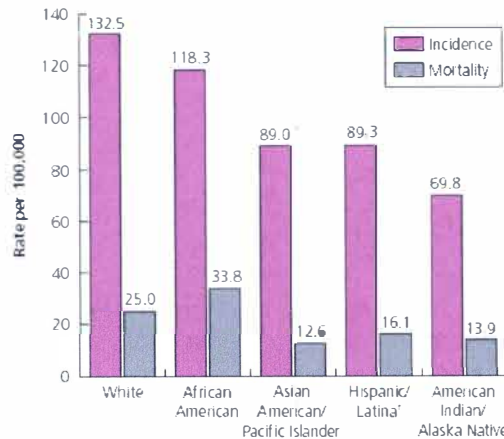
Although all races and ethnic groups are susceptible to breast cancer, white and black women seem to have higher incidence of the disease than Asians and Hispanics, with black women having higher mortality rates (Figure 7). The disparities that exist between black and white women with breast cancer are also evident in the fact that African American women have poorer survival rates and they are less likely than whites to survive five years after diagnosis regardless of stage and age (Figure 8)⁴³. When trying to explain the higher mortality rates and poor health outcomes of African American women with breast cancer, popular discourses offer three explanations, access to health care, black women's attitudes and practices and biology.

⁴² Although the majority of these deaths are women, less than 1% or 460 deaths will be that of men.

⁴³ While these statistics clearly indicate that disparities exist in mortality rates between black and white women a closer examination needs to be made in order to account for the fact that during the early 1980's breast cancer deaths for white and black women were approximately equal yet in 2002 to 2003 black women had 36% higher deaths than white women (ACS 2005; Newman, 2005).

Figure 7: Female Breast Cancer Incidence and Mortality Rates by Race and Ethnicity US, 2000-2004. American Cancer Society. Breast Cancer Facts & Figures 2007-2008. Atlanta: American Cancer Society Inc.

Figure 2, Female Breast Cancer Incidence and Mortality Rates* by Race and Ethnicity, US, 2000-2004



* Rates are age-adjusted to the 2000 US standard population. *Persons of Hispanic origin may be any race.

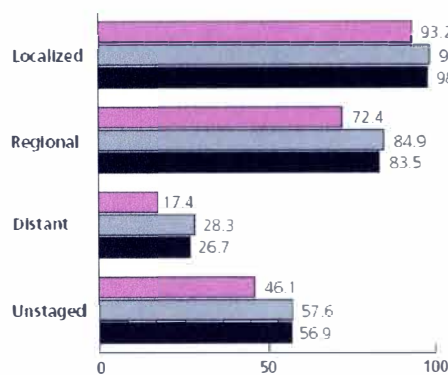
Data sources: Incidence – Surveillance, Epidemiology, and End Results (SEER) Program, SEER 17 Registries, 2000-2004, Division of Cancer Control and Population Science, National Cancer Institute, 2007. Incidence data for Hispanics exclude cases from the Alaska Native Registry and Kentucky. Mortality – National Center for Health Statistics, Centers for Disease Control and Prevention, 2007. For Hispanics, information is included for all states except Minnesota, New Hampshire, and North Dakota.

American Cancer Society, Surveillance Research, 2007

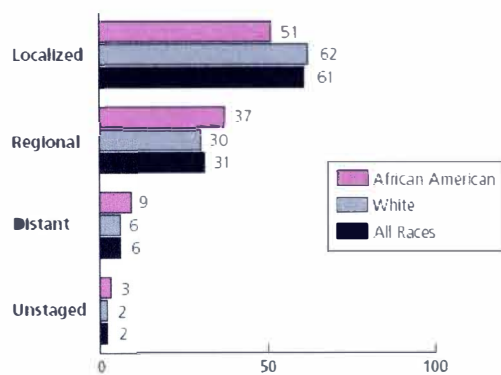
Figure 8: Female Breast Cancer- US, 1996-2003. American Cancer Society. Breast Cancer Facts & Figures 2007-2008. Atlanta: American Cancer Society, Inc.

Figure 8. Female Breast Cancer – US, 1996-2003

A. Five-Year Survival Rates* by Stage at Diagnosis and Race (%)



B. Percent Diagnosed by Stage and Race



* Survival rates are based on patients diagnosed between 1996-2003 and followed through 2004.

Data source: Surveillance, Epidemiology, and End Results (SEER) Program, SEER 17 Registries, 1973-2004, Division of Cancer Control and Population Sciences, National Cancer Institute, 2007.

American Cancer Society, Surveillance Research, 2007

Access to Healthcare

There is much speculation that socioeconomic status (SES), which is measured by factors such as education, income, and occupation as well as racial bias, contributes to inequalities in breast cancer survival. African American women compared to whites are more likely to lack medical insurance and rely more on public insurance such as Medicare (Newman, 2005). This inequity in wealth and/or income generally determines the quality and type of treatment received for breast cancer and women who receive poor medical care have an increased chance of poorer survival. For example, Mount Sinai researchers, who examined data from Chicago's cancer registry, public health department, and Behavioral Risk Factor Surveillance System, suggest that mammograms done on African Americans might be of less than optimal quality (Ritter, 2006). "Their study notes that mammogram centers typically spot five to seven cancers for every 1,000 mammograms. But they found that at one Chicago center serving low-income women, only 2.4 cancers were spotted for every 1,000 mammograms" (Ritter, 2006). It is also important to note that like all x-rays, there are no definitive results because the accuracy of mammograms relies on the efficiency of technicians in capturing images of breast tissue and radiologists, correct interpretation of the results.⁴⁴ Unfortunately, many women's narratives also confirm poor quality treatment with mammography screening even in spite of having adequate insurance in some cases:

Mae Phillips: She found a knot and was sent to a breast specialist for an ultrasound and a needle aspiration. I was told that everything was OK. I was told I had nothing to worry about, just to see my primary physician for a mammogram the following year. When she changed insurance she developed a rash under her breast and went to see her new doctor for a surgical biopsy and he found cancer.

⁴⁴ There are many controversies associated with mammograms regarding the overall accuracy at detecting tumors, especially in dense breast tissue. There are also concerns that prolong use, especially in younger women, may cause cancer, since radiation is the only known cause of cancer.

They performed the surgery...I was so angry, and so frustrated. I could not believe that I had gone to the doctor; done all the things I was supposed to do and now, all of a sudden have cancer. And it is in the second stage...I later found out that the first ultrasound I had revealed some suspicious cells. Also, my cancer was present on my first mammogram. The more I found out the angrier I got because I realized I almost slipped through the cracks of the system (Dunnavant, 1995, 83-89).

Karen Eubanks Jackson: All the time I was having mammograms no one ever told me that 10 percent of women who get cancer don't have it show up through mammograms. So every year I would sigh with relief after I would have my mammogram. I felt I was taking care of myself. Every time my results were negative, I felt like I was passing the test. I was wrong! Lo and behold, my cancer had been there all along but it was never detected (Dunnavant, 1995, p. 191).

Pat Brewer: After finding some calcium deposits in her breasts from a mammogram the doctor requested a biopsy and told her everything was fine. The next year I went back as usual, but my mammogram was the same. They requested another biopsy and I was then informed that they had missed the correct spot last year. They had collected the wrong sample. Right away this let me know I needed another surgeon (Dunnavant, 1995, p. 143-144).

Beverly: I did not receive adequate treatment from my primary HMO doctor. When I was on the operating table and prepped, the surgeon finally looked at the x-rays just before entering the room. He determined that a biopsy was not possible because there were too many calcifications in my left breast! This sloppy treatment made me very nervous and doubtful. When I wanted a second opinion, my primary physician requested that I go to a breast center via my HMO and the request was denied. The second doctor in my HMO also gave me poor treatment. As he was asking me questions about what the first doctor had told me, I realized that he hadn't seen my file or my x-rays either... I stormed out of the office in a rage (Stanford, 2005, p. 31).

Economic constraints, not only affect quality of care and services received from health care clinics, but it also affects black women's participation in clinical trials.

Clinical trials are important because they foster state of the art medical care as well as determine new treatment regimens and their affects on breast cancer (Mwaria, 2006).

However, many of these trials are not available to black women because they lack insurance. Lack of insurance particularly limits enrollment because it affects the ability to get preparatory work done to establish eligibility for a given trial such as blood tests,

X-rays, scans and dental work to name a few (Eisenstein, 2001). Although clinical trials are free, follow up care costs money. Likewise poor women may not have ample time to participate in clinical trials because of their job(s), they lack adequate transportation to travel to medical facilities, or affordable childcare services may not be available. Thus, it becomes apparent that participation in clinical trials is directly connected with economic networks that bespeak class and racial location (Eisenstein, 2001).

However socioeconomic status and inequality do not fully explain the disparities that exist in mortality rates between black and white women. There is another factor that needs to be considered...racial bias. Many studies focusing on equal access to healthcare facilities, such as the Department of Defense and Veteran Affairs, indicate that racial bias in treatment, such as differences in the types of treatment administered, delays in initiation of therapy or even failure to administer adjuvant therapy in some patients in treatment, may also contribute to health inequalities in breast cancer (Jatoi et al., 2003). It is not surprising that race accounts for health differences because it is an entrenched social construct that is a pervasive issue in every area of life. In 1990, the American Medical Association formally acknowledged that “the existence of black-white disparities⁴⁵ in health care may reflect the existence of subconscious bias....the health care system, like all other elements of society has not fully eradicated this [racial] prejudice” (Geiger, 2006 p. 268-269). For example, not only do studies indicate unequal cardiac treatment between black and white patients, but a recent study looking at how emergency rooms administer pain medication, also concluded that blacks are discriminated against with regards to pain management (Pletcher, 2008).

