“Survivor Gene”: Navigating Survivorship and the Strong Black Woman among African-American Breast Cancer Survivors in Los Angeles, California

Anneliese Wilson

Anthropology Departmental Honors Thesis
University of Colorado at Boulder

March 29, 2016

Thesis Advisor
Donna Goldstein | Anthropology

Committee Members
Carla Jones | Anthropology
Bianca Williams | Ethnic Studies
Abstract

The objective of this study is to investigate how African-American women who have been diagnosed with breast cancer living in Los Angeles County perceive breast cancer survivorship in relation to their personal lives and the broader community of breast cancer survivors. Looking closer at their perspectives, a larger analysis and critique of the United States’ campaign for breast health promotion will be made. This project explores how the national breast cancer culture may unwittingly exclude the stories and needs of African-American survivors. While the breast cancer activism movement has changed the way Americans have responded to breast cancer survivors and more philanthropic actions have been taken to support breast cancer awareness, the fact remains that African-American women have the highest breast cancer mortality rate in the United States. For this study, 14 black female breast cancer survivors and 6 survivor supporters from the Southern California region were interviewed. Through an ethnographic lens and secondary quantitative data, this research highlights the importance of survivors’ voices as contributors to the larger discussion of how to ameliorate the disparities in breast health among African-American women.
Acknowledgements

I could not have completed this thesis without the help of so many important and intelligent people. First, I would like to extend my sincerest gratitude to the breast cancer survivors that took the time to speak with me about their stories. I have learned so much from your journeys and you have inspired me to continue being a proud black woman. I hope that this thesis does justice to your stories and highlights just how powerful your voices truly are. I also wish to thank the medical professionals and community organizers that provided me with an invaluable perspective on what it means to serve black women in our community. I greatly appreciate the hard work that you do.

To Dr. Goldstein, thank you for being my champion. Your words of wisdom have carried me since my freshman year and still continue to inspire me. I have learned how to be a better anthropologist, student, activist and all-around person from you. Muitíssimo obrigada.

To Dr. Jones and Dr. Williams, I could not have asked for better advisors and mentors throughout this process. Dr. Jones, it has been a pleasure to be in your class and to learn from you. I truly thank you for reading every page, providing great advice, and for the protein bar that day I did not eat. Dr. Williams, you have been such an amazing example of what it means to be an activist and an academic for your community. You have provided me with great advice that I will carry with me for the rest of my life. Thank you both for being a part of this project and truly supporting what I do.

Furthermore, I extend my sincerest gratitude to UROP for funding this research project. This would not have been possible without your generous and thoughtful support.

I also wish to thank my co-workers, former teachers, acquaintances, friends, and family for the support. Your words of encouragement have meant the world to me. To the Banana Rum Jam Crew (Hibaq, Nithya, and N’gadi), you do not know how much your love and sisterhood has meant to me.

Lastly, I want to acknowledge and dedicate this honors thesis to my mother, Marie. Being your daughter has been the greatest honor of my life. No milestone has been achieved without you standing right beside me. I want you to know that every sacrifice you have made has not gone unnoticed. I can only hope that my light shines as brightly as yours. I’ll love you forever. I’ll like you for always. As long as I’m living, my Mama you’ll be.
Contents

Abstract 2
Acknowledgments 3

1. Introduction: Breasts on the Brain 5
2. I Can Do Bad All by Myself 18
3. Sound of Silence 43
4. For Colored Girls/ When Screening Isn’t Enough 53
5. I’ve Been Through Something 63
6. Conclusion 82

References 86
Appendices 92
Introduction: “Breasts on the Brain”

Before this thesis was ever a concept, breast cancer has always been a part of my life. While some children carried imaginary friends throughout their childhood, breast cancer was my very real and very destructive friend. In a way, it was a “frenemy” before the term was ever popularized. I call breast cancer a friend and an enemy because of the impact it has had on my life. My family tree is laced with the stories of women battling the disease: a great grandmother dead, a great aunt who also succumbed to the disease, an aunt who died in her early thirties, and my mother surviving it three times.

Looking back, my standard childhood milestones were interwoven with memories of breast cancer. I watched many family members and loved ones be affected by breast cancer, many of whom were black women. Listening to these women and watching their stories evolve, I saw many conversations come up in the process. Who could drive them to treatment? Who would take care of their kids if they died? How do they get time off from work for treatment? Does anyone really understand what they are going through? Having been raised by a single mother who is a survivor, I saw many of the challenges she faced coordinating her care. I remember distinctly having to help her tuck in her surgical drains so she could look “normal” and have a smile on her face while she attended my school recital. At a young age, I saw this as my mother being Superwoman. I now realize this was a performance involving her having to mask pain. A year ago, I experienced a similar situation of having to mask pain when I faced my own personal reality with breast cancer.

I could hear the hesitation in the nurse’s voice. It let me know that she was not comfortable with the sentence she was about to utter: “Your results came back and you do test
positive for the BRCA 1 gene.” I could hear pity in her voice and I was annoyed more than I was comforted. She made it feel like a death sentence before I could even process what the results meant to me. I was not surprised but I had also hoped for a different result. Thinking back to my initial visit with my physician a month prior, I had felt ready to take the gene test at the time. After all, with an extensive family history of breast cancer and my mother being a gene carrier, it only seemed like the right thing to do.

On the day I decided to take the gene test, I was sent to the lab room following a brief check up with my doctor. The nurse fumbled with the package, reading all of the instructions as best as she could. She informed me that this was her first time ordering lab results for the BRCA gene test. Her eyes nervously scanning the form, she asked me a series of questions. “Do you have any family members with a history of breast cancer?” I went on to list the names of too many women. “What is your race or ethnicity?” I identify as African-American but I know I have European ancestry. I started with African-American but then fumbled to reiterate my European ancestry, hoping that would satisfy their need to link race to genetics. After the awkward questionnaire ended, the nurse began the process of drawing my blood. While grazing my forearm for a vein, she asked me, “What do you think you’ll do if you test positive?” Without hesitation, I gave my rehearsed response detailing my knowledge on the importance of getting a mammogram and breast MRI before the recommended age of 40 and then potentially taking preventative measures like undergoing a double mastectomy and other prophylactic measures once I was finished having children. I assured her I wasn’t going to get swept up by the Angelina Jolie frenzy. There was no way I would be getting preventative surgery at nineteen-years old.
She flippantly responded, “Well that’s what I would do. I wouldn’t even want to worry about that.” I assured her that no matter the outcome I felt prepared.

Being on the other end of the phone while the same nurse had just told me I have the BRCA 1 gene, I felt much different than prepared. I felt like the game show contestant that was asked the million-dollar question and didn’t know the answer. In that moment, I felt I had lost the genetic lottery. My usual defense quickly arrived and I confidently thanked her for telling me the news. I found a time to have a follow-up appointment with my doctor and then calmly hung up the phone. I believed that I was fine. The numbness I felt told me otherwise. Like any child seeking comfort, the first thing I thought to do was call my mother. My mother is very optimistic by nature, so I knew her words would be of some comfort. She was always candid about teaching me the importance of assessing my cancer risk, but she has always hoped for my life to not be touched by cancer. She always said with confidence, “I prayed to God when you were born that the threat of cancer would pass over you and that this disease would never touch you like it did me.” I now felt like I had failed her hopes.

My conversation with her was much like the five stages of grief. There was denial, anger, bargaining, depression, and ultimately acceptance. Elizabeth Kübler-Ross (2007) originally developed this model to describe the range of emotions felt by those who recently lost a person close to them, but later ascribed the stages to those dealing with other forms of loss or recent health diagnoses. At first, I could hear shock and disbelief in my mother’s voice. She was not registering the fact that her prayers were not answered this time. She told me soothing words about how well I was handling things. I was afraid to tell her that I was just as confused as she was. As she nervously rambled on more, she started to reflect on her own breast cancer journey.
“I just thought that with everything I went through you would be spared of all of this. I’m honestly really mad at God right now.” For a woman I have always known to have tremendous faith, I was surprised at her confession. I tried to appease her by saying that I would accept whatever life gave to me. She cooed:

See that’s where my baby is different than me—she never lets things get ahold of her. Mama always used to let things bother her and bottle it up inside. I think all that stress throughout my life is one of the reasons I’ve had so many cancers. If you keep being the same direct person you are, then I think you stand a chance of never getting cancer.

I tried to understand her reasoning, but I could not see how a life devoid of stress would protect me from breast cancer. The 87%, denoting my lifetime risk of breast cancer, kept taunting me from the page. How did I manage to get that high of a percentage? Even with that high number, would I even get breast cancer? If I do, what stage of my life would I be in? All I could picture is having my future children be forced to watch me suffer from some horrible disease and feel helpless. Many a time during my mother’s journey, I had wished that I could have done more to take away her pain. It was not just physical, but also emotional and spiritual. Even if it meant having the cancer go to my body for a moment, I had hoped for my mother to not know cancer so intimately for just one moment. Now I was thinking about my unborn kids going through this thought process. This realization hit me hard and so did my tears. My mother confirmed my feelings of helplessness and expressed her sadness over not being able to fix the situation. Through the exchange of tears, a moment of clarity came from the conversation. It was an acceptance that left both of us in a state of peace. With a smoothness and strength, she said to me, “God chose me as your mother for a reason. He used my journey with cancer to help guide you on your own path and give you the tools to navigate it. While I may have passed on the cancer gene to you, I also gave you the survivor gene.”
The Black Death

The topic of cancer has always been complicated. As Lochlann Jain (2013, 4) writes in *Malignant: How Cancer Becomes Us*, cancer is an interconnected relationship that draws on the economic, sentimental, medical, personal, ethical, institutional, and statistical. Breast cancer as it relates to African-American women illustrates this complexity even further. One of the biggest questions posed in the discussion of black women’s relationship to breast cancer is “Why are black women still dying from breast cancer?” The latest national research reports that black women now have a slightly higher delay-adjusted incidence rate of breast cancer compared to white women.¹ Until recently, black women had a lower incidence rate than white women. The increase in the breast cancer incidence rate only weakens the prognosis for black women, given the well-documented fact that black women have the highest breast cancer mortality rate of any racial or ethnic group.²

As this research suggests, black women are dying at the highest rate from breast cancer and this reality is only becoming worse. Many attribute this disparity to African-American women not getting mammograms, yet data suggests that black women over the age of forty-years-old have the highest rates of mammography screening of any racial or ethnic group (National Center for Health Statistics, 2015). So, the question that remains is this: If black women are getting screened, then why are they still more likely to die from breast cancer? Death may be feasible to quantify, but the effect it has on people’s personal lives speaks volumes.

---

¹ Howlader et al. (2015) report black women’s incidence rate at 135.2 per 100,000, while white women have an incidence rate of 135.0 per 100,000.
² Ibid. The report also notes that the breast cancer mortality rate for black women is 30.2 per 100,000, while white women have a mortality rate of 21.3 per 100,000.
Michel Foucault (1978) theorizes biopolitics to discuss the idea of population control by means of politicizing biomedicine. New technologies of power do not deal with society or the individual body—it deals with populations instead. By focusing on the control of populations, the individual’s perception of the body is lost. In the context of this research topic, a disconnect exists where statistics reveal the diligence of black women getting screened for breast cancer as well as their deaths from the disease in high numbers.