⁴⁵ Black-white disparities refer to the fact that when looking at numerous illnesses blacks have significantly higher mortality and morbidity.

Attitudes and Practices

Explanations that focus on the black women's attitudes and practices suggest that they have increased mortality rates because they have fatalistic attitudes towards breast cancer, in which they view the disease as a death sentence (Anglin, 2006). As a result, African American women delay in seeking diagnosis and treatment, and they under use preventive screening programs, such as mammography. This generally results in late stage diagnosis whereby African American women present with advanced stages of breast cancer.⁴⁶ Consequently, late stage cancers are less responsive to both hormonal and chemotherapy treatments, which contributes to higher mortality rates. In contrast to the dominant discourse of black women's fatalism causing late stage diagnosis, their narratives had another story to tell, one that focuses on medical negligence, which without doubt is linked to race:

Cynthia V. Vaughan: I went back to my original doctor and he insisted it was nothing but a clogged milk duct. He wanted me to watch it and come back in six months. I started to watch it and it started to grow and grow and grow. After three months I went back. My doctor still assured me there was nothing to worry about because of the statistics – there was nothing that showed I should be susceptible to breast cancer. After all, I was only 29 years old (Dunnavant, 1995, p. 101).

⁴⁶ There are four stages of breast cancer. **Stage I** is characterized by tumors that are not more than 2cm in diameter, which is slightly less than one inch; the cancer has not spread to the lymph nodes nor a distant part of the body. The five year survival rate for women treated at this stage is 98%. **Stage II** tumors are 2 to 5cm in diameter, the cancer may or may not have spread to the axillary (underarm) lymph nodes, the tumor is more than 5 cm in diameter, but the cancer hasn't spread to the axillary lymph nodes, and the tumor is less than 2cm in diameter, but the cancer has spread to less than four of the axillary lymph nodes. The five year survival rate for stage II breast cancer is 76 to 88 percent. **Stage III** is known as locally advanced cancer, which may have spread to the lymph nodes near the breast, under the arm or the collar bone, but not to more distant parts of the body. There is not estimated time of survival at or beyond stage III breast cancer. **Stage IV** represents the most advanced form of breast cancer; cells have spread to distant parts of our body, such as bones, organs or lymph nodes located far from your breast. Treatment may help shrink or control the cancer for a while but it usually won't completely cure the cancer. At this stage, symptom relief becomes a priority (Mayo Clinic, 1998-2008). It is important to note that I do not agree with the use of the word "cure" for breast cancer. There is no known cure for cancer and while treatment options may cause remission there is still exists the possibility that one could relapse and the cancer may become active after no specified length of time.

Dorothy Ballard: There is one thing that left a bitter taste in my mouth. I was working in a factory at the time I was diagnosed. I had ample insurance. Every year I got my annual check up. My doctor never did suggest I have a mammogram or examine my breasts or teach me to examine my breasts... each year when I would go to him he would pat me on the back and say, "Mrs. Ballard, you are just fine. He gave me a false sense of security (Dunnavant, 1995, p. 186-187).

(Jordan's encounter with a oncologist in 1992): From my own examination and from what the mammograms indicate, I'd say you could go ahead and wait to have a biopsy for five to even ten years. There's absolutely no hurry, no need to worry! At this point my friend exclaimed: But what if the biopsy could turn out positive:' Dr. Gardner smiled such a warm big smile. Don't even think of that! It's not a possibility! Despite this optimism from the doctor June says she followed her gut and went ahead and got a biopsy which turned out to be cancer. (Jordan, 2002, p. 63)

These examples, which are just a few of the many encountered, clearly suggests that delay in diagnosis may not totally be a result of fatalistic attitudes, but rather that sub par and ineffective care from doctors, is partly to blame. Although the ethnicity of these physicians is not known, the "wait and see" approach is not acceptable for anyone, and it is even worse when considering that black women have significantly poorer survival rates. While I am not proposing that this practice is uniquely present among black women, I am arguing that these examples show that even when black women actively seek care and in some instances present with clear indications of breast cancer, their concerns are either ignored or not taken seriously.

Luckily many of these women were active agents in their own health or in the case of June Jordan, had someone to advocate on her behalf. However, many women do not know or feel comfortable in challenging a doctor nor do they have the economic means for a second opinion.⁴⁷ It is sad to think that when African American women place

⁴⁷ Ironically many doctors are entrenched in this position of power and authority that to challenge or question their suggestions or diagnosis is to be deemed a "non-compliant patient". For African American women the issue of non-compliance impacts negatively on their health because in many instances doctors

faith and trust in their doctors and rely on their medical authority their concerns are not legitimated. This indicates that despite the tremendous gains of the women's health movement, women still have not achieved full equality in the examining room. In fact, approximately 50 to 80 percent of breast tumors are first detected by patients, which may be a result of inadequate mammography screening. Nonetheless, the 1st and 2nd largest numbers of malpractice suits are related to the failure to diagnose breast cancer, particularly in younger women, and a lack to follow up care respectively (Kasper, 2000). The most common explanation for failure to diagnose was that a patient's physical findings did not impress the doctor that cancer should be considered a risk (Kasper, 2000).⁴⁸ Thus, "doctor's authority" is in fact contributing to increased mortality rates among black women.

Biology

The most popular explanation offered to account for differences in mortality rates among African American women is that differences in tumor biology may lead to more aggressive forms of breast cancer that are harder to treat. For example, a larger number of black woman have estrogen-receptor negative or ER negative tumors that are not fed by the hormone estrogen, which is believed to stimulate growth in breast tumors. As such, these tumors are not affected by the most successful breast cancer drugs such as Tamoxifen and Aromatase inhibitors, which block estrogen receptor sites on cells thereby

make assumptions about them based on the generalized belief that black women, especially poor black women are more likely to not follow doctor's "orders".

⁴⁸ It is important to note that this relates to Foucault's (1978) notion of subjugated knowledges, which refers to "knowledges that have been disqualified as inadequate to their task or insufficiently elaborate: naïve knowledges located low down on the hierarchy, beneath the required level of scientificity" (p.82).

preventing further growth (Reuters 2006; Jones et al, 2004)⁴⁹. Furthermore, a study conducted by Dr. M. Catherine Lee of the University of Michigan Comprehensive Cancer Center indicated that ER-negative tumors were more common in black women at every stage of disease and at all ages. However, these tumors are not specific to African American women. 17% of early stage tumors in white women are ER-negative, compared to 31% in black women and of the more advanced cancers there was 31% in whites and 46% in blacks (Marchione, 2007). Nevertheless, these biological differences in tumors suggest that black women may have a genetic predisposition for more aggressive forms of breast cancer.

However, this biological explanation continues to suggest that black bodies are more prone and inherent to disease. This is primarily indicated in the suggestion that there is some genetic component among black women that renders their tumors more “aggressive” and “hard” to treat”.⁵⁰ These words are not race neutral because they are primarily used in reference to black women. While there is evidence there are some differences in the tumors of black women, these same tumors also exist in white and Hispanic women. However, there is hardly, if ever, any mention that these tumors are equally ‘aggressive’ and ‘hard to treat’ in white and brown bodies. This characterization, in my opinion continues to situate black women as the antithesis of white women,

⁴⁹ It is important to note that Tamoxifen can cause thrombosis/pulmonary emboli in relatively high numbers among black women (Newman 2006 p. 6), which means that it increases the incidence for the formation of blood clots and stroke.

⁵⁰ What is interesting about the assumed connection between genetic predispositions in black woman for “aggressive” or different tumors is the fact that while many African American women may identify as black this does not take into account that many of their ancestors may have been white or Native American. In fact, many people who identify as white may also have black ancestors. Thus, in many regards to say that ER negative tumors is related to the genetics of a specific group is in fact simply rely on phenotypical differences, which in this case is primarily skin tone.

whereby breast cancer is an altogether different disease in black bodies that seems to befuddle scientists and current treatment methods.

Surprisingly, black women's narratives did not mention the idea of 'aggressive' breast cancer. In the only account that speaks of breast cancer as 'aggressive' D. T. Negrin states:

I think healing requires the nurturing of the spirit, the mind, and the body. Perhaps there is a gene that causes the cancer to be more aggressive in African American women. I don't know. But I don't believe that that's particularly important. Too often for African American women, the mind and spirit are not integral parts of their treatment plans. Healing is a holistic process. Of course my doctor didn't talk to me about a plan of treatment that was specifically for African American women. But isn't that just like everything else in this society? What I found out I discovered on my own (Stanford, 2005, p. 71).

In my view this further shows that the notion of 'aggressive' and 'hard to treat' is primarily terminology used by scientists and doctors and reflects racial bias on their part. In fact, as the example shows, as well as many others, black women are more concerned with a holistic form of treatment that includes mind, body, and spirit, rather than simply focusing on whether breast cancer is 'aggressive'. When looking at online chat rooms many African American women also expressed wonder and disdain about what exactly does 'aggressive' means and why is this term primarily used in reference to black women.

Nevertheless, while most current research in racial disparities 'has abandoned racist ideology...much of it still assumes that racial variations in disease are due to underlying differences in biology'; that racial taxonomies are meaningful classifications of genetic differences; and that genes determining race also determine the number and type of health problems (Mullings & Schultz, 2006). This growing tendency to

distinguish people from one another on the basis of genetics and defining most disorders and physiological variations as wholly or part genetic in origin is referred to as geneticization (Lippman, 1998). Geneticization is an emerging ideology and set of practices that divert attention from the structural changes necessary for true health promotion but instead emphasize patient's responsibility in keeping themselves healthy (Lippman, 1998). This includes the notion that women need to understand their genetic predisposition for certain diseases and make the appropriate "lifestyle" changes to counter or limit genetic effects. Relying on genetics to explain health variation not only leads to the further devaluation of specific groups of people, but it is also a powerful discriminator, considering that American society is already hierarchically gendered, racist, and classist (Lippman, 1998, p.65-66).

Concluding Thoughts About Race and Breast Cancer

Multiple national studies of majority beliefs about minorities affirm that negative racial and ethnic characterizations, though often subtle in open expression, continue to be widely held and have been stubbornly resistant to significant change (Geiger, 2006). The ideology of white superiority and minority inferiority is used to attribute the causes of disparities in minority health status to the alleged behavior of people of color and ethnic minorities, rather than to the realities of the nation's social class and racial stratifications and the hazardous social, economic, and physical environments they have created (Geiger, 2006, p. 266). These views are further substantiated with the increasing reliance on genes to explain health disparities.⁵¹

⁵¹ There is current epidemiological research being done that seeks to understand how inequality and the environment affect biology in ways that contribute to disease. With this type of research the focus on genetic disposition is not solely attributed to the 'pathological' nature of specific groups. However, despite

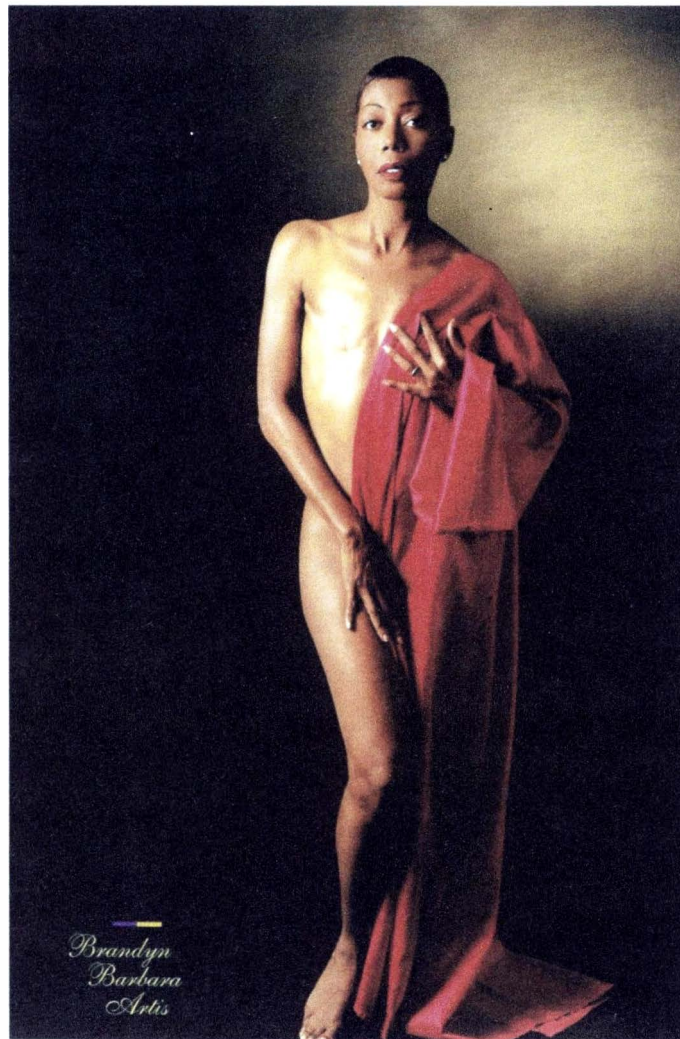
Genetic explanations for racial disparities in health ignore the historically situated and contextual nature of processes of racialization shifting the lens away from the ways that those processes are linked to the social, political, and economic conditions that influence health. Instead by locating the cause of health disparities within the genes of racialized groups they suggest that there is something innately pathologic about that group, reinforcing their “essential physical inferiority in the modern world” (Lippman, 1998). Such interpretations obscure the social processes that create inequality, contribute to the stigmatization of racialized groups (and thus perpetuate inequalities) and allow whiteness to remain invisible and un-interrogated (Daniels & Schultz, 2006, p.115). Therefore, explaining racial differences in health in terms of individual biology, can locate health problems in the bodies of those most negatively affected by social inequalities.

The profit driven nature of the US health care system often translates into serious compromises in the quality, coordination, and continuity of care for women with breast cancer (Kasper, 2000). Social inequality not only undermines access to quality health care, but being female, a racial or ethnic minority of young or advanced age and being apart of a lower social class, are all factors that predict poorer care and outcomes (Kasper, 2000). Rather than looking solely to the bodies and behaviors of black women as the causes of their own disease, it is important to focus on how mutations themselves can be environmentally created, which suggests that black women may suffer from mutations that are not simply biological but instead are environmentally produced specifically through racism and poverty (Eisenstein, 2001). Nevertheless, similar to the

this promising work it seems that within the public discussion of breast cancer, these nuanced issues are not presented or explored. The dominant discourse seems to suggest that it is easier to implicate the source or causes of disease in genes rather than the inherent inequality that exists in American society.

scars of racism and poverty that is impressed upon the psyche of black breast cancer sufferers; this disease leaves its “true” biological implications on their bodies through the disfiguring scars left from breast cancer treatment.

Figure 9: Photograph of Brandyn Barbara Artis. Featured in *Celebrating Life: African American Women Speak out About Breast Cancer*. Photographed by Sylvia Dunnavant.



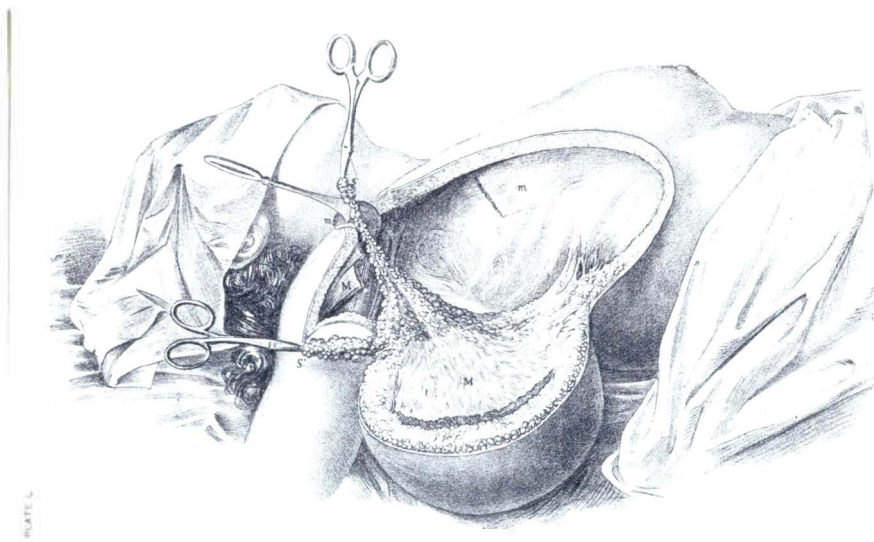
CHAPTER V

RECONSTRUCTING WOMEN: I AM A SURVIVOR

Treatment

The first major treatment for breast cancer during the 19th and early 20th centuries was surgery, which was made possible with the introduction of aseptic practices and anesthesia. Leading the way was the aggressive procedure known as the Halsted radical mastectomy. This operation entailed the removal of not only the infected breast, but also the lymph nodes and underlying chest muscle as indicated in figure 10.

Figure 10: Illustration of the Halsted Radical Mastectomy. Courtesy of The Alan Mason Chesney Medical Archives of The John Hopkins Medical Institutions.



Although the Halsted radical Mastectomy slowly improved survival rates, it left women disfigured emotionally and physically because the procedure resulted in concave chests, which women then attempted to hide since breast cancer was a private affair. Fortunately,

the late 20th century not only ushered in a lessening of the use of this procedure, but it also brought about detection technology and more treatment options.

Breast tumors were originally detected primarily by palpation of the breast, either by women themselves or by doctors. In the contemporary framework this is generally referred to as breast self-examination (BSE), first introduced in 1948 by Alfred Pompa (Leopold, 1999) and clinical breast exam respectively. However, through the work of Thomas Egan in 1960, who developed an easily reproducible low kilovoltage technique using inexpensive film a more efficient means of detection was introduced called mammography (Olson, 2002). Due to the 1965 American College of Radiology's establishment of the Committee on Mammography and increased funding to train radiologists and technicians around the country, mammography became and continues to be the dominant diagnostic tool in detecting breast tumors (Olsen, 2002).