Since the feminist breast cancer movement emerged in the late 1980s, breast cancer has become included in the conversation of comprehensive women’s health care in the United States. One would think that this movement would provide significant change to health disparities affecting African-American women, but a large critique of this pink activism is that it excludes the needs of black women and other women of color. Certainly any death from breast cancer is tragic. However, when African-American women are continuously dying at high rates from the disease, then a separate and more urgent issue emerges.

Dissatisfied with this reality, I began to participate in breast health education within the Southern California community in my early teens. I spent weekends and even school nights sitting in meetings and attending community events, listening to people talk about “the next steps” in breast cancer. I quickly learned that black women were underrepresented at the table. Continued emphasis was put on increasing breast health awareness at community events that targeted affluent white women, despite their outcomes being best among all racial and ethnic groups. With more pink ribbons, longer walks, and more survivor stories from white women, it was harder to see black faces in a crowd of pink. The sisterhood of pink that has emerged with the national acceptance of breast cancer awareness is important but it has limitations. As more
diagnoses are made every day and more survivors are identified, it is crucial that the breast cancer narrative adds new chapters that include stories from all walks of life. Now that survivors are pushing to stand at the forefront of this movement and a new cultural shift is changing breast cancer culture, the question remains: Where do black women fit?

Literature Review

Before the twentieth century, very few public discussions about cancer occurred. During the 1940s, this conversation reached new heights. In *The Emperor of All Maladies: A Biography of Cancer*, Siddhartha Mukherjee (2011) tells the story of socialite Mary Lasker. Lasker became the champion for bringing cancer from behind closed doors to the labs of scientists and the steps of government. After the death of her mother, Mary believed that more medical research was necessary to understand chronic diseases like cancer. She famously stated in an interview, “I am opposed to heart attacks and cancer the way one is opposed to sin” (Mukherjee, 110). Using her networking skills, Lasker bridged the gap between fundraising and political lobbying at an unprecedented rate. She recognized that without support (especially financial support) from the government, scientists would not have many resources to conduct research. Within five short years, Lasker and her team were able to convince scientists and politicians to invest more in cancer research. She continued to advocate for cancer research until her death, leaving a legacy that enacted significant change in the United States. In many ways, Mary Lasker’s vigilance was the precursor to the War on Cancer that Nixon declared in 1971.

Since the passage of the National Cancer Act in 1971, over $105 billion has been invested in cancer research. The act expanded the privileges of the National Cancer Institute, which put the majority of its efforts into increasing biomedical research. Even with the scientific
breakthroughs that occurred because of this act, cancer survivors were often stigmatized for their illness. Susan Sontag (1978) was one of the first to openly criticize this treatment of survivors in her book *Illness as Metaphor*. To Sontag, the most honest way of understanding illness was to strip metaphors away from illness and to cease viewing cancer as a mythological evil brought upon those diagnosed. She notes how cancer as a metaphor is understood as a disease of space—cancer “spreads” and tumors are “excised”—instead of a disease of time. She also writes that the only thing worse than death is mutilation or amputation of the body. Through the analysis of cancer as a metaphor, Sontag is able to highlight the prevailing thought that cancer is the disease of the Other. She strengthens this argument by noting how cancer is perceived as “an invasion of “alien” or “mutant” cells, stronger than normal cells” (1978, 68). With cancer as the disease of the Other, stigmatization of those diagnosed became normal. Given that not many before her discussed illnesses such as cancer to this extent, Susan Sontag’s work was seminal in shifting the language of survivorship and the meaning of illness in society.

By the 1980s, a more comprehensive look at cancer was forming, including discussions of race, class, gender, and sexuality. Black feminist scholar Audre Lorde (1980) detailed her personal account of breast cancer through poetry, journal entries and analysis in *The Cancer Journals*. Lorde peels back the curtain on the historical silence and bureaucratic nature of the cancer industry through the lens of a black lesbian feminist writer. She examines how discourse about breast cancer in the 1970s focused on masking illness and beautifying women, despite the raw and horrific evidence of treatment such as scars, burns, and emotional trauma. Lorde saw the vanity driven, white heterosexual depiction of breast cancer as a failure to those who possessed different identities and wanted to comprehend the emotional and physical challenge of going
through breast cancer without a mask. She also questions the environmental factors that cause cancer, deviating from the normal focus on finding a cure. Since literature discussing black women’s relationship with breast cancer was relatively non-existent, Audre Lorde was a breath of fresh air to the cancer world.

Around this same time period, Dr. Fitzhugh Mullan (1985) wrote an article titled “Seasons of Survival: Reflections of a Physician with Cancer” in The New England Journal of Medicine, which was the first discussion about the conception of cancer survivorship. Mullan urged that perceptions of those diagnosed with cancer should move away from “victim” and instead have people seen as cancer survivors. Dr. Mullan’s work was integral to expanding the studies of survivorship in academic literature.

Over the last three decades, literature on cancer survivorship has increased significantly. However, research pertaining to African-American women’s connection to cancer, especially breast cancer, has been relatively limited. This has often been attributed to black women being medically and clinically underserved (Belin, Washington, and Greene 2006; Conway-Phillips and Millon-Underwood 2009). From the research conducted on African-American women and breast cancer, a multitude of disparities have been identified: diagnostic and treatment delays, lower socioeconomic status, advanced stage of disease at diagnosis, biological characteristics and treatment differences (Gullatte et al. 2010, Jemal et al. 2008, Kinney et al. 2002, Millon-Underwood 2006). In regards to screening rates, Lende and Lachiondo (2009) interviewed black breast cancer survivors and found that embodied understandings of the body, personal considerations of screening and treatment, and the quality of doctor-patient interactions played a significant role in women's decisions to screen for breast cancer. Moreover, Paskett et
al. (2008) reported significant disparities for health-related quality of life between African American breast cancer survivors and white survivors in regards to physical functioning, role limitations due to emotional health, and general health. However, these disparities were not found in other outcomes such as emotional wellbeing, sleeping patterns, and depression. Other scholars have noted the strong influence of socioeconomic status on quality of life, revealing that women of lower socioeconomic status perceive poorer quality of life (Ashing-Giwa & Ganz, 1997; Beder, 1995; Ell & Nishimoto, 1989). Many of these studies noted that African-American women with low socioeconomic status suffered especially.

Little to no anthropological studies of breast cancer among black women exist. One notable study conducted by Mathews (2000) consisted of interviewing both black and white breast cancer survivors in a self-help support group in rural eastern North Carolina. Mathews found that survivors rejected many of the assumptions underlying the dominant biomedical view of cancer “survivorship,” particularly its emphasis on the individual as decision maker and its gendered, military imagery. These assumptions led many of the support group members to shy away from formal support groups and look to create their own. I wish to build upon the research already conducted on African-American breast cancer survivors, providing an anthropological lens to the topic of survivorship and cancer activism.

**Objective**

The objective of this study is to analyze how African-American women who have been diagnosed with breast cancer living in Los Angeles County perceive breast cancer survivorship in relation to their personal lives and the broader community of breast cancer survivors. Rejecting the concept of a single breast cancer story, I sought out to interview fourteen black
female survivors about their breast cancer experience to establish a series of objectives: How do women diagnosed perceive the identity of breast cancer survivor? Are there unique challenges that they face as black women while going through breast cancer? Lastly, how has becoming a breast cancer survivor changed their vision of being a community organizer? As breast cancer awareness expands into new markets and gains more visibility, it is essential to understand where black women see themselves in this larger conversation.

This study is not being conducted in order to discredit the breast cancer awareness movement in the United States. It is instead a call to action to those heavily involved in breast cancer research and awareness to listen to African-American survivors and allow them to contribute their knowledge of the disease to the discourse so a more progressive shift can occur that changes the story of breast cancer within the black community from negative to positive. Following the message that Audre Lorde (1980) put forward in Cancer Journals, this thesis calls for breast cancer among black women to be seen as an urgent matter, instead of a chance for women to slowly die. This project attempts to aid in the investigation of how breast cancer has been able to affect the African-American community so deeply. I argue that the burden of breast cancer in the black community is not solely quantitative. From analyzing ethnographic data and using theories of black feminist thought, neoliberalism, and biological citizenship, this study seeks to highlight the health disparities that survivors ultimately believe affect the quality of their survivorship and influence their sense of community in breast cancer culture.

Methods

This research was accomplished through the ethnographic method of key informant interviews. A total of twenty people were participants in this research. I interviewed fourteen
African-American breast cancer survivors and six survivor supporters in the Southern California region. I define survivor supporters as medical professionals, grassroots organizers, public health employees, and religious leaders. The specific area of focus, Los Angeles, California, was chosen because of my pre-existing connections to the breast cancer community and because of the large disparities that exist in the region. Through my personal connections to various grass-roots breast cancer organizations, I was able to interview key informant breast cancer survivors and survivor supporters. In addition, I relied on snowball sampling and distributing emails to local breast cancer support groups targeted towards black women to obtain other key informants. The majority of the breast cancer survivors I interviewed were members of one support group in Los Angeles, whose name I will not disclose to ensure anonymity for interviewees.

The ethnographic content for this research was generated through a series of in-depth semi-structured interviews with African-American breast cancer survivors, community organizers, and medical personnel. Interviews were either conducted via telephone or in a location of the interviewees choosing such as their home, a restaurant, or a commercial shopping mall. IRB clearance was granted for this project, ensuring that participants were not subjected to any abuse during this process. In order to participate in this study, participants had to be an African-American woman between the ages of 30 and 95 who had been diagnosed and gone through treatment for breast cancer at some point in their life or a medical personnel, community organizer, or other professional involved in helping African-American women diagnosed with breast cancer. It should be noted that pseudonyms were provided for each participant and certain location identifiers were withheld to ensure anonymity and confidentiality.
Structure of Thesis

This first chapter details my rationale for conducting this research, a review of the existing literature and the objectives I plan to address in later chapters. Chapter Two examines how the image of the strong black woman is used as a coping mechanism among African-American breast cancer survivors to navigate their roles within the family, community, and health system. Theories of neoliberalism and biopower will also be explored to further support the argument that black women utilize strength as a coping mechanism to assert independence in a health system that requires people to take care of themselves. Chapter Three discusses how silence and silencing have played a significant role in inhibiting discussion about breast cancer in the African-American community. Chapter Four analyzes how the health education model of early detection is problematic because it fails to acknowledge the disparities in breast health treatment, which survivors believe significantly affect their survivor outcomes. This chapter also explores the actions survivors have taken to change the discussion around breast cancer in their communities. Chapter Five provides an in depth analysis of survivorship as understood by women diagnosed with breast cancer, in addition to examining how factors such as appearance and community action influence ideas of survivorship. Lastly, in Chapter Six, I share concluding thoughts on how this study of black women’s perceptions of breast cancer can lead to future research ideas as well as offer a new perspective on how to address the needs of not only African-American breast cancer survivors but other breast cancer survivors as well.
I Can Do Bad All by Myself: The Paradox of the Strong Black Woman in a Neoliberal Health System

Francis is a woman with a warm spirit. A naturally elegant woman, she sits across from me with her silver hair slicked back into a neat bun and her teal eyeliner matching her blouse that is a swirl of cerulean and sky blue. At fifty-four years old, her tawny face is impressively taught with faint laugh lines and freckles splayed across her cheeks, giving away that she has been here longer than she shows. Her voice is gentle in tone without a rush or lull to it. It is as if she speaks in song. When talking about her job as a healthcare executive, she speaks passionately. Her honey colored eyes flash with excitement and her hands dance around as she speaks of her over thirty-year career in public health. What began as a young girl’s dream of becoming a doctor turned into a career as a director of a cancer center, a professor, a community health advocate, and, most importantly, a mother.

Growing up, Francis was the seventh of eight children living in a small suburban community in California’s Inland Empire, a region of Southern California encompassing cities within Riverside and San Bernardino County. After high school, she went on to get her B.A. in Psychology and her M.P.H. in Health Services Management at a local university. Being the first to go to college in her family, she set out to make a lasting impact on the world. Unfortunately, her plans became complicated when her mother died in 1986. After the death of her mother two months shy of her graduation, at 24-years-old, she became the caretaker of the family to help lift the burden from her father. She juggled being a young professional and a young matriarch to her siblings and their kids. Francis felt this relationship was one-sided, often finding herself as the giver and not the receiver. She reflects, “[It was often] ‘Call Francis. What can she do for us?’
As opposed to, ‘What can we do for Francis to lighten her load?’” This situation is what Francis believes prompted her four cancers.

When talking about her cancer experience, she does not move her hands excitedly but instead has them calmly rested by her sides. Her usual expressive eyes hold a focused gaze, shifting between staring intently at me or off to the side at nothing in particular. It is clear that her cancer experience is something that she has thought about extensively.

Francis was first diagnosed with Stage I breast cancer at the age of thirty-one in 1993. She had originally found a lump in her right breast and gone to the doctor to get a mammogram. After the doctors performed a follow-up biopsy, her fears were confirmed that she in fact did have breast cancer. She shares:

   It was a shock, but I wasn't totally surprised. I was fearful because everybody I knew with cancer died. My grandmother, aunt, and my sister all died of breast cancer. So I thought, "Oh gosh, am I going to be here?"

   Her initial oncologist strongly advocated for her to have chemotherapy as part of her treatment, however Francis decided that she did not want chemo in large part because she watched her older sister, Paula, die from breast cancer. Francis tells me how she believed the harsh chemotherapy killed her sister faster than the disease itself. One of the most poignant moments of their relationship is that Francis made a promise to her sister that she would avoid certain treatments. When navigating her own care, the doctor still pushed for chemotherapy and went as far as claiming that she would be dead in a year if she did not take the chemo. She would later find out that research suggested the type of breast cancer she had would not benefit from chemotherapy. With the doctor still adamant, she went to another oncologist that agreed with her decisions. In Francis’ eyes, what made him more amicable is that he encouraged her to seek second and third opinions before deciding. Even with this encouragement, she resolved, “I knew
I was ready because I had the right person.” Seven days later, she had a lumpectomy on her right breast and had her lymph nodes removed.

In 1998, breast cancer threatened again. Initial feedback from the radiologist was that she had amassed radiation scar tissue and should check back in six months, but Francis felt otherwise. She expressed, “Something in my gut told me get a sample of that tissue.” After pushing again for a biopsy, she finally underwent a needle aspiration biopsy. Tests confirmed that she had a second primary Stage II breast cancer. What made this diagnosis different from the first is that she now had a two-year-old daughter, Nina. Since she now had a second cancer, doctors wanted to be more aggressive with treatment. However, Francis knew that as a single mother her treatment options were limited. I questioned how she came to this conclusion so quickly and she explained, “Once I had a child, then what kind of treatment I got was based on my availability to mother my child. I can't be weak and throwing up and can't get out of bed, I got a child to take care of.” Her doctors tried to convince her otherwise and felt she was being stubborn but she challenged them to look at her life: The majority of her siblings had mental disabilities that rendered them incapable of caregiving, the father of her child was nowhere to be seen, and many of her friends were single women who could not take time off of work to take care of a friend. This time, she elected to have the same treatment as her first breast cancer, undergoing a lumpectomy and radiation. After experiencing two cancers, Francis believed that her intuition played a significant role in her treatment. She reflected, “In my case, not taking the chemo and pushing the doctor to do the biopsy, I ended up saving my life and saving my quality of life.”
In 2004, she was diagnosed yet again with breast cancer. This time her journey involved a double mastectomy and breast reconstruction. She now relied on her eight-year-old daughter and a few friends to help her plan the next six weeks of recovery. Most of this help came in the form of groceries and pre-prepared meals. Despite this help, many unknowns remained. Who would drive Nina to school if she was not feeling too well some days? How could she negotiate enough time off from work when her boss was calling her to come back two weeks into medical leave? In these instances, Francis had to drive her daughter to school no matter how she felt and had to stand up to her boss to have the full six weeks of medical leave. With all of this hardship at the forefront of her mind, she jokingly expresses how even when you call on people to help, you end up taking care of problems on your own. After being released from the hospital and driven home by her friend Jamie, Jamie had to abruptly leave after learning that her sister suffered a serious miscarriage. Francis understood Jamie’s predicament and encouraged her to go home to her sister. Francis’ sister, Peggy, was present as well, but decided to leave once she saw that Francis made it home and appeared to not be in need. Jamie, a nurse, was horrified at the thought of Francis at home without help, but Francis encouraged her to still tend to her sister. Once settled in the house, Francis realized that she had not picked up her prescribed antibiotics. Without anyone nearby to take her to the pharmacy, she made the decision to drive with Nina to pick up her medication, forgoing strict orders from her doctor to be on bed rest. She muses that her risk of infection would have been too high without the antibiotics, therefore she took the risk to drive. “Sometimes rules have to be bent in order to be the good patient.”

The concept of the good patient has neoliberal features. David Harvey explains the theory in his book, *A Brief History of Neoliberalism* (2005). He defines neoliberalism as a political
economic theory that suggests humanity can progress by liberating individual entrepreneurial freedoms and skills within an institutional structure that supports private property rights, free market economies, and free trade (2). He explains how this theory connects more clearly to people by stating, “The founding figures of neoliberal thought took political ideals of human dignity and individual freedom as fundamental, as ‘the central values of civilization’” (5). In essence, neoliberal thought asserts that humanity cannot survive without people embracing individualism and all responsibility for wellbeing should fall back on the individual. This individualistic environment can be stressful for any person, but it can especially create conflict for black women navigating a space that requires them to be strong while experiencing day-to-day stress, as well as endure racialized, gendered, and class-based oppression. Ideas of freedom and individuality can sound appealing to many, particularly African-American women. However, as Harvey asserts, a neoliberal state depends on the freedoms it embodies “to reflect the interests of private property owners, businesses, multinational corporations, and financials capital” (7). These interests draw further away from social welfare services like health care, making the healthcare system an institution that relies on individualized freedom for economic success. When thinking about the expectations that exist for patients, monitoring one’s own health is at the top of the list.

In addition to theories of neoliberalism, the concept of the good patient can also be understood through the lens of biopower. Michel Foucault initially discussed biopower in the first volume of his three-part study, The History of Sexuality, Vol. 1 (1976). Foucault described biopower “to designate what brought life and its mechanisms into the realm of explicit calculations and made knowledge-power an agent of transformation of human life” (143).
According to Foucault, this concept of power over life exists because of the anatomo-clinical method which encourages “numerous and diverse techniques for achieving the subjugation of bodies and the control of population” (1976, 140). The public health system is modeled around the control of populations to keep illnesses under control. In this external space that he refers to as “the clinic,” an unequal power structure is evident through the relationship that doctors and patients possess. He argues that the doctor-patient relationship is non-reciprocal because in order for diagnosis to occur the doctor must abstract information in a way that “the patient is only an external fact; the medical reading must take him into account only to place him in parentheses” (8). The patient is understood as an individual for their body and not for their own understanding of illness. Further analyzing this power dynamic, Foucault also discusses the idea of the “speaking eye” which emphasizes the notion that the patient does not possess a voice in the matter of treatment, but rather is a body that doctors use to interpret both the words of the patient and what is visible on the body to be translated as medical fact and incorporated into case history. When thinking about the diagnosis stage, the doctor has the final say on diagnosis. In earlier cancer treatment methods, doctors had the final word on treatment as well, but now patients have more autonomy. This unbalanced relationship is essential to producing forms of knowledge and maintaining productivity within the health system.

To keep medicine productive, the relationship between doctor and patient also relies on discipline. Much of Foucault’s work identifies health care as a primary field in which the individual is subjected to discipline (1973, 1976, 1980). By disciplining those subjugated, it is easier for the institution to function and for knowledge to be produced. Part of this discipline comes in the form of self-regulation, an inherently neoliberal principle. Lisa Diedrich (2007)
argues that much of patienthood relies on obeying rules and self-discipline. She notes, “The ability to monitor oneself effectively indicates one’s desire for health, and one’s desire for health indicates one’s fitness for citizenship in a normalizing society” (Diedrich, 13). Part of the expectations for survivors includes a newfound desire to strengthen their health. Survivors living a healthy and active lifestyle “prove” that they wish to continue living cancer free. For the survivors with whom I spoke, part of their survivorship plan includes changing health behaviors in a way that encourages life longevity. These lifestyle changes ranged from taking yoga classes to walking every day to even enrolling in vegan cooking classes. With this lifestyle change, a conflict exists where the women recognize the usual habits of being the selfless strong black woman are unhealthy but they also wish to distance themselves from the threat of breast cancer by being a proactive patient. By becoming the good patient, they must avoid unhealthy habits such as stress from family responsibilities, but the sociocultural pressure to continue the caretaking role discourages this behavior.

This chapter will analyze how intersecting identities as the strong black woman and the “good patient” creates a unique experience for African-American women navigating a health care system built on neoliberal principles. I argue that some black women who are breast cancer survivors place importance on being strong in order to better internalize their identities as an important member in their community and as a medical patient. For many of these women, their cancer experience brought their roles as patients, mothers, wives, friends, and employees into question. Understanding the strong black woman as patient can potentially add insight as to why society expects a particular decorum from patients and the complexity of this expectation when incorporating intersections of race, class, and gender. I argue that for African-American breast
cancer survivors, the adoption of the strong black woman role by the survivors themselves is perceived as integral to survival in a health system that expects patients to take care of themselves.

*Constructing the Black Woman: From Mammy and Matriarch to Strong Black Woman*

In order to understand the pressures that African-American women face, it is imperative to examine the construction of the black female identity in the United States. Popular images of African-American women include Mammies, Jezebels, Sapphires, and Welfare Queens. Those with power have subjected black women to these inaccurate stereotypes and controlling images in order to oppress black women in what bell hooks calls a “white supremacist capitalist patriarchy” (1984). Patricia Hill Collins suggests that the purpose of these stereotypes is “to make racism, sexism, poverty and other forms of social injustice appear to be natural, normal, and inevitable parts of everyday life” (2000, 77). Black feminist scholar Barbara Christian argues that in the United States, “the enslaved African woman became the basis for the definition of our society’s Other” (1985, 160). By making African-American women the Other, it is easier to justify the gendered and racialized oppression they experience.

The images of the mammy and matriarch serve as the prototype for the now popular image of the strong black woman. The image of the mammy serves as an example of how the construction of African-American women as the Other allowed for exploitation of their bodies to be normalized. During the 19th century, the idea of the cult of true womanhood arose from the traditional family ideals that pervaded this time period. “Real” women were thought to possess ladylike characteristics such as piety, purity, submissiveness and domesticity. White women who were landowners and those of the emerging middle class were encouraged to aspire to these traits
African-American women were held to different standards because of the systemic racism that frequently exploited their bodies, forcing them to assimilate as the mammy in a sea of “real” women. The mammy is characterized as a faithful, obedient domestic servant (Collins 2000, 72). Examples of this are visible in popular culture, seen in film characters such as Mammy in Gone with the Wind and Aibileen Clark in The Help.