While surgery still remains the primary treatment method for breast cancer, both past and present, the 20th century also introduced conjunctive treatment options such as radiotherapy, chemotherapy, immunotherapy, and hormonal therapy. First, with regard to surgery, new techniques were utilized that lessened the disfigurement associated with the radical Halsted mastectomy. These procedures are known as lumpectomy, which involves removing cancerous tissue in addition to a rim of normal tissue surrounding the area and mastectomy, which is the simple or total removal of the entire breast (Komen, 2007). In the case of mastectomy the modified radical deviates from the Halsted radical procedure because it only removes the breast and lymph nodes under the arm, leaving the chest tissue intact.

Other treatment options, which are used in conjunction with surgery, are radiation therapy and systemic therapy. Radiation therapy uses radiation to destroy remaining cancer cells that may be in the breast, chest walls, or under the arm after surgery. However, in some instances radiation is also used to reduce the size of a tumor before surgery. Systemic therapy, which is the use of a variety of pharmaceutical drugs to fight breast cancer includes: biological therapy, which involves the use of Herceptin in late stage cancer or metastatic cancer; chemotherapy, a combination of various anti-cancer drugs, and hormonal therapy which uses drugs such as Tamoxifen, which is an antiestrogen drug that blocks estrogen receptors on tumors (Komen, 2007).

Although these advancements in treatment and early detection have proven to be more beneficial to white women when compared to African Americans and other racial and ethnic groups, these techniques play a vital role in the continual fight against breast cancer (ACS 2005). However, there still remain numerous stigmatizing effects associated with treatment such as hair loss and mouth sores resulting from radiation treatments and lymphedema, which is increased swelling in the arm due to the removal of underarm lymph nodes. Nevertheless, the major drawback that still persists in breast cancer treatment is the alteration or removal of one or both breasts. Mainstream breast cancer culture and discourse address the negative impact of breast cancer treatment by promoting breast reconstruction and wearing prosthetic breasts as a way that women can return to normalcy. This is coupled with a message of survivorship and hope that suggests breast cancer is a transformative and positive experience.

When looking at black women's experiences with breast cancer treatment, their narratives show that they simultaneously occupy positions both on the margins and

within breast cancer culture. What this means is that although there are differences that run counter to the dominant discourse surrounding this disease, African American women also express concerns that support many of the previous mentioned suggestions about how women should deal with the negative effects of breast cancer treatment.

Nevertheless, as will be shown, black women are in agreement with the culture of pink in emphasizing a desire to return to normal, questioning notions of femininity in relation to the post-mastectomy body, and viewing breast cancer as a positive experience, while also displaying emotions that are not acceptable to mainstream breast cancer discourse and ideology.

Reconstruction: A Return to Normalcy

To some degree biomedicine has attempted to divorce the body from the person as a rational agent, ignoring the profound alterations to self that medical intervention brings (Kasper, 2000). What this means is that biomedicine is not concerned with the “person”, rather doctors are only concerned with treating the body. However, Anthony Synnott (1993) argues that the body and the self are connected and when changes occur with the body, especially when they are drastic, unexpected, and noticeable to others, change also occurs with the self. Thus, to have a body felt to be feminine, albeit socially constructed, is crucial to a woman’s sense of herself as female and sexually desiring⁵². However, mastectomy disrupts what it means to be female and black women sufferers clearly indicate the accuracy of this notion in their experiences with the repeated reference about their ‘scar’ as a significant reminder of their disfigurement:

⁵² I do not posit that all women view their breasts as connected to their femininity. Nor are breasts only desirable with regard to men. For example, many of the works by lesbians in this thesis expressed deep desire from and for women. However I would argue that their presentation was not in the sense of viewing breasts as “objects”.

Patsy Harris: I had a towel wrapped around my chest. I later realized that my towel was my way of avoiding looking at my scar, which was my reminder that I had breast cancer. By the time I had surgery I was definitely OK with giving up my breast. I wasn't OK with what I was going to be like as a human being and as a woman. I didn't quite know what I was going to do, or how I was going to adjust. Undoubtly {sic} the hardest part for me was looking at the scar and having it be a constant reminder that I had breast cancer (Dunnavant, 1995, p. 82-83).

Lillie Day: As long as I have my clothes on I am fine. When I take my clothes off, it is then I am reminded that my body is one-sided and that has been hard to deal with (Dunnavant, 1995, p. 44).

Having a stitch instead of a scar makes you crazy, terrified of love, never want to undress in front of anybody, it means references to future time frighten you or leave you feeling ignored or irrelevant or both, the absence of long range plans, and abundance of tests with regard to anything unusual, and it means you represent an unbearable emotional rollercoaster to your family and friends (Jordan, 2002, p.73).

Karen stopped at the full length mirror with her loosely draped robe dangle open. Covered in protective emotional armor, she dodged the imaged that came hurling back at her. It was an ongoing battle. Her adversary had been put on the canvas time after time and wouldn't stay down. Her trembling hands glided over the leveled mounds and lingered at the jagged scar lines of where both of her breasts had once resided (Haley, 2002, p. 31).

What these examples reveal is that there are fears among breast cancer sufferers, irrespective of race and ethnicity, and within society about the notion of a woman who lacks breast(s) because it generates ideas of disfigurement, damage, and mutilation (Saywell, 2000). Since breasts represent images of ideal femininity, the asymmetry of mastectomy and lumpectomy is indicative of an assault on perceptions of beauty and normality (Saywell, 2000). In fact, these women have developed a stigma. According to Goffman (1983) the Greeks originated the word stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier (p. 3). When coupled with the idea that the surface of the body is treated not only as the boundary of the individual as a biological and psychological entity, but as the frontier of the social

self, it is of no surprise that women with breast cancer want to hide the 'stigma' of their amputation(s), which goes against proper socialization regarding how a woman should look (Goffman, 1983; Turner, 1980). However, with the rise of aesthetic surgery as a widely accepted practice, there is a popular belief that surgery can correct bodily deviance and deformation, as well as 'cure' and 'restore' the psyche damaged from this stigmatizing procedure (Gilman, 1985). The remindful scars can be erased, thus returning a woman back to 'normal' as evidenced in the following example.⁵³

Patsy Harris: Her friend bought her prosthesis and said, Girl if we can get you back to looking normal, I think you will start feeling better (Dunnivant, 1995, p. 83).

Stephanie Reed: I don't want the cancer to come back. Maybe after some time have [sic] passed I will get back to normal and won't think about it as much (Dunnivant, 1995, p. 55).

Wilma Carroll: It seems the constant fear of death is lurking over your heads....relief that life will return to normal (Dunnivant, 1995, p. 141).

Pat Brewer: When they called me in and told me the tissue was malignant, I didn't freak out, I didn't get emotional; I just wanted to have the surgery the next day...All I wanted to do was remove the cancer and get on with my life (Dunnivant, 1995, p. 144).

Not surprisingly, breast reconstruction, is increasingly offered immediately after surgery. Despite the argument that this procedure, along with wearing prostheses, returns women their previous selves, it in fact takes advantage of the medicalization of women's breasts. Medicalization consists of defining a problem in medical terms, using medical language to describe the problem, adopting a medical framework to understand a

⁵³ In the United States, personal responsibility for health is paramount, and people feel a keen sense of responsibility for regaining their health when they become ill. The question of what caused the illness raises a moral question for the ill person: Is he or she responsible for the illness. Regardless of the answer to this, the person is seen as responsible for restoring normalcy (Becker, 1997, p. 45-46). This idea of a return to 'normalcy' coincides with Irving Goffman's (1980) 'normification, which is the effort on the part of the stigmatized individual to present himself/herself as an ordinary person.

problem, or using a medical intervention to treat it (Williams, 2003). Women's breasts have been medicalized for several years. This did not begin with breast cancer, but in fact it began with the idea that women with small breasts were deviant and steps were necessary to make them bigger.⁵⁴

Physicians and especially, plastic surgeons have been prominent actors in the medicalization of women's breasts. They have contributed to the belief that women who undergo breast cancer surgery are "deformed" by including reconstructive surgery in the definition of breast cancer treatment. By suggesting that reconstruction is a natural part of breast cancer treatment, physicians and the FDA, who agreed with this idea, contributed to the belief that women with one or no breasts are unnatural (Kasper, 2000). Unlike many of the women's narratives, Audre Lorde (1997) in the *Cancer Journals* profoundly disagrees with the notion that women need to wear prosthetic breasts⁵⁵:

When I mourn my right breast, it is not the appearance of it I mourn, but the feeling and the fact. But where the superficial is supreme, the idea that a woman can be beautiful and one breasted is considered depraved or at best bizarre a threat to 'morale'...I realized that the attitude towards prosthesis after breast cancer is an index of this society's attitudes towards women in general as decoration and externally defined sex object. Prosthesis offers the empty comfort of Nobody will know the difference...The real truth is that certain other people feel better with prosthesis because they do not have to deal with me nor themselves in terms of mortality nor in terms of difference. But it is that very difference which I wish to affirm because I have lived it, and survived it and wish to share that strength with other women. If we are to translate the silence surrounding breast cancer into language and action...then the first step is that women with mastectomies must become visible to each other. For silence and invisibility go hand in hand with powerlessness. By accepting the mask of prosthesis, one breasted women proclaim ourselves as insufficient upon pretense (Lorde, 1997, p. 62-65).

⁵⁴ Before, plastic surgery, paraffin or wax was injected into the breasts and sea sponges and fat transplantation was used to try to enlarge the breasts (Kasper, 2000). Women have also sought to have their breasts reduced when they are larger and heavy and consequently cause back pain.

⁵⁵ I also add that while she does not directly mention reconstruction, her insight speaks both reconstruction and prosthesis.