By loving, nurturing, and caring for her white children and “family” better than her own, mammy symbolizes the dominant group’s perception of the ideal black female relationship to elite white male power (Collins 2000). Mammy never complains about work and is happy to work hard if it means pleasing her family. Noted black feminist scholar bell hooks asserts that black women were depicted by whites as “an Amazon because they saw her ability to endure hardships no ‘lady’ was supposedly capable of enduring as a sign that she possessed an animalistic sub-human strength” (1981, 82). This myth of contentment and tenacity while experiencing labor exploitation found in the mammy image is the prototype of the characterized strength found in the strong black woman stereotype. Patricia Hill Collins maintains that while the mammy image becomes less prominent, the basic economic exploitation that assures African-American women either make less for the same work or work twice as hard for the same pay persists (2000). This is key in understanding how the strong black woman is portrayed to be selfless in all aspects of her life—even the workplace.

The image of the black matriarch, or Sapphire, plays an important role in the construction of the strong black woman as well. First seen with the character Sapphire on the 1940s and 1950s radio and television show Amos ‘n’ Andy, this character is depicted as hostile, nagging, and masculinized (West 2008). With Sapphire being harsh, loud, and uncouth, a twist is added to the
narrative of African-American women as invulnerable and tireless (Jones and Shorter-Gooden 2003). This image depicts African-American women as having the ability to control situations through an aggressive personality, with their aggressiveness serving as a shield and a point of criticism. The idea of impermeability and tenacity also prevails in the strong black woman image, suggesting that oppression and suffering are incapable of affecting black women. The matriarch figure differs from the mammy figure in that it focuses on the African-American mother figure in black households, as opposed to white households. In the now infamous government report, *The Negro Family: The Case for National Action*, the argument is made that the African-American matriarchy is representative of black women who failed to fulfill their traditional “womanly” duties at home, thereby contributing to social problems in the black community (Moynihan 1965). This report attempted to link cycles of poverty and oppression to black female single-headed households. As Patricia Hill Collins notes, by doing so, it helped to characterize black matriarchs as overly aggressive, unfeminine women who emasculated their lovers and husbands. Comparisons can be made with the image of the strong black woman, who is characterized as “not needing a man” to meet her goals.

The report attempts to further demonize black motherhood by claiming that slavery destroyed black families by creating gender role reversal (Moynihan, 1965). This idea—that the black matriarch does not know her place as a woman—serves to depict black women as unfeminine and too strong. This institutionalized stereotype further served to limit African-American women’s ability to display their self-assuredness. By not conforming to the cult of true womanhood, black women’s rebelliousness can be perceived as the source of black cultural deficiency (Collins 2000). This nexus of ideas puts black women in a tough position:
they are expected to possess mammy-like qualities in the workplace, but then are penalized as overbearing matriarchs for being strong leaders within their households.

Where mammy and matriarch meet is in the construction of the strong black woman. Many black feminist scholars use Zora Neale Hurston’s novel, *Their Eyes Were Watching God*, to illustrate the burden of the strong black woman. This sentiment is best summarized when Janie’s grandmother says to her, “De nigger woman is de mule uh de world so far as Ah can see. Ah been prayin’ fuh it tuh be different wid you” (1937, 29). The strong black woman narrative relies on the myth that black women can take it all from the world. Tamara Beauboeuf-Lafontant contends that the strong black woman image has common themes of selflessness, abuse, expectations of superhuman abilities and inequality (2005, 105). In addition, she recognizes how strong black women are recognized for their relationships to others rather than their connection to themselves. Thinking back to Barbara Christian’s argument that the subjugation of enslaved African women as the Other normalized their oppression, the strong black woman image mirrors this conflict by normalizing the so-called “good” qualities of the strong black woman, like selflessness and Superwoman strength, in a neoliberal society that reveres the individual. With a nation encouraging individualism, the strong black woman stands out.

The dichotomy between black women and white women is especially emphasized with this stereotype. Where white women are traditionally depicted as the perfect representation of “true” womanhood, black women are placed in comparison with white women in order to alienate black women’s femininity. Bell hooks poignantly describes this concept in her book, *Ain’t I a Woman*, when she discusses the fallacy of the strong black woman image.

The stereotypical image of the black woman as strong and powerful so dominates the consciousness of most Americans that even if a black woman is clearly conforming to sexist notions of femininity and passivity she may be characterized as tough,
domineering, and strong. Much of what has been perceived by whites as an Amazonic trait in black women has been merely stoical acceptance of situations we have been powerless to change (83).

This stoic acceptance of powerlessness is complex in that it highlights admirable qualities that black women possess but it also highlights the subjugation that black women experience at the hands of those in power. In order for some African-American women to cope with historical instances of oppression, they have chosen to reclaim the strong black woman image and use it as a tool for empowerment. In the next section, I will discuss how some women I spoke with found strength in the strong black woman image.

Reclaiming the Strong Black Woman as a Coping Mechanism

This idea of reclaiming and finding strength in the strong black woman image while going through breast cancer occurred often among the women I interviewed. Francis, who was introduced at the beginning of the chapter, reflected this idea when she stated, “I think overall when I look at the culmination of my life, being a black woman has been positive because we’re so resilient, we always rise above anything and have a smile on our face despite what we go through.” In her eyes, her complicated and often unfair journey represented a time to demonstrate her resilience and strength. Many of the women spoke of seeing no other option than to remain strong while going through breast cancer. I argue that for African-American breast cancer survivors, the adoption of the strong black woman role by the survivors themselves is a method of survival that ensures their safety in a health system that expects patients to take care of themselves. Black feminist scholars have long argued that the adoption of the strong black woman persona is a method of coping by African-American women looking to control feelings of powerlessness in a system that does not value their worth as human beings (hooks
Black feminist writer bell hooks notes this shift, focusing on how the feminist movement celebrated the strength of black women in a way that ignored the nuances of the black female identity.

Usually, when people talk about the “strength” of black women they are referring to the way in which they perceive black women coping with oppression. They ignore the reality that to be strong in the face of oppression is not the same as overcoming oppression, that endurance is not to be confused with transformation… The tendency to romanticize the black female experience that began in the feminist movement was reflected in the culture as a whole. The stereotypical image of the “strong” black woman was no longer seen as dehumanizing, it became the new badge of black female glory (1981, 6)

Thinking about historical power dynamics between whites and blacks, African-American women have experienced a silencing that is rooted in control by those in more powerful positions. For many black women, putting impossible pressure on themselves to be strong is easier than being vulnerable in front of their historical oppressors, i.e. white people (Williams 2008). This avoidance of vulnerability can also be found within the family structure, ensuring that their role as caretakers is never questioned or compromised. Black women may view being emotionally reserved as a form of protection, but it can be harmful to their overall health.

Existing literature about black female cancer survivors discusses coping mechanisms such as religion and avoiding negative people (Henderson et al. 2003, Reynolds et al. 2000, Bourjolly and Hirschman 2001, Ashing-Giwa et al. 2004). I will discuss these coping mechanisms later on, but the focus of this chapter is about how emotional suppression through embrace of the damaging strong black woman stereotype is present among African-American breast cancer survivors. The image of the strong black woman relies heavily on the notion of control—especially control of emotions. When women can suppress emotions to appear as if their issues are under control, then the perception of constant strength is perpetuated through a “myth of unshakability” (Jones and Shorter-Goode 2003). One doctor I spoke with confirmed
this message when she described how women of different races respond to diagnosis. Specifically, black women appeared to be the most unbothered. She shares:

Black women are a little bit more calm. There’s not so much of this why is this happening to me. Maybe it’s because we’re a bit more used to traumatic events—violence in the community or health disparities that have been around you since childhood. I think there is a better coping mechanism for bad news. Keeping up the appearance of having things under control often requires black women to adopt a "warrior mode" in which "individual and group responsibilities are distorted, personal and political boundaries are blurred, and personal and community priorities are unbalanced" (Scott 1991,11). This warrior mindset supports this relationship where the focus is on remaining strong for others and making group responsibilities personal. The language of “warrior mode” parallels the “cancer warrior” image presented in breast cancer rhetoric. The warrior mode seen in the strong black woman image relies on ideas that are militarized in nature: a warrior must think of not only protecting himself but also all of the people around him. Being a cancer warrior emphasizes the mindset of remaining strong to fight the possibility of dying from cancer. This clash between the two warrior identities creates contention for black women because the warrior language that originates in the strong black woman image expects black women to be selfless and strong, yet the cancer warrior image was constructed to shift the depiction of those diagnosed from victim to survivor. The dichotomy between survivor and victim is prevalent in cancer discourses. Women diagnosed with breast cancer do not want their names added to the list of victims, so they instead actively adopt a mindset that embraces the idea of the survivor. The impulse to not “lose one’s battle with cancer” traps those diagnosed with cancer in a binary: they are either the victors or the defeated, the survivors or the victims (Khalid 2008, 703). Through the struggle of navigating this binary, the idea of strength remains at the center. When adding an
intersectional lens that highlights African-American women’s navigation of this dichotomy, it becomes evident that black women embodying the strong black woman role while going through breast cancer face a set of challenges that make the experience more complicated.

**Being Strong and Going Through It**

For the breast cancer survivors I interviewed, three main challenges exist when reclaiming the strong black woman image. One of the first and most evident challenges is not being able to admit pain or fear of dying or recurrence. Roberta, a sixty-four-year-old survivor, spoke in great detail about this complicated relationship. I first met Roberta at a local mall in the Baldwin Hills area of Los Angeles. Dressed in workout clothes, she sat down with me while shoppers around us frantically looked for last minute holiday presents. She informed me that she regularly drives down from her home in the San Fernando Valley to Baldwin Hills for Zumba classes. During our time together, she scanned the crowd as if she were expecting someone. In some ways, this was not out of the ordinary because she encountered two people that she knew during the duration of the interview. It was quite evident that she was a very social woman. Whenever she wanted to convey something important, she would tap the arm of the chair and look straight at me with focused eyes and pursed lips. A languid speaker with a brassy voice, she spoke in great detail about her breast cancer journey. Before talking about her diagnosis, she said to me, “Girl, this is the worst thing you ever wanted to hear.”

After a routine mammogram in 2012, a lump was evident on her imaging so the doctor called Roberta back for additional imaging. Since a lump was still evident on the imaging, the doctor ordered a biopsy. Roberta recounts how no local anesthetic was provided while getting the biopsy, so she experienced significant pain while the doctor took multiple samples of the
Following this biopsy, she was diagnosed with ductal carcinoma in situ in her right breast. This moment was pivotal in her eyes. She reveals:

Well, I was devastated but I went back into my religious upbringing and I said, “God, I’m not special. I ain’t any more special than anyone else.” This is my first time ever having surgery. I was afraid, of course, and I had to get over the point that I’m not special. If I want to live, I got to do what I need to do.

In April of 2012, she underwent a lumpectomy, which entails the removal of the suspected lump as well as surrounding tissue that may house cancerous cells—commonly referred to as clearing the margins. After her lumpectomy, the doctor informed Roberta that the lump was indeed cancer free but there were cancerous cells surrounding it. Since the doctor did not clear the breast margins in the initial surgery, Roberta had to undergo an additional surgery. She was unhappy with how the doctor handled the situation, so she requested another surgeon within the health network for the second surgery. Since the new doctor she chose was located at another office, her treatment was considered out of network and she therefore had to wait almost three additional months for the second surgery. Roberta eventually had her second surgery in July to clear the margins as well as remove some lymph nodes. This surgery was successful but she mentions that she now suffers side effects from the cancer treatment. Two of the treatments she attributes this suffering to are the cancer drug Arimidex and the surgeries. Arimidex is an oral tablet prescribed to postmenopausal women with hormone receptor-positive early breast cancer. This drug was suggested to be a part of many participants’ treatment plans, given their age and diagnosis. With Arimidex, Roberta says she experiences a form of memory loss similar to what other survivors call “chemo brain.” In addition, she has also experienced mild hearing loss. After having both surgeries, Roberta developed a severe keloid that has caused significant pain and irritation. She explained how treating the keloid has been a journey of its own,
including visits to the dermatologist to receive cortisone shots and other remedies. All of these adverse experiences have left Roberta with a negative feeling towards her cancer experience. When asking her how other people responded to her survivorship, she gave an honest answer that highlighted the issue of the strong black woman image. She laments,

They feel that I’m strong. They think things don’t phase me, but I’ve had a lot of things phase me. They just haven’t asked me about it. They just assume certain things. They don’t know that every night when I go to bed I got to have a pillow under my breast. I toss and turn all night because I can’t get comfortable… There are some challenges that I still have but it’s nothing that I dwell on.

By openly sharing her vulnerability, Roberta reveals one of the major problems associated with the strong black woman image: the pain that African-American women experience, whether mental or physical, often goes unheard. When she shares how people fail to ask how she is feeling, I am reminded of how the strong black woman role relies on the silence of black women to perpetuate the normalcy of their emotional labor. This expectation to be the strong black female patient is problematic because it prevents women from being able to claim weakness. One community health advocate recognizes this difficulty and shares:

Some are strong because they have to be strong to maintain some type of normalcy in their lives. Our saying is, “You don't have to be the big girl right now.” Usually the women who have been strong really understand that. Some black women, they're scared that they're going to die and become stressed because their family is stressed about them dying.

This concept is confirmed by the realizations that survivors had of their cancer experience changing their outlook on life in a manner that shifted their attention from others to themselves. Opportunities exist for survivors like Roberta to be emotionally vulnerable in spaces such as support groups or professional counseling offices, but a barrier exists for some women because of the responsibilities they have which put their health needs in the background. With
few spaces to be vulnerable, they instead compartmentalize these emotions—choosing not to “dwell on it”.

These negative feelings towards cancer do not develop strictly in the survivor stage. Another survivor, Lydia, voiced this reality of fear when she was diagnosed. She recounts, “I cried every single day until my surgery. It was just scary because there’s this thing in there and it’s been in there for two months.” Even after treatment, Lydia still fears annual mammograms and the threat of cancer returning. For breast cancer survivors, the fear and pain associated with the disease is swept behind the larger image of the strong survivor. Just as bell hooks argued that coping with oppression is not the same as overcoming oppression, some women who are diagnosed with breast cancer and recognize being a breast cancer survivor do not accept the challenges that come with survivorship. Barbara Ehrenreich (2001) discusses in her Harper’s Magazine article, “Welcome to Cancerland,” how the larger narrative written in breast cancer culture pressures breast cancer survivors to fit the image of the happy breast cancer survivor. She writes, “In the breast cancer culture, cheerfulness is more or less mandatory, dissent a kind of treason” (50). While women going through breast cancer can possess positive feelings about their experience, the pressure for survivors to be happy and grateful about their cancer experience detracts from the reality that anger, pain, and suffering are just as integral to the survivor identity. For black women, this expectation to be strong and remain positive is especially problematic, considering the historical pressures to accept suffering and oppression.

Many of the women were vocal about the pain, mistreatment, or sadness they experienced while on the path to survivorship, but they were also quick to assert that there was no point in dwelling on the negative experiences. These women were adamant that being strong
is the key to survival. Additional studies have found that black women view being emotionally impermeable as critical to demonstrating strength within their families and communities (Black and Woods-Giscombé 2012). Carmen, an inflammatory breast cancer survivor who is both a religious leader and community cancer advocate, provided further explanation to blocking out her cancer experience when she stated:

When I went through my journey, the thought that I had to carry with me was “I have a bad cold and it will be over soon.” That’s why when I say I did not give cancer authority over my life that was my mentality.

It is evident that contrasting feelings are felt towards the strong black woman image adopted by those diagnosed with breast cancer. Another challenge that arises with accepting the strong black woman image is survivors feeling like they can only rely on themselves. This sentiment was evident through women’s admission of the lack of familial support. While multiple women spoke of their highly supportive networks, a significant number of women also spoke of their struggles to gain support from spouses, children, and other family members, especially during the treatment stage. This lack of support encouraged certain women to have even more negative feelings towards breast cancer. A surgical oncologist I spoke to explained how limited support often presents itself in the exam room. She shares:

Sometimes there’s kind of an attitude like I don’t have time for this. I have to take care of my mother and my daughter and her kid—that sandwich generation between the ages of 45 and 60. It happens with all women, but I see it more with black women. It can sometimes make them delay treatment.

With limited to no familial support, some women feel confined to fewer options for treatment. Francis spoke of this earlier in the chapter when she asserted that being a single mother affected her treatment plan. In her case, she felt that she only had herself to rely on during her long cancer journey. Speaking with her more in depth, I gained further insight as to
how the strong black woman coping mechanism can be exhausting physically and mentally. When I asked her how she viewed her breast cancer experience in hindsight, she became very emotional when talking about the aspect of support, stating:

I realize that my journey wouldn't have been as hard if I had someone to help me. My daughter was my greatest source of help, but I had to balance and make sure I didn't take away her childhood and her life. So sometimes I'd toughen myself up to say, "Oh, I'm fine. I can do it," so that she didn't miss out on fun things.

Listening to Francis’ story, parallels can be made to a study conducted on African-American parents’ experiences navigating breast cancer while raising children. The study reported that seven common themes emerged from the data collected: parents had an increased desire to protect their children, they were concerned about how their children would cope, parents focused on transparency with children, they relied on their children for support, they suppressed their emotional responses to breast cancer to benefit the children, they used the illness as a teaching moment for children, and lastly they relied on others for parenting support (Davey et al., 2012). Francis’ testimony highlights themes discussed in the study such as increased desire to protect her child, concern for her child’s coping abilities, emotional suppression, and reliance on her child for support. Through these actions, it is evident that African-American women utilize the strong black woman image as a survival mechanism to ensure their strength and stability as not only a patient, but also as a vital member of the family. I cannot fault women for wanting to feel like a valuable member in their family. The desire of the women diagnosed to find confidence in strength reveals commendable traits that exist within the strong black woman image. However, this relationship becomes complex when the desire to be strong adversely affects their wellbeing as well as others.
Two of the survivors’ stories highlight the complex relationship that can exist between survivors and their family. For Phyllis and Carolyn, this complexity is reflected through their relationships with their daughters. Phyllis, a thirty-year survivor, casually mentioned her daughter’s absence while going through treatment. After being diagnosed with Stage II breast cancer, Phyllis had a lumpectomy and received chemotherapy and radiation treatment. She recounts that while going through treatment, her fifteen-year-old daughter was not frequently present. When I inquired why she believed her daughter was absent, she thought carefully about her answer. After being silent on the phone for a moment, she stated:

I think it might have been a combination of her age and maybe we just didn’t talk to her that much about it. I think I didn’t know the potential seriousness of what I had been diagnosed with. I think that she just couldn’t handle being at the hospital.”

Phyllis went on to discuss how remaining strong while moving from treatment to treatment was the strategy that brought her the most sense of control while going through breast cancer. Her understanding of her daughter’s absence draws parallels to the results found in the study on parenting referenced earlier. For Phyllis, not going into extensive detail about her treatment plan with her daughter reveals how she was willing to protect her daughter as well as preserve her own strength by remaining focused.

Another survivor, Carolyn, comments on her daughter’s absence from her breast cancer experience. For Carolyn’s daughter, she blatantly avoided her mother’s journey with breast cancer by constantly working and traveling—an excuse that Carolyn feels reflects her daughter’s “weak” personality. Patricia Hill Collins notes how black mothers’ influential role in socializing their daughters to be strong, independent and self reliant creates a relationship fraught with emotional intensity that can only come from an environment where an oppressed woman is
attempting to teach her daughter how to navigate freedom and independence in a society that constantly attempts to control her (Collins 2000). The sacrifices that many black mothers make to raise their daughters to be independent come with the expectation that their daughters will become more successful than them. Strength is at the center of this socialization, so daughters who cave to the pressures of constantly having to be strong can be perceived as weak. From my own experience, I understand the difficulty as a young girl of coping with a parent’s illness while also being expected to be a source of support. For children of cancer survivors, it is important to have other family members around who can be a source of help as well. When asking Carolyn if she had any other supporters, she acknowledged that her son and ex-husband provided support to the best of their ability but their help was limited. Overall, she felt she was not supported by family and was conflicted about her family’s absence. She mused:

    My daughter’s always been one to run away from things. Some people just stronger than others. Your family supposed to come together but nah not mine. I would see other people with everyone and I was alone. They didn’t know how to be there for me.

    Both women’s stories are helpful in understanding how family support is a significant determinant of whether or not women diagnosed with breast cancer feel supported. Family support and other factors help these women gauge how strong they have to be while facing adversity. If the system does not readily help these women and their families do not help, then they are left to take care of themselves. This self-reliance touches on some of the problematic characteristics found in the strong black woman image, as well as the neoliberal ideas of patienthood. It is evident that the self-discipline required to be the good patient in a neoliberal health system does not work with every patient’s life when black women are stressing the importance of family support to cope with diagnosis and some do not receive the support. For
African-American women, the pressure to remain strong is not exclusive to post-diagnosis health awareness. It also relates to their broader understandings of illness and health.

The last challenge associated with the strong black woman image is the belief among breast cancer survivors that stress in their lives caused their illness. Susan Sontag writes how mythologizing cancer allows for beliefs such as emotional suppression as the cause of cancer to be a dominant idea of the time period (1978: 22). Her work, along with black feminist scholar Audre Lorde, was critical in analyzing the non-biomedical perception of cancer. Sontag elaborates further on in the book about the changing meaning of cancer, providing the example of doctors in the Victorian era believing that cancer patients got cancer because of “overcrowded lives, burdened with work and family obligations, and bereavements (51-52). While seemingly antiquated, this perception of cancer risk was common among the black women I interviewed. Many women heavily contemplated how stress has had an impact on their health:

Francis: Chronic stress is just that day-to-day grind that eats at you and is actually very bad for your health. Many researchers suspect that it’s the thing that causes hypertension, diabetes, and perhaps cancers in many people of color. It’s that constant “I never can get away from this”—the grocery store, the car wash, my job. If you’re expecting to change today or next week, then it will cause you cancer.

Roberta: The other thing we didn’t talk about is stress. One of my good friends that lives in the Bay Area had triple negative breast cancer. She had to battle for two years and she told me that everybody’s situation is different. She said, “I go to three different support groups. I have one where there are working women without insurance and young children they have to take care of. That’s a different reality. Another reality is the wealthy women who can do anything and get anything. Then there’s us in the middle—the so called middle class.” It’s interesting how our different experiences are based not on diagnosis but economics. This other woman I work with tried to bother me about something like we were in high school and I explained to her, “Look, I try my best to keep my stress level down because I know that stress also can bring on breast cancer.” In fact, some of the things that I read talked about the fact that there’s something you’re grappling with that causes you to have breast cancer. You have to stay as stress free as you can.