It is important to note that Audre Lorde realizes that each woman must deal with breast cancer in her own way, even if this includes wearing a prosthetic or getting reconstruction. What she specifically seeks to address is society's continuance to control women through suggesting that there are ideal standards to which a woman must subscribe. The processes surrounding mastectomy and post-operative recovery are designed to reaffirm and reproduce gender identities whereby women are encouraged to direct their energy towards covering up signs of this stigmatized disease and the effects of its treatment (Saywell, 2000). More specifically, they must make society feel comfortable because it is easier to wear pink ribbons, buy "breast cancer products" and participate in races, than it is to face the tangible disfiguring affects that breast cancer have on women.

Positive Transformation, Survivorship and Hope

Organizations exist as systems of meanings which are shared to varying degrees. A sense of commonality, or taken for grantedness is necessary for continuing organized activity so that interaction can take place without a great deal of re-negotiation of meaning at each encounter (Linda Smircich, 1983). Within the 'culture of pink' this commonality and/or cohesiveness is maintained by regulating women's emotions in how they respond to breast cancer. Emotions are important in organizations because they influence group membership through the perceived similarity of emotional experience and expression, which enhances the likelihood that individuals categorize themselves as belonging to the same group (Parkinson, 2005). If an organization is cohesive, then its members are more likely to be influenced by one another and to develop shared representations (Parkinson, 2005). The primary emotions encouraged by the culture of

pink are being happy, positive, cheerful, upbeat and energetic.⁵⁶ More specifically, Barbara Ehrenreich (2002) suggests that there is not a lot of complaining in breast cancer culture and when she expressed anger many of the women suggested that she needed counseling and her bad attitude would not help her. She needed prayer. However, many of the emotions expressed by black women regarding their breast cancer experience do not reflect emotions encouraged by mainstream breast cancer organizations:

Tina: It was difficult to describe the pain and suffering of chemotherapy. It is really hell! I was devastated to be a cancer victim. For more than a year, I was in denial and refused to wear prosthesis (Stanford, 2005, p. 92).

Minnie Pryor: It seems after Marge touched me who also had an experience with breast cancer, I connected with all the feelings I was avoiding: sadness, terror, uncertainty (Dunnavant, 1995, p. 119).

Anesha: The day after I received the first doctor's recommendation, I woke up feeling helpless, alone, and scared. I felt that my life was over. I tried holding back the tears because I didn't want my family to see the mental state I was really in. I didn't want them to worry about me (Stanford, 2005, p. 61).

Stephanie McKissic: I am ticked off by cancer and I am not happy with how it has taken part of my life (Dunnavant, 1995 p. 38).

Unfortunately, these emotions are considered 'negative' and are not viewed as acceptable ways to deal with disease nor are they representative of the emotions espoused by the culture of pink, which creates cohesiveness. Instead, there is an emphasis on hope that postulates that winning the war against cancer and achieving a successful recovery is intimately linked to having a positive attitude to getting better. To despair or lose hope are frowned upon as strategies of dealing with this disease. People with cancer are

⁵⁶Emotional codes specific to each gender are learned as language is acquired. These codes interact with the sexual selves and sexual identities that circulate in the various arenas of popular culture in everyday life. The masculine code in our society represses emotionality, while the feminine code expresses vulnerable and nurturing forms of emotionality (Denzin, 1995, p. 54). Ironically with the extremely feminine 'culture of pink; their desire to suppress emotion is gendered along masculine in ways men in American society deal with emotion. For example, while it is more acceptable for men to suppress their feelings, anger is an emotion generally deemed appropriate, whereby women expressing anger do not coincide with cultural beliefs about women.

lauded if they appear to be brave, never allowing themselves, to give in to the disease. In fact, these are the primary characteristics of breast cancer 'survivors'. Against all odds 'survivors' remain smiling women in charge of their lives and active against the fight against breast cancer. Survivors are successful representations to all women that a positive attitude brings about full recovery and a 'normal' life.⁵⁷

There is also an emphasis on 'will', which argues that if one has enough hope one may will a change in the course of the disease in the body, is related to notions of individualism, fighting spirit, and the power of thought to shape one's life course which are increasingly promoted in America (Lupton, 1994). However, the discourse of hope can be problematic when despite the patient's and the doctors' best efforts to remain optimistic, the illness worsens or there is a reoccurrence of breast cancer. Despite these relapses in recovery, women are still encouraged to view the disease as a transformative experience.⁵⁸

Notions of transcendence and transformation are embodied in the Judeo-Christian tradition and in philosophical ideologies of the West. (Becker, 1997) and not surprisingly, many African American women's narratives viewed religion and faith as an integral part of not only their overall breast cancer experience, but also as responsible for their

⁵⁷ In analyzing the 1999 national race for the cure Samantha King (2006) author of *Pink Ribbons Inc.* points out that anger, dissent, or criticism of any kind were absent. No questions were asked about, nor was there any mention of persistently high rates of breast cancer, in the US and worldwide. "Survivors stood as symbols of hope for the future, rather than of urgency in the present" (King, 2006, p.105). Yes, they are celebrated if they appear to be strong, courageous, and 'perky', but this is limited to the confines of submitting to mainstream scientific knowledge and reliance on doctors. In addition, breast cancer sufferers are discouraged from critically engaging biomedical research, questioning underlying structures, such as access to health care, poverty, and environmental racism, and expressing anger at governmental inaction or resistance to social discrimination and inequality (King, 2006, p.105).

⁵⁸ In the West people believe that personal transformation begins with alterations to ways of seeing. The notion of transformation is a Western interpretation of the effort to maintain order in life: by looking at things differently, people can reorder experience. Transformation is part of the process of integrating disruption and restoring a sense of continuity to life (Becker, 1997).

healing. Thus, many of their narratives upheld this notion that breast cancer positively changed their lives:⁵⁹

Thermalene Brown: I adapted to surgery very well. For me it was a total re-birthing experience. I had a new beginning...a chance to start all over again (Dunnavant, 1995, p. 137).

Karin: Cancer has a way of changing the course of one's life. Had it not been for cancer, for the fact that I thought I might die in my thirties, I might not have taken the opportunity to consider my life, to examine its purpose and to explore its possibilities (Stanford, 2005, p. 19).

Cheryl Renee Basye: I think as a result of having breast cancer I have learned to appreciate life more (Dunnavant, 1995, p. 81).

Charisse Cossey: I believe cancer was not just something that happened to me, it was something that happened for me. Dealing with this disease has allowed me to become more in tune to myself, as well as those around me...Now, I really don't spend a lot of time talking about my prognosis or my treatment. I am more concerned about how my soul has been altered and how my spirit has blossomed as a result of my experience (Dunnavant, 1995 p. 45-46).

I do not want to deny the reality or possibility that breast cancer is indeed a transformative experience to women, but I want to call attention two things: first, it is wrong to suggest, by mainstream organizations, that 'all' women must have a positive or spiritual experience with breast cancer. This 'sameness' does not reflect the diverse group of women affected by the disease, nor does it allow women to express the full range of human emotion, which seems to reflect patriarchal and sexist ideas of 'reason over emotion', whereby women are associated with the latter and deemed inferior. Thus, this indicates that there is a gendered emotional response encouraged by mainstream breast

⁵⁹ While black women are clearly in accordance with the idea of the transformative nature of breast cancer, I suggest that there are still unique differences with 'lived experience' of religion and faith that continue to alienate black women from predominately white groups. I think that for many blacks religion has been and is a historical tool of survival in this racist society. Thus, while there is still an emphasis on transformation, 'race' creates nuanced meanings of how religion operates, particularly with regards to a historically oppressed people.

cancer organizations... 'Real' women don't get angry, they just 'grin and bear it' and continue on.

Secondly, it is shameful that there is no open discussion regarding how breast cancer has negatively disrupted women's social lives, identities, jobs, and families. This is clear indication that the culture of pink is not concerned with poor women of all backgrounds who deal with this disease. For example, In addition to breast cancer survivors, there is a second category of women who are singled out for special attention at the race for the cure, "the medically underserved". However, instead of having these women visibly marked or present at the Race, whereby they can share their stories, they are signified by a mobile mammography van (Klawiter, 2000). Not surprisingly, "there is no discussion of why they are medically underserved or why they are situated as members of particular racial, ethnic, cultural, social, sexual, generational, or geographic categories or communities. They are just individual who just need help" (Klawiter, 2000, p. 75). Thus, with no discussion of the negative impact that breast cancer has on women's lives one could rightly ask, why are these women organizing, marching, and raising money if everyone is so happy?

CHAPTER VI

CONCLUSION: THE JOURNEY ENDS

Sickness is not just an isolated event or an unfortunate brush with nature. It is a form of communication, the language of organs through which nature, society and culture speak simultaneously. The individual body should be seen as the most immediate, the proximate terrain where social truths and social contradictions are played out, as well as a locus of personal and social resistance, creativity and struggle (Lock & Hughes, 1996, p. 71).

At the onset of this thesis, I set out to understand the connections between cancer and black breasts. After the death of my aunt, I wrote a poem in her memory that urged me to search for other narratives from black women that addressed their experience with this disease. In my search to find comfort in their words and writings, I also found alienation, at the overwhelming conceptualization of breast cancer as a white middle class disease and anger at the repetitive ‘slogan’ that insisted “breast cancer in black women is aggressive and hard to treat”. I soon learned in deconstructing the text of breast cancer, that these comments, as well as the ways in which scientists understand the disease, is intimately related to and influenced by historical, cultural and social factors. Breast cancer is impacted through gendered and racialized constructions of the female body.