Lisa: I tend now to overlook some stuff, take the high road. Everything is not worth getting upset about. I think getting upset gives you stress and stress gives you disease.
These thoughts build on Sontag’s argument that cancer thought to be caused by stress ultimately aims to blame those diagnosed. Sontag touches upon this sentiment when she argues:

> Illness is interpreted as, basically, a psychological event, and people are encouraged to believe that they get sick because they (unconsciously) want to, and that they can cure themselves by the mobilization of will; that they can choose not to die of the disease. (57)

> While stress is viewed as no good for the body, it is hard to eliminate if women speak about a lack of familial support and other stressors. It is beneficial for black women to recognize that stress has an effect on their lives, but it can become problematic when they feel it is the reason for their cancer. Sontag asserts this point, stating, “The view of cancer as a disease of the failure of expressiveness condemns the cancer patient: expresses pity but also conveys contempt” (48). Carolyn explained this balance between pity and contempt when she described how people were devastated to learn about her diagnosis but also attempted to discourage her from taking care of her ill father and ex-husband because they felt it would cause another cancer. She muses, “They said to stop doing that and I told them, “You don’t know that. You’re not God.” It is harmful language to say that a woman’s actions are the cause of her breast cancer diagnosis. This additional task of gauging stress levels encourages women to conform to the self-discipline that Foucault argues is essential to biomedical institutions. Black women’s belief that stress causes their cancers is an extension of the problematic idea that individuals are at fault for their cancer and therefore should conform to all expectation requested of “good patients”.

African-American breast cancer survivors exist as both the strong black woman and the good patient in a health system built on neoliberal principles. The core of these identities shares a common characteristic: black women are expected to be independent and self-reliant. From
listening to the survivors interviewed, this expectation can become emotionally and physically taxing. Multiple challenges were identified from speaking to survivors. First, women have difficulty admitting their pain and fear of dying or recurrence. Second, women believe that they can only rely on themselves for support. Lastly, women diagnosed surmise that their cancer is caused by stress. Each of these challenges illustrates the unique difficulty that black women experience in balancing the identities of the strong black woman and the good patient. As health systems move to more patient-centered care models, it is important that they adopt an intersectional lens to accommodate the cultural influences that impact patients’ health behaviors.
Sound of Silence

“If you are silent about your pain, they’ll kill you and say you enjoyed it.”—Zora Neale Hurston

It is a sobering fact that African-American women are dying from breast cancer at the highest rate of any racial or ethnic group in the United States. The New York Times (2015) recently covered a startling new report from the American Cancer Study in an article titled “A Grim Breast Cancer Milestone for Black Women.” The 2012 study reports that, for the first time, black women’s incidence rate for breast cancer is equal to that of white women’s incidence rate. With this increasing incidence rate, data suggests that the mortality rate will only increase for African-American women. The Times article also reported an analysis published in Cancer Epidemiology, which looked at breast cancer mortality trends across 41 of the United States’ largest cities. The study found that black women diagnosed with breast cancer in Los Angeles are approximately 70 percent more likely to die from the disease than white women. This is a stark contrast to the national average of 42 percent. Compared to other major cities, Los Angeles has the second highest incidence of racial disparities between black and white women.

Knowing this troubling reality, I cannot help but question how black women’s health has reached this point. From talking to survivors and survivor supporters, silence surrounding breast cancer in the community was recognized as one of the major influences on the relationship that African-American women have to breast cancer. Many spoke of the silence that occurs within families and within the larger community, however I argue that a silencing from the medical community exists as well. In this chapter, I will discuss how silence takes many forms, thereby strengthening the health disparities for African-American women diagnosed with breast cancer.
The first type of silence that occurs among African-Americans is silence within families. Historically, African-Americans have placed great importance on kinship structures given the separation of families that occurred during slavery. Close family relationships allow stories to be shared, especially from elders in the family. For many of the older survivors, sharing health knowledge in the family was a taboo and any health information disclosed was meant to stay within the family. One survivor, Debra, explained these circumstances best when she retold a conversation she had with her sister. She recounts:

With black families, and especially on my mother’s side, everything’s a secret. Everything is a secret. My sister who’s only two years older than me was trying to tell me, “You don’t be tellin’ people you had that.”

I said, “Had what?”

She said, “You know.”

I said, “What difference does it make? You oughta be glad I’m so open about it because you have a daughter and both of you are women. So it’s not a secret and it’s not something I did that caused this to happen. You oughta be glad I’m sharing information about it with you to make you more vigilant.”

This reluctance to share health status can arguably be attributed to fear: fear of death, fear of exploitation, and fear of stigmatization by the community. In addition, black breast cancer survivors’ inability to share their health experiences with others without fear of stigmatization arguably functions as a form of emotional suppression that encourages black women to cope through the strong black woman role. Admitting that they are sick means also having to admit they are very vulnerable. As mentioned previously, some survivors see maintaining emotional impermeability as critical to appearing strong to family members. Considering the mistreatment of African-American women in the medical system and its effects on the community, it is understandable why people are reluctant to disclose health information. Through the story of an
aunt that died from breast cancer, another survivor, Jill, spoke in detail about how this silence is passed to future generations.

You didn’t talk about those things in public because it wasn’t talked about in the home. People called cancer “consumption” back then. I had an aunt who had breast cancer and I’m going around with my grandmother to see her. One of my aunties said, “Oh she’s breeding these tumors. She just grows these tumors.” I was confused but I wasn’t going to look it up because I’m a young kid. I’m like sixteen or seventeen. I’m interested in what she’s saying but I’m not interested enough to look it up. I knew people who had cancer and when they opened you up and saw they couldn’t do anything, they wouldn’t close you. They knew that was it.

This example of generational silence parallels a phrase that another survivor stated: “If parents don’t stress it, then children don’t check it.” By failing to create an open dialogue about health at home, women diagnosed with breast cancer may feel apprehension towards divulging their diagnosis to family. One doctor shared with me that occasionally patients request that she does not mention their diagnosis to family members present during the appointment. Women choosing not to share can be for a number of reasons. A primary reason survivors may not share is because of their desire to maintain privacy while they navigate the emotional impact of being diagnosed with breast cancer. One survivor, Dot, felt this when she was first diagnosed, choosing not to share her diagnosis widely because the uncertainty she felt towards her survival mirrored similar feelings of the first trimester of pregnancy. She often asked herself, “Would everything turn out to be fine? Would there be any unexpected complications?” Upon asking Dot why she was so secretive about her diagnosis, she shared:

I think part of it is my upbringing. It’s kind of like what happens in Vegas stays in Vegas. In my family, you don’t tell everything that goes on in the family. Also I wanted to make sure that the people who I told, people who I really knew, were the closest to me and cared about me. I have friends and cousins on Facebook, but I didn’t want to become the Facebook talker. Let me deal with this first because you never know what’ll happen.
All things considered, knowledge of family history is very important to assessing breast cancer risk. From understanding a patient’s family history, health care providers can offer treatments suited to their specific needs. Lack of knowledge about the disease because of silence within families can also be detrimental because family members may perpetuate myths generationally that do a disservice instead of being informative. Josephine, a community health educator and organizer, spoke about how a large portion of her community work is dispelling myths. When asking her if there are any challenges helping black women with their breast cancer journey, she states:

Yes, one of them is cultural--where a lot of the myths need to debunked. Unfortunately, African Americans historically were not treated fairly in different types of research so usually diagnosis is shared only in the family or not spoken at all. I think it's just a journey of unlearning what they knew and what they believed. I think it takes time with consistency and building relationships of people valuing and trusting you with the information.

Diverging from families, community silence also complicates the relationship black women have with breast cancer. It is thought that much of the silence around breast cancer that exists in the black community is due to fear. Generalized fear can be related to a fear of dying. Since cancer still holds the stigma of equating to death, many are apprehensive to discuss cancer at great lengths. Fear of death is arguably a newer concept in society. Philippe Ariès (1974) discusses how Western attitudes towards death have seen four major eras since the Middle Ages: Tamed Death, One’s Own Death, Thy Death and Forbidden Death. Ariès argues that the Forbidden Death era is represented in our current time period as secrecy about illness, the silencing of discussions about death and the belief that science should not fail the sick individual. He asserts:

One must avoid--no longer for the sake of the dying person, but for society’s sake, for the sake of those close to the dying person--the disturbance and the overly strong and
unbearable emotion caused by the ugliness of dying and by the very presence of death in the midst of a happy life, for it is henceforth given that life is always happy or should always seem to be so.

As the survivors previously mentioned, open discussions about death and illness were frowned upon in their families. Some survivors also made a point to discourage friends and family from discussing death around them. They felt that by not discussing the negative aspects of breast cancer treatment, they were avoiding the possibility of their diagnosis becoming worse. By shrouding illness in secrecy, it allows people to disassociate from the reality that death is imminent for all living beings. Considering the violent historical trauma that African-Americans have experienced as it relates to illness, the desire to focus on the positive aspects of life can be understood. Comprehending the Forbidden Death era helps to acknowledge how breast cancer has come to be viewed as definitively life-threatening in the black community partly due to the limited discussion about the disease among African-Americans. Research has identified that much of the fear about breast cancer is related to lack of knowledge about breast cancer and breast cancer screening, as well as fear of finding a cancerous lump (Long, 1993; Phillips & Wilbur, 1995). With people continuing to be ill informed about the disease, poor education about breast cancer continues to influence patients’ health behaviors and encourages continued fear of the disease. For survivors that are active in community outreach, many have noted disinterest from community members about learning about breast cancer. As one survivor and community advocate noted, “People would rather remain dumb and blind about the disease. It’s very much the what they don’t know won’t hurt them.” This synergistic relationship between fear and lack of information creates a vicious cycle that poorly affects the health outcomes of African-American women in the community.
Lastly, another form of silence exists through the silencing tactics historically used by the health system to devalue African-Americans. Black women have had a tumultuous relationship with the medical community for centuries. Much of this tension comes from the history of medical exploitation at the hands of health institutions. Harriet Washington (2006) writes about this in her book *Medical Apartheid*. Washington notes how experimentation has had a large effect on African-Americans. She states, “The experimental suffering of black Americans has taken many forms: fear, profound deception, psychological trauma, pain, injection with deadly agents, disfigurement, crippling, chronic illness, undignified display, intractable pain, stolen fertility, and death” (8). Unfortunately, this exploitation has occurred since the days of slavery.

During the height of slavery in the American South, physicians were dependent on slaves for economic security and “clinical material” that would help them advance their medical research and gain notoriety (26). One of the most explicit examples of this exploitation is seen with the “Father of Modern Gynecology,” Dr. J. Marion Sims. Sims developed many surgical and diagnostic techniques that advanced the field of gynecology more than ever before. However, much of his discovery was built upon the use of enslaved black women who had surgery and experiments conducted on them without any anesthesia. Many revere Sims for his medical advancements, but others criticize him for his abuse of black women. Black women continue to experience exploitation of their reproductive organs in modern times through issues of forced sterilization and lack of reproductive rights, especially in low-income neighborhoods and prisons. At the heart of this issue is black women not having informed consent. Lack of informed consent was brought up by some participants, but was most evident with Carolyn. After having her first mammogram, doctors found what they believed were cancerous cells in her breasts. She
later went in for a surgical biopsy and, upon waking up, found that she had been given a mastectomy. Doctors had diagnosed Carolyn with Stage III breast cancer. Carolyn felt deeply bothered by this action because she felt she did not get a choice in her treatment options. With this continued mistreatment at the hands of the medical system, Sims’ exploitation of black women’s bodies does not appear to be an isolated incidence.