However, these narratives also provided insight into many perplexing questions regarding breast cancer in black women. For instance, although doctors implicate African American women’s attitudes, behaviors and bodies as the source of disease, ‘risk’ and increased mortality, their narratives suggest that negligence on the behalf of doctors, socioeconomic inequality, racial bias in treatment, and living with the effects of environmental racism is to blame. These accounts also reveal that despite their marginalization, black women’s experiences with breast cancer still coincide with

dominant breast cancer ideologies particularly as it relates to viewing the disease as a transformative experience and questioning their feminine identity in the face of breast(s) removal.

Nevertheless, while, the health status of any group of women is surrounded by complex issues, it must be argued that nonwhite women in the U.S. are faced with an even greater array of complexity because their health status, historically, has been determined by issues of race, class, and culture, all of which have economic, political, and social implications (Bayne-Smith, 1996). In other words, racial categories reflect racialized social systems in the United States, and those systems have an impact on the health of groups defined by race differently (Daniels & Schultz, 2006). For example because black women are silenced within the racialized discourse of white femininity and fantasized female beauty assumes white breasts, breast cancer is white and this silencing and marginalizing of black women overlap with their later detection of breast cancer, lesser access to preventive medical care and increased mortality rates (Eisenstein, 2001).

Total divorcement from racialized discourse is not the answer to the many perplexing questions that surround poor survival in black women with breast cancer; rather, attaining equitable health outcomes can be assessed only if we continue to monitor the health of racially defined groups, recognizing that these differences are produced through social and political processes (Daniels & Schultz, 2006, p. 93). The strategies for improving this situation must include sociological and anthropological perspectives that will assist people in understanding the behaviors of African American women. Thus, by focusing on black women's own experience with breast cancer and the knowledges derived from those experiences, this study underscores the ways that dominant

biomedical knowledge often falls short of articulating the truths that women come to know through their own experiences (Fosket, 2000). In addition, I sought to shed light on the unheard stories and experiences of black women with breast cancer.

The hierarchies of difference within breast cancer discourse and imagery that persists over time represent the intersecting systems of power relationships, whereby dominance and subordination reveals that the privilege of one group, in this case white women, rests on the subordination of others, women of color (Weber, 2006 p. 36). This power is used to secure material and social resources such as wealth, income and access to education and health. However, despite the privileging of 'whiteness' within breast cancer discourse and culture, the lives of all women are at stake because "there is no known cause of breast cancer except radiation and with no cause there can be no real prevention" (Fosket, 2000, p. 15). Furthermore, "with an enormous amount of money spent each year on diagnosis and treatment, breast cancer is also big industry and big business; people and corporations throughout the US economy have benefited from the preeminence of breast cancer as a means to create wealth (Kasper, 2000, p. 120). As such, in my opinion, it is highly unlikely that a 'cure' will be found any time soon and unfortunately for many African American women, they will continue to have poorer survival rates, regardless of stage at diagnosis, when suffering from breast cancer.

Finally, besides learning about black women's experience with this disease I also wanted to better understand my 'risk' for breast cancer. This is what I learned:

I am at risk because I have breasts
Contradictory symbols displayed upon my chest
I am at risk because I am black
Environmental pollutants seeping through cracks
I am at risk because I desire to achieve
A life that my forebears only could dream

I am at risk because doctor knows best
Negligence, discriminatory treatment
Wait six months
Don't worry about performing tests...

The anger inside me swells
All breasts unite!
It's time for us to yell
Do not forgo your duty
To question and critically think
We must reveal and address the silences
Inherent in the culture of pink.

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APPENDIX A

List of Materials Researched and Analyzed

POETRY

Clifton, L. (1996). *The terrible stories*. Brockport, NY: BOA Editions, Ltd.

Henderson-Holmes, S. (1999). "C"-ing in colors. In Raz, H. (Ed.). *Living on the*

Margins: Women writers on breast cancer (p.). New York, NY: Persea Books.

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Books.

COLLECTED WORK OF WOMEN'S NARRATIVES

Dunnavant, S. (1995). *Celebrating life: African American women speak out about breast*

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Stanford, K. (2005). *Breaking the Silence: Inspirational stories of black cancer survivors*.

Chicago, IL: Hilton Publishing Company.

FICTION

Haley, P. (2002). *No regrets*. Washington, DC: BET Publications, LLC.

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BIOMYTHOLOGY

Lorde, A. (1982). *Zami: A new spelling of my name*. New York, NY: Persephone Press.

MEMOIR/ESSAYS

Jordan, J. (2002). *Some of us did not die*. New York, NY: Basic Civitas Books.

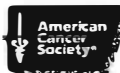
Lorde, A. (1988). *A burst of light*. Ithaca, NY: Firebrand Books.

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Books.

APPENDIX B

Copyright Permission for Figures 1, 7, & 8 from the American Cancer Society



American Cancer Society

March 5, 2008

COPYRIGHT LICENSE AGREEMENT

Cleothia Gill
Western Michigan University
1800 S. 11th St. Apt. 26
Kalamazoo, MI 49009
cleothia.gill@wmich.edu

Dear Ms. Gill:

In accordance with the following terms and conditions, the American Cancer Society, Inc. ("ACS") grants your request to reprint the image of the Women's Field Army Uniform from the article "ACS History" and reprint the figures "Female Breast Cancer Incidence and Mortality Rates* by Race and Ethnicity, US, 2000-2004" and "Female Breast Cancer- US, 1996-2003" from the ACS publication *Breast Cancer Facts & Figures 2007-2008* as set forth on Exhibit A attached hereto and incorporated herein (the "Material"):

1. The following credit line must be prominently placed on the pages in which the Material appears:

For the Women's Field Army Uniform image:

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www.cancer.org. All rights reserved."

For the figures "Female Breast Cancer Incidence and Mortality Rates* by Race and Ethnicity, US, 2000-2004" and "Female Breast Cancer- US, 1996-2003":

"American Cancer Society. *Breast Cancer Facts & Figures 2007-2008*. Atlanta:
American Cancer Society, Inc."

2. ACS grants Cleothia Gills the one-time, nonexclusive, nontransferable license to reproduce the Material in her master thesis "Living and Dying on the Margins: A Journey into the Culture of Pink and Black Women's Narrative Accounts of Breast Cancer".
3. The rights granted herein are for the English language print only and do not apply to revised editions, foreign language editions, or any form of electronic media. Use of the Material for future reproductions, translations, or any derivative works without the express written

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Upon receipt of the executed agreement, permission will be granted to reproduce the Material. Please return the originally executed agreement to the attention of TaSonja Hibbler, American Cancer Society, Inc., 250 Williams Street, Atlanta, GA 30303. Should you have any questions regarding this matter, please contact TaSonja Hibbler at (404) 329-7638.

Signature: 

Printed Name: Geetha Gill

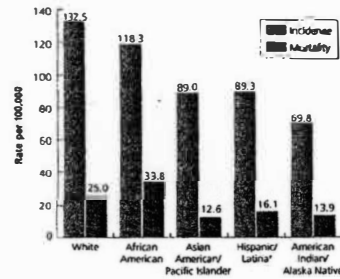
Date: 3/24/08

The American Cancer Society is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service.

Exhibit A



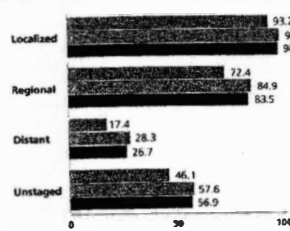
Figure 2. Female Breast Cancer Incidence and Mortality Rates* by Race and Ethnicity, US, 2000-2004



*Rates are age-adjusted to the 2000 US standard population. *Persons of Hispanic origin may be any race.
 Data sources: Incidence - Surveillance, Epidemiology, and End Results (SEER) Program, SEER 17 Registries, 2000-2004; Division of Cancer Control and Population Science, National Cancer Institute, 2007. Incidence data for Hispanics exclude cases from the Alaska Native Registry and Kentucky; Mortality - National Center for Health Statistics, Centers for Disease Control and Prevention, 2007. For Hispanics, information is included for all states except Minnesota, New Hampshire, and North Dakota.
 American Cancer Society, Surveillance Research, 2007

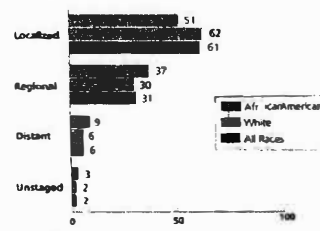
Figure 8. Female Breast Cancer - US, 1996-2003

A. Five-Year Survival Rates* by Stage at Diagnosis and Race (%)



*Survival rates are based on patients diagnosed between 1996-2003 and followed through 2004.
 Data source: Surveillance, Epidemiology, and End Results (SEER) Program, SEER 17 Registries, 1973-2004; Division of Cancer Control and Population Science, National Cancer Institute, 2007.
 American Cancer Society, Surveillance Research, 2007

B. Percent Diagnosed by Stage and Race



The American Cancer Society is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service.

APPENDIX C

Copyright Permission for Figures 4 & 5 from the Breast Cancer Fund

Page 1 of 1

From Marisa Walker <marisa@breastcancerfund.org>
Sent Thursday, February 28, 2008 8:34 pm
To Cleothia Gill <cleothia.gill@wmich.edu>
Subject RE: Permission to Use Copyright Photos
Attachments Permission Form for Ad 56K Victorias Secret.jpg 916K Obsessed.jpg 988K
Reproduction.doc

Hi Cleothia,

Thanks for your call and your e-mail. Here is our standard memo of understanding for reproduction of these images, along with the high-resolution graphics files for the two images we can use.

Please let me know if you have any questions. Best of luck on your thesis!

Marisa

Marisa Walker + senior communications coordinator
Breast Cancer Fund + www.breastcancerfund.org
1388 Sutter St., Suite 400 + San Francisco, Calif. 94109
tel 415.346.8223 x17 + fax 415.346.2975

Join our community to learn more about breast cancer's environmental causes +
www.breastcancerfund.org/signup

-----Original Message-----

From: Cleothia Gill [cleothia.gill@wmich.edu]
Sent: Thursday, February 28, 2008 5:06 PM
To: Marisa Walker
Subject: Permission to Use Copyright Photos

Dear Marisa,

Hello. I am sending this email to request permission to use two of your photos from the 'Obsessed with Breast' campaign. I would like to use the image from 'It's No Secret' and 'Mastectomy'. They will be used in my thesis which focuses on breast cancer in black women. These images are useful in the section that discusses the historical development of breast cancer in American Society. The source will receive full credit in the manuscript. Please send a reply email indicating that I have permission to use these images. I will print out the email and include it in the appendices of my thesis. If you need any more information please feel free to contact me. Thank you for your time and cooperation in this matter.

Sincerely,
Cleothia Gill
Western Michigan University
Graduate Student
Department of Anthropology
1800 S. 11th St. Apt. 26
Kalamazoo, MI 49009
269-544-1546 (home)
269-547-7-87 (cell)
cleothia.gill@wmich.edu

<https://webmail.wmich.edu/frame.html?&rtfPossible=true&security=false&lang=en&chars...> 2/29/2008



MEMO OF UNDERSTANDING

DATE: Feb. 28, 2008

TO: Cleothia Gill
Western Michigan University
Graduate Student
Department of Anthropology
1800 S. 11th St. Apt. 26
Kalamazoo, MI 49009
269-544-1546 (home)
269-547-7-87 (cell)
cleothia.gill@wmich.edu

SUBJECT: Use of "Obsessed with Breasts" images (JPG)

FROM: Marisa Walker
Senior Communications Coordinator
Breast Cancer Fund

The Breast Cancer Fund grants permission for Cleothia Gill to use the "Obsessed with Breasts" and "Victoria's Secret" images for her Master's thesis on breast cancer in black women, specifically in the context of discussion about the historical development of breast cancer in American society. High-resolution files of these images accompany this memo.

Because the Breast Cancer Fund does not have a signed model release for the "Mastectomy" image in this series, this image may not be used in materials that will be reproduced and/or distributed.

The following credit should accompany any use of the "Obsessed with Breasts" and "Victoria's Secret" images:

"Image taken from the Breast Cancer Fund's *Obsessed with Breasts* campaign.
www.breastcancerfund.org
Photographer: Heward Jue."

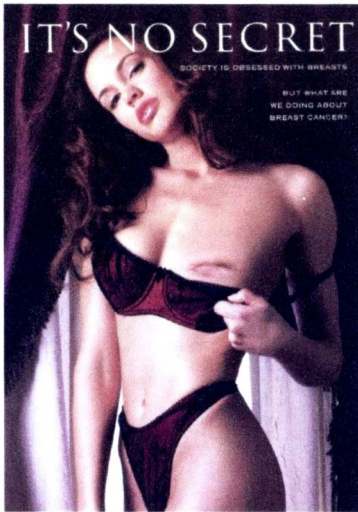
Please don't hesitate to contact me with any questions.

*** **

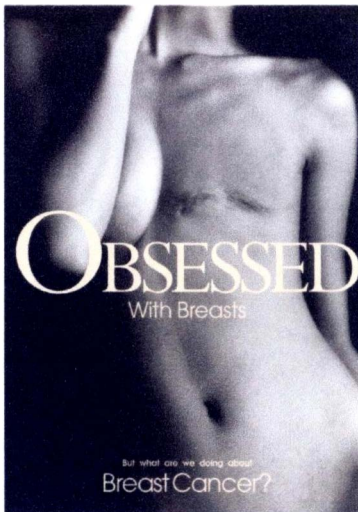
Marisa Walker, Senior Communications Coordinator
Breast Cancer Fund

Dated: February 28, 2008

Victoria's Secret



Obsessed with Breasts



APPENDIX D

Copyright Permission for Figure 6 from Benetton Group S.P.A.

Page 1 of 1

From info@benetton.it
Sent Wednesday, March 12, 2008 12:52 pm
To Cleothia Gill <cleothia.gill@wmich.edu>
Subject

Dear Ms. Gill,

thank you for your interest in our company.

Further to your kind request, I am pleased to inform you that we generally grant for free the rights for all the educational purposes, therefore as for the use of our advertising image "Breastfeeding" in your thesis, no problem on our side. I would like to invite you to download it from the Image Gallery section of our Press Site
http://press.benettongroup.com/ben_en/image_gallery/campaigns/?branch_id=1114.
The credit line could be: © Copyright 1989 Benetton Group S.p.A.- Photo: Oliviero Toscani.

It is expressly understood that the present authorisation is granted exclusively for the purposes mentioned above. It does not consent the use of our trademark or any institutional materials for commercial purposes and in different manners or forms if not with the previous written approval of our company.

Wishing you the best success in your studies, I send you my best regards

Greta Gamba
Public Relations Department
Benetton Group

<https://webmail.wmich.edu/frame.html?&rtfPossible=true&security=false&lang=en&chars...> 3/12/2008

Breastfeeding



APPENDIX E

Copyright Permission for Figure 9 from Sylvia Dunnivant

Page 1 of 1

From Sylvia Dunnivant <Sylvia.Dunnivant@airtran.com>
Sent Wednesday, March 5, 2008 5:00 pm
To Cleothia Gill <cleothia.gill@wmich.edu>
Subject RE: Permission to use Photo

To: Cleothia Gill

From: Sylvia Dunnivant
Black Pearl Publishing

I would like to extend you permission to use the photograph of Brandon Barbara Artis featured in Celebrating Life: African American Women Speak out about Breast Cancer, in your term paper for your course work at Western Michigan University.

I would love to get a copy of the paper when you finish. You may reach me at 214-404-6477.

-----Original Message-----

From: Cleothia Gill [cleothia.gill@wmich.edu]
Sent: Wednesday, March 05, 2008 3:28 PM
To: Sylvia Dunnivant
Subject: Permission to use Photo

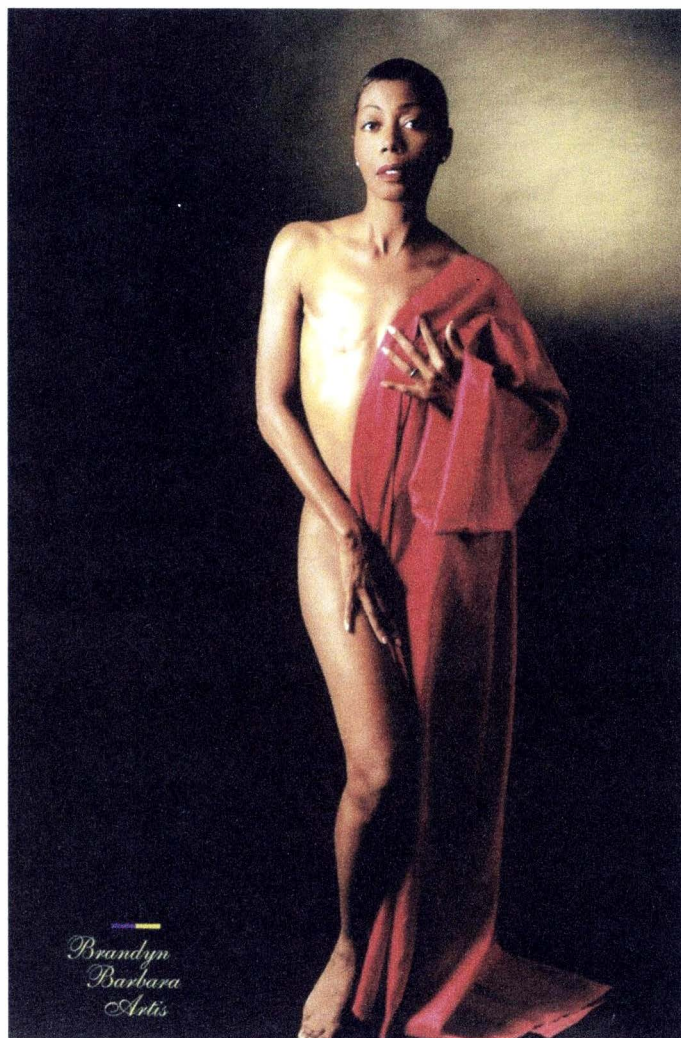
Dear Ms. Dunnivant,

Hello. My name is Cleothia Gill and I am a graduate student at Western Michigan University. I am working on my masters thesis, which deals with breast cancer in black women. I would like to use your photo of the 'lady in red' that shows what a black women's post-mastectomy body looks like. The image will be used as an introduction to the section that discusses how black women feel about their bodies after having a mastectomy. The source will receive full credit in the manuscript and will be solely for educational purposes and not for profit. If you agree, please send an email indicating that I have permission to use the photo, which will be printed out and included in the appendices section of the thesis. I am truly thankful for your time and consideration.