Another well-known example of black women being exploited by the medical system is the story of Henrietta Lacks. Rebecca Skloot (2010) chronicles the story of Lacks in her book, The Immortal Life of Henrietta Lacks. Henrietta Lacks was a poor black tobacco farmer from Virginia whose cells were taken without her consent in 1951 during a routine treatment for her advanced staged cervical cancer. Her cells were then turned into the first immortal cell line by Dr. George Otto Gey. These cells have been instrumental in advancing medical technologies such as the polio vaccine, cloning, gene mapping, in vitro fertilization, and much more. Lack’s cells continue to live on and have generated a billion dollar industry, yet her descendants still live in poverty. Her story is yet another reminder of the exploitation that black women have experienced at the hands of the medical system. Medical exploitation is especially a reality for African-Americans in low-income areas. This mistreatment has created a serious distrust among African-Americans.

A lot of the social acceptance of black bodies being exploited stems from the days of slavery. Orlando Patterson (1982) writes about the theory of social death as it relates to enslaved people. He discusses how in almost all slaveholding societies, the initial response was to define a slave as a socially dead person (38). With this designation as socially dead, masters introduced their slaves into society as the permanent enemy, a variation of the Other. Since those enslaved were
viewed as a stranger and socially dead, what happened to them was of no concern to the dominant society. This is where horrors like medical experimentation became justified. While African-Americans are no longer enslaved, remnants of social death still exist in the medical system, which has historically silenced the voices of black women in the medical system. This reality ties into Foucault’s idea of the speaking eye and how patients’ bodies are used for the doctor’s interpretation of their illness.

Ideas of social death can also be related to the experiences of African-American women diagnosed with breast cancer. Some women spoke of the alienation that comes with being diagnosed with breast cancer. When people found out that they had breast cancer, people were reluctant to associate with them or questioned their ability to perform tasks, such as being a caretaker in the family or an active member in the church. Illness has the ability to create new forms of discrimination, which allows for people to be treated as socially dead. If people do not possess the same social capital after illness or loved ones are unable to take care of them, then many are viewed as inept and cast to the shadows of society. A stark example of this social death unfolds in João Biehl’s *Vita: Life in a Zone of Social Abandonment* (2005). The book follows the story of a Brazilian woman named Catarina who lives in an asylum called Vita where the unwanted, mentally disabled, terminally ill, and homeless are left to die. Biehl’s account of this center illustrates how social death can marginalize people perceived as abnormal to the point of being forgotten. While these women have not reached this severe point of social death, their struggles to be perceived as healthy and proactive members of society illustrates the battle they face between defining themselves while also handling people’s perceptions of their body and ability.
Revisiting Foucault’s theory of knowledge production in the clinic, much of the medical canon has relied on revering biomedical understandings of the body and shaming the knowledge produced by African-Americans. As Harriet Washington argues, oral histories of medical abuse told by African-Americans are often dismissed as mythological and the bias against black medical narratives is related to the Western literary bias against oral history (9). For African-Americans, oral tradition has played a significant role in how health information is passed down through generations. Nearly every survivor I spoke to mentioned that they learned of family health history from conversations with relatives. The dissonance between Western medical knowledge and African-American medical knowledge persists, but there are some efforts to merge the two forms of thought. However, the differences that still exist have left some survivors feeling like their doctors do not value their knowledge. As Carolyn asserts, “They don’t expect you to be smart. They don’t think I’m coming in with all the knowledge I have.” A doctor confirmed Carolyn’s sentiment when she stated:

The trust issue is real. Women do not trust the system. I can’t blame them because sometimes people are judged based on their grammar. Sometimes they’re judged based on their appearance, so I do put my colleagues at some blame for that.

The silencing of black breast cancer survivors is rooted in historical incidences of systemic racism in the medical community. Survivors have been vocal in addressing the mistreatment and discrimination they experience from the medical community. With increased roles in cancer activism, many survivors are ardently resisting the familiarity of remaining silent. As researchers work harder to eliminate health disparities among African-American breast cancer survivors, focus should also be placed on reforming the medical system’s process of knowledge production so histories of medical abuse can be acknowledged and rectified.
Silence within the black community has an effect on how breast cancer is experienced by African-American women. It is generational, communal, and institutional. As evident through the testimonies of various survivors, silence influences what safe spaces exist for women to share their experiences with breast cancer. Furthermore, silence can be destructive by alienating black women diagnosed and forcing them to adopt the strong black woman role as a coping mechanism. Through survivors’ community health activism, it is apparent that a shift is occurring regarding the dialogue surrounding breast cancer. For these women, going through breast cancer taught them about how health outcomes can positively change when the community begins to advocate more vocally for their needs and the biomedical community begins to recognize their role in supporting the communities they serve.
“Black women get mammograms at the same rate—if not better than white women. So is that not caring about our health? We care about our health but if we get diagnosed we may not have the resources to do anything about it. Yes, some black women may be obese, but we don’t have the money to eat the Whole Foods kind of diet. We’re being blamed. We’re dying more from breast cancer, but instead of trying to figure out what’s wrong in the chain, they start blaming us.”

—Francis

For Colored Girls/ When Early Detection Isn’t Enough

The first step towards survivorship is diagnosis. Diagnosis mainly occurs through mammography screening. The standard recommendation for women over 40 years old in the United States is to get a mammogram screening every year. Depending on risk, some women may be encouraged to get screening earlier and more frequently. With the breast cancer activism movement, breast health awareness became visible in the public eye and a larger push for a focus on breast screening became important during annual physicals. What ultimately emerged out of this movement is the message of early detection through breast screening as the key to survival.

Currently, most organizations rely on early detection as a form of health prevention. This method has been viewed positively, but it does not come without criticism. Scholars have argued that the push for early detection through screening places a large responsibility on women getting health services (Jain 2013; Ryan 2004). When reaching out to marginalized groups such as African-American women, this message is broadcasted more urgently given the high mortality rate and poorer prognosis. The message is clear: if women want to avoid being diagnosed and dying from breast cancer, then they must be proactive about early detection and get mammograms. I argue that this message is troublesome because it fails to factor in
post-diagnosis health disparities that negatively impact black women’s survival, in addition to employing neoliberalist ideas of individual responsibility that disproportionately places blame on black women. In the United States, African-American women have the highest screening rates of any racial or ethnic group (SEER 2012). This statistic is true for the state of California as well (California Health Interview Survey 2011). If black women have the highest mammogram screening rates in the country yet still have the highest mortality rates, where does this message of early detection go wrong? One doctor mentions how she follows a metastatic breast cancer group via social media and their conversation about early detection is much different from the norm. The doctor notes that many of the women believe that the theme of early detection saving lives shames women like them for not having a tumor that could be detected early. The doctor asserts:

> While that is the case for the majority of cancers, it may not be the case biologically for every single cancer. A lot of those triple negative, even if we find them and they’re small in size, can spread very fast.

Josephine, another survivor supporter, cautions the message of early detection as the only means of survival. She argues:

> It's not all about the pink. Now it's a social thing. Now it's about raising funds to have fun for somebody else to have a job. Our community is not benefiting from all about the pink. It's not about the pink for us, it's about saving people's lives. Until our numbers drastically decrease for late-stage, I'll keep saying that it's not enough. Telling women to go get mammograms is not enough.

> African-American women dying from breast cancer is not solely because black women fail to get mammograms on time. Sufficient evidence exists that recognizes the disparities in health that black women encounter not only in the diagnosis stage, but also in treatment and survivorship stages. In this chapter, I will highlight the ways in which African-American breast
cancer survivors and their supporters vocalize the disparities in their care, as well as the actions they take to change the discussion around breast cancer in their communities.

As stated previously, early detection has been viewed as the key to survival in numerous breast health awareness initiatives. However, it has only been in recent times that African-American women were specifically targeted. Susan G. Komen for the Cure has led one of the most prominent initiatives in Southern California. In October 2007, they created a statewide initiative, entitled Circle of Promise, which “seeks to motivate and empower the black community by mobilizing women and men to get active about their breast health and involved in the larger community, encouraging others to do the same” (Komen). The initiative gained financial support from companies like Anthem and Kaiser Permanente and media support from various black celebrities and magazines like Essence. Circle of Promise is easily one of the largest initiatives ever seen by the state focused on black women. Its mission of promoting early detection and creating “ambassadors” out of community members is no small feat, but I argue that the initiative, like many others, fails to address the barriers that exist for women already diagnosed with cancer. From the interviews conducted, participants identified various issues that they have with breast health promotion in the United States.

The first issue identified is the dearth of information provided to the community. Many survivors shared that they had to learn about breast cancer on their own. As Carolyn stated, “Being a black woman, we don’t know about things. We have to find out by word of mouth.” Since many of the women did not know women who survived breast cancer or people around them did not talk about the disease, women diagnosed often relied on their own investigation. When listening to Roberta talk about the importance of health information in the community, she
pointed out an ironic situation in the mall where we met. She motioned her hand to her left and said, “You see that right there? That used to be a place where women could get information on breast cancer. Now, they turned it into a Victoria’s Secret.” What was once an effort to educate a predominately black population about breast cancer now was an opportunity to buy high-end bras.

This is not to say that health education cannot occur in a consumerist environment. Josephine, a grassroots organizer and health advocate in Southern California, used her former occupation as a beauty supply owner to distribute pamphlets on health with each purchase. Recognizing that, without proper knowledge, people cannot advocate for their health rights, Josephine turned her desire to educate women into a non-profit organization that provided health education services and patient navigation services to women diagnosed with breast cancer. She has found herself in environments ranging from health fairs in the community to going to appointments with the women she serves. Josephine believes that educating women about their rights as breast cancer patients has inspired them to become health advocates within their community and homes. I found that most of the women interviewed did see their survivor status as a way to inform other women about their risk.

Another issue identified is lack of survivor support services. Survivors desire financial, physical, emotional, and institutional support. Financial support to survivors included having the money to remain active in breast cancer activities and having the money to pay for additional medical treatments. A few survivors spoke of the hypocrisy of making survivors pay for events that both educated and celebrated them. Carolyn spoke of a survivor luncheon that cost fifty-five dollars, an amount she found absurd for any woman but especially for women who are lower
income. She reasoned, “If you can’t work, then how you gonna pay for a ticket to eat a pigeon?” Many of the survivors are enthusiastic to learn about breast cancer further, but they look for those resources to be free.

In addition to opportunities for further education, women desired financial help that extended beyond the treatment stage. As one survivor stated, “My life didn’t stop because I had cancer. I’m still living with cancer and I still need to heal.” Carmen mentioned that from doing work in the community, she saw that survivors still had trouble paying for medical bills and buying basic necessities like groceries. This reality is especially troubling when survivors are often asked to promote breast health awareness in the community for free. Francis also highlighted this problem when she talked about the free labor many survivors do in the community. She contends:

That woman sitting up there--she's on the survivor panel, she's speaking at an event, she's rallying everybody up. Why is it that when she goes home she can't pay her utility bill or she's struggling to keep a roof over her head? My feeling is that if you're going to push somebody out on stage, put them in T.V. ads, put them in newspaper ads, then you need to make sure that person's bills are paid. Instead of putting people out there and saying, “Oh, what a tragic story,” are you helping them deal with their tragedy? Sometimes the issues that come in survivorship may even be greater than when the person is first diagnosed.