Sincerely,
Cleothia Gill
Western Michigan University
Graduate Student of Anthropology
269-544-1546
269-547-7087
cleothia.gill@wmich.edu

<https://webmail.wmich.edu/frame.html?&rtfPossible=true&security=false&lang=en&chars...> 3/12/2008

Photograph of Brandyn Barbara Artis.



APPENDIX F

Copyright Permission for Figure 10 from The Alan Mason Chesney Medical Archives The Johns Hopkins Medical Institution

Enclosure 1
Page 1 of 3

The Alan Mason Chesney Medical Archives
The Johns Hopkins Medical Institutions
5801 Smith Avenue, Suite 235, Baltimore, Maryland 21209 USA
Phone: 410-735-6800 • Fax: 410-735-6770 • E-mail: archives@jhmi.edu • Web: http://www.medicalarchives.jhmi.edu

Registration for Research and Request for Access (Please type or print)

Name of Patron Cleothia Gill
Position Graduate Student at Western Michigan University
Johns Hopkins Affiliation: SOM ___ SON ___ SOPH ___ JHH ___ Bayview ___ Homewood ___
Other ___
☒ Other Institutional Affiliation Western Michigan University
☐ Independent Researcher
Please indicate sponsoring party and/or name the individuals or entities with which information will be shared: N/A

If you are acting on behalf of another party or you intend to share this information with additional parties, they must submit a completed Registration Application, and have approval for access before this information can be shared.

Your Contact Information:
Street 1800 S. 11th St. Apt. 216
City, State, Mail Code, Country Kalamazoo, MI 49009 USA
Phone 269-544-1546 Cell Phone 269-544-1051
Fax N/A
E-mail Cleothia.gill@wmich.edu
Web Site _____

How will the information provided by Archives be used? (Check all that apply and specify use)
☐ Research for publication, broadcast, distribution, or exhibition _____

☐ Research for legal purposes _____
☒ Research for educational purposes Image will be used in master's thesis
☐ Other _____

Describe and state the purpose of your inquiry in detail: (Please type or print.)

I am requesting to use a photo which illustrates the Halsted radical mastectomy. It will be used in my master's thesis. The photo will be in the chapter that discusses the historical development of breast cancer treatment methods. This section also discusses how women feel about their bodies after getting a mastectomy. It is for educational purposes only. If possible, I would need the image before March 22, 2008.

Revised 11.04.05

The Alan Mason Chesney Medical Archives
The Johns Hopkins Medical Institutions
5801 Smith Avenue, Suite 235, Baltimore, Maryland 21209 USA
Phone: 410-735-6800 * Fax: 410-735-6770 * E-mail: archives@jhmi.edu * Web: <http://www.medicalarchives.jhmi.edu>

Agreement with Respect to Rights, Regulations, and Procedures

Name of Patron Cleothia Gill

Part 1: Rights to Privacy

I understand that the materials to which I have requested access may contain protected health information ("PHI") as defined under Privacy Regulations issued under the Health Insurance Portability and Accountability Act ("HIPAA Privacy Rule")¹. If I encounter PHI in my access to the materials, I agree to make no notes or other recordation of the PHI and agree not to re-disclose the PHI to any other party for any purpose without the express permission of the Alan Mason Chesney Medical Archives ("Archives").

I understand that the materials to which I have requested access may contain confidential information, which is otherwise protected under federal or state law or regulation or Johns Hopkins policies. I agree to make no notes or other recordation of confidential materials and agree not to re-disclose the confidential material to any other party for any purpose without the express permission of the Archives.

I understand that if I request copies of materials in the Archives, any PHI or confidential information will be redacted unless I have specific authorization to copy the materials or other specific exceptions apply.

Part 2: Rights to Intellectual Property

The Johns Hopkins University and The Johns Hopkins Hospital hold intellectual property rights to some, but not all, materials in the Archives. Some material to which you have requested access may still be protected by copyright and by the intellectual property laws of the United States² and the Berne Convention³. You are solely responsible for obtaining permission for use from the holder (the institution, the author, heirs, legatees, or literary executors) of the intellectual property. After release to you of the materials, The Johns Hopkins University and The Johns Hopkins Hospital assume no responsibility for any infringement of intellectual property laws or for any other improper or illegal use that may arise from your utilization of materials from the Archives.

¹ Protected Health Information means "individually identifiable health information, held or maintained by a covered entity [such as the Alan Mason Chesney Medical Archives] or its business associates acting for the covered entity, that is transmitted or maintained in any form or medium [. . .]. This includes identifiable demographic and other information relating to the past, present, or future physical or mental health or condition of an individual, or the provision or payment of health care to an individual that is created or received by a health care provider, health plan, employer, or health care clearinghouse." Reference: U.S. Department of Health and Human Services, National Institutes of Health, HIPAA Privacy Rule, Information for Researchers web site. Address: http://privacyruleandresearch.nih.gov/pr_07.asp

² The copyright law of the United States (Title 17, USC) governs the making of photocopies or other reproductions of copyrighted material. Under certain conditions specified in the law, archives and libraries are authorized to furnish a photocopy or reproduction. One of these specified conditions is that the photocopy or reproduction is not to be "used for any purpose other than private study, scholarship or research." If a user makes a request for, or later uses, a photocopy or reproduction for purposes in excess of "fair use," that user may be liable for copyright infringement. This institution reserves the right to refuse a copying order if, in its judgment, fulfillment of the order would involve violation of copyright law. For more information please refer to U.S. Copyright Office: <http://www.copyright.gov/tit17/>

³ The Berne Convention is an international copyright treaty signed by 96 countries. The United States became a member of the Berne Convention on March 1, 1989. The regulations of The Berne Convention are more far-reaching than US Copyright Law. For more information please refer to U.S. Copyright Office: <http://www.copyright.gov/bs/B100.html/>, <http://www.copyright.gov/tit17/circ92.pdf>

Revised 11.04.05

The Alan Mason Chesney Medical Archives
The Johns Hopkins Medical Institutions
5801 Smith Avenue, Suite 235, Baltimore, Maryland 21209 USA
Phone: 410-735-6800 • Fax: 410-735-6770 • E-mail: archives@jhmi.edu • Web: <http://www.medicalarchives.jhmi.edu>

Part 3: Rules and Regulations for use of the Alan Mason Chesney Archives

1. Research visits are by appointment only.
2. All patrons, on site or remote, must complete the **Registration for Research and Request for Access** application, and the **Agreement with Respect to Rights, Regulations, and Procedures**.
3. Patrons may take only paper, pencils, and laptop computers into the Reference Room.
4. Patrons visiting the archives must check all backpacks, briefcases, coats.
5. Patrons may not use cell phones, digital cameras, scanners, or voice dictation equipment in the Reference Room.
6. Patrons may not bring any food or beverages into the Reference Room.
7. All materials must be used in the Reference Room, and may not be removed for any reason.
8. Patrons may work with one box at a time. Please remove only one folder at a time from the box. After viewing the folder, replace it in the box, preserving the existing order, and initial the Call Slip indicating materials reviewed.
9. Patrons should exercise care in the handling of materials.
10. Reproductions will be made at the discretion of the reference staff. They will show you how to request items for reproductions. The cost of services is available from the reference staff or at: <http://www.medicalarchives.jhmi.edu/forms/FeeSchedules%20reproduction%201-1-04.pdf>.

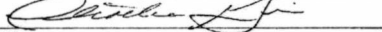
I understand that it is my obligation and responsibility to maintain the confidentiality of any PHI or confidential information that I may encounter. Improper re-disclosure of this information is a breach of confidentiality which could result in the loss of my access to the Archives. I also understand that improper re-disclosure of this information may constitute a violation of the Privacy Rule or other federal or state laws that could result in fines or other legal penalties.

I understand that it is my obligation and responsibility to obtain authorization for the use of information and materials from the owners/licensees of intellectual property and persons of interest with respect to private information that is protected by law. I hereby waive any claim against The Johns Hopkins University and The Johns Hopkins Hospital for any liability should my use of materials from the Archives violate any state or federal laws concerning intellectual property or privacy. I also agree to indemnify and hold harmless the University and the Hospital for any liability resulting from any disclosure by me or redisclosure to others of the materials from the Archives.

I understand that the Archives does not waive any proprietary rights to the materials being used, and that the Archives reserves the right to restrict access to any and all materials in its holdings.

I agree to abide by the Rules and Regulations of the Archives.

Signature



Date

2-29-08

(For each subsequent visit, please sign and date below.)

The Alan Mason Chesney Medical Archives
The Johns Hopkins Medical Institutions
5801 Smith Avenue, Suite 235, Baltimore, MD 21209, USA
Tel. 410.735.6800, Fax. 410.735.6770

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Name: Cleothia Gill Date: 3-14-08
Affiliation: Western Michigan University
Address: 1800 S. 1st St. Apt. 26
City/State/Zip: Kalamazoo, MI 49009
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Signature of Applicant

3-14-08
Date

Cleothia Gill
Please type or print name

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“Illustration of Halsted Radical Mastectomy”