Francis is correct in that some issues do become more burdensome for women post-diagnosis. For women seeking additional procedures after treatment, the financial support from insurance companies became even scarcer. Francis waited two years to have breast reconstruction, a decision she based around growing tired of being operated and treated on throughout her journey. Once she decided to have reconstructive breast surgery, her insurance company deemed the procedure cosmetic and was refusing to cover the reconstruction. After writing a detailed letter of why this procedure was important to her overall quality of life, the
insurance company decided they would cover the costs. Other survivors struggled to pay for surgeries that fixed side effects from taking certain cancer treatments like Tamoxifen and radiation. While these situations are obviously economical, they are also an example of the mistreatment that black women face in the medical system.

Another aspect of support that cannot be stressed enough is physical and emotional support for survivors. A lot of the women spoke of the importance of feeling supported to get through their care. One of the ways in which this support is fostered is through breast cancer support groups. Many survivors attributed their happiness with being in a support group with other black women. Phyllis summed up this feeling when she said, “There’s nothing like being with other survivors who know what you’ve been through.” For many survivors, emphasis was put on being in a support group with other black women. The experience of sharing in a space dominated by black women brought comfort to many of them. When I had a conversation with Jill, a long time survivor, I told her how I struggled sometimes with connecting to survivors during interviews. Some women hinted at the feeling of not being strong, but would never clearly state it during interviews. Her insight as to why is as follows:

Even though you haven’t had breast cancer, you know just as much from having your mother go through breast cancer. These people who come to our meetings, I can see them on the street and they would never say that they had breast cancer. When you come to that meeting, you can get off guard, you can let your hair down, you can do all this because you’re with your peers. See what I’m saying? Whereby somebody that didn’t cross that road, you might not let your guard down with them.

It is through Jill’s words that I understood the importance of black women who are survivors being able to create a space of their own. In support groups, no strong black woman exists. Support groups instead serve as a space where these women are able to be complex and recognize the impact breast cancer has had on their life. Another survivor informed me that
support groups are now becoming more holistic. A support group she frequents offers opportunities such as yoga, nutrition classes, day trips, and opportunities to volunteer. With more and more women coming together, ideas of support have expanded to be well rounded. Thinking about the roles that many black women play in their families, support groups are a great space to forget about those roles for a moment. As support services for survivors become more comprehensive, it is necessary that support groups remain a viable option for women looking for emotional support.

For many support groups led by African-American women, there is a risk of the support groups falling apart because of limited funds. This challenge causes some women to decide to stop attending support groups. Roberta provided me with an example when she told me that she once found a support group for breast cancer survivors near her house that provided excellent services and focused on community outreach. Despite these accomplishments, the support group did not receive any grant money from large organizations and therefore they had to disband. Many survivors spoke of the bureaucracy that exists in non-profit grant donations. It is because of this bureaucracy that Carolyn decided to leave her favorite support group. She stated, “You get discouraged sometimes when you see the back of the house.” Debra also discussed the imbalance of power that exists between support groups and large organizations when she told me a story of how a support group she joined received a large grant from a local hospital after participating in a research study. The grant made many of the survivors happy, but she recognized something else. She recalled, “They were so grateful, they weren’t aware they were being short changed. They should have gotten a much larger portion of the million-dollar grant. If they were the backbone of the project, then they should have gotten more.”
Moreover, some survivors and survivor supporters felt that larger organizations controlled grassroots efforts too stringently. The majority felt that breast health initiatives should begin with the people already involved in the community. Josephine told me about a project she was very excited to work on with a very prominent breast cancer awareness organization. However, she quickly learned that the partnership would not be collaborative. She instead found her ideas taken for free and the project moving on without her. She reflects:

They wanted to do a portion and take it away from an organization that really knew the community and because of money thought they were able to do it on their own. They want you to do it for free. The way I see it, if you're not able to do it for free, why would you think we'd be able to do it for free?

Another community organizer’s words paralleled this statement. She explained:

They need to stop playing slave master and plantation owner. They say we have the connections and the power to get the resources but we need to now trust grassroots organizations and put the resources in their hands to go reach people in a way that's culturally relevant. They don't always need to be the person doing it. Stop treating the black community with a plantation mentality like we need to be overseen or watched. Give them the resources to do the work that they're already doing with limited resources. Look how much they've gotten done with limited resources! How much more could they do with other resources?

In addition to these views of institutional support, some survivors and survivor supporters also noted the absence of other key institutional support systems. Carolyn elaborated on the criticisms of breast cancer organizations when she pointed out that the locations that she is usually assigned to as a volunteer community health educator are in middle to upper-class communities. She comments, “When I volunteer, it’s in El Segundo or Westwood. It’s never in this neighborhood.” She stresses that the people that need the health education most are the people in her own community. Carmen also shared this sentiment and divulged that working in South Central can sometimes become frustrating when she sees the injustices that continue. The
first example she mentions is the food deserts that exist in the area. She asserts that many in low-income neighborhoods are willing to change their dietary habits, but many become discouraged when they continuously find no fresh, quality food. When thinking about preventative health behaviors for breast cancer, a balanced diet is often one of the key recommendations. If people do not have access to a nutritious diet, then how are they able to control their health risks? The second injustice Carmen notes is the poor healthcare infrastructure in South Los Angeles. She laments:

I wish doctors would not run from that community. We have had ten hospitals close in the last ten years in our area. The specialty doctors, like oncologists, have all moved away except a few that are still at Martin Luther King Jr. Hospital and a few that are at Harbor-UCLA. Because there are only a few, the people that get treated at one of these hospitals go in at eight for chemo and may not get into the chemo chair until four o’clock. There’s nobody over there to serve them and the people over there don’t have enough humanness about them to realize that that just can’t continue to go on.

Lack of healthcare facilities has been noted as one of the major health disparities that exist in low-income African-Americans’ care. Without competent medical care in these communities, any delay in care can cause serious setbacks for cancer patients. Another issue that raised concern for Roberta was lack of institutional support for environmental matters. After completing treatment, Roberta began to inquire about the high number of breast cancer cases at a school she worked at in the Los Angeles Unified School District. Fourteen women who worked at the school developed breast cancer and six of those women died. Roberta and a few others decided to request that the school be tested for environmental toxins. After a representative of the state came out to test the grounds, they received a note informing them that officials deemed the cases coincidences and found no foul play. Roberta still has a hard time believing this, stating “You tryna tell me that fourteen breast cancers in one place is a coincidence?”
With black women dying from breast cancer becoming a greater crisis, many survivors and community organizers are growing impatient with the larger system. As many survivors have pointed out, structural violence within the community has prevented them from meeting their needs as survivors and as human beings. African-American breast cancer survivors are at the front line advocating for better breast health education in the community, yet their efforts are not always supported. This situation is even more troubling, given survivors are still advocating for their own health and wellbeing. For the sake of improving breast cancer in the African-American community, larger institutions, the community, and survivors will have to work to create a partnership that makes all parties feel respected and understood.
I’ve Been Through Something

Within breast cancer culture, a common sentiment exists—celebrate survivors. From citywide races to commercial products to communities, people take pride in honoring women who have endured breast cancer. What is most interesting is that this culture depicts a standard narrative of the breast cancer survivor: a woman with scars and a new sense of hope. While this survivor narrative attempts to promote positive feelings about breast cancer, it is not the same story for every woman. This narrative reaches another level of complexity when considering the relationship that African-American women have to breast cancer. Given that health disparities among African-American women are quite evident, the idea of survivorship has a different meaning among black breast cancer survivors compared to the narrative seen in the larger breast cancer culture.

In my interviews, I found that many of the women viewed their survivorship beyond breast cancer. To some, breast cancer was yet another thing they survived as a black woman in the United States. Others viewed their survivorship as a teaching tool. Through their vulnerability, it became apparent that a paradox exists in the breast cancer culture’s understanding of the survivor. On one hand, survivors encountered people who spoke of them as being strong, courageous, and inspirational. Conversely, they also encountered people who did not believe that they were survivors based upon their preconceived notion of what a breast cancer survivor looks like. It is through this paradox that the strong black woman image once again becomes troubling when examining the lives of survivors. In this chapter, I explore how the survivor identity is understood by those inside and outside of the survivor community through definition, religion, notions of appearance, and theories of biological citizenship.
Survivor History

Understanding previous connotations of the term survivor are pertinent to understanding the meaning of the cancer survivor in modern times. Early references to survivors in the late 16th century were generally associated with survivors in relation to the death of a loved one. This meaning is still present in language today, especially in obituaries (e.g. John Smith is survived by Jane Smith and their two children). When thinking about the relationship that breast cancer survivors have to one another, this meaning is especially relevant. One of the survivors, Carolyn, spoke of this meaning of survival when she mentioned that all of the women she originally was in a support group with have passed away from breast cancer.

By the late 1800s, survival had a new connotation with the emergence of Darwinism. Survival of the fittest referenced the idea that organisms best adapted to their environment would continue to survive and have offspring, unlike less adapted species that were most likely going to die off. This connotation emphasized evolutionary fitness, competitiveness and superiority (Bell and Ristovski-Slijepcevic, 2013). Scholar and breast cancer survivor Barbara Ehrenreich draws parallels to Darwinism and the rhetoric that exists in breast cancer culture to make the argument that society values survivors more than the women who died from the disease. She claims:

But in the overwhelmingly Darwinian culture that has grown up around breast cancer, martyrs count for little; it is the “survivors” who merit constant honor and acclaim. They, after all, offer living proof that expensive and painful treatments may in some cases actually work (48).

In the 1960s, the popularity of emerging fields of psychology introduced a new and more clinical definition of a survivor. Survivor syndrome was defined as an individual who had survived a dehumanizing and degrading experience of terror and experienced symptoms such as disintegration of personality, nightmares, tension, and guilt (Oxford English Dictionary, 1989).
With the meaning of survivor becoming more clinical, trauma became central to understanding the survivor. The majority of the women I spoke to said they had positive experiences, but some women were vocal about how breast cancer was a negative experience that greatly affected their life. Lois, a seventy-three-year-old breast cancer survivor, described this experience best through the metaphor of divorce:

```
Everybody is different but you’re not gonna find no breast cancer ribbon in my car window. It’s not that I’m ashamed or anything like that but you just gotta let that stuff go. It’s like if you divorce somebody, what are you gonna do? Put a ribbon on your car and say you’re divorced? No, that’s crazy. You gotta move on. Why do you want to keep honoring something that was bad for you? Breast cancer was bad for me. That’s something I don’t want to continue to think about and relive. That wasn’t a good deal.
```

Many scholars credit Dr. Fitzhugh Mullan, a cancer survivor, as the first scholar to conceptualize the term cancer survivor (Rowland et al. 2006, Khan et al. 2012, Morgan 2009). Mullan argued against the dominant view that for those diagnosed, only two paths exist: those who are cured and those who are not. He ultimately argued that the only path for those diagnosed and treated was survival, which acknowledged the physical and psychological effects of diagnosis and treatment (Mullan 1985). With this path, he divided survival into three parts: acute survival, extended survival and permanent survival. Acute survival is defined as the period after diagnosis when those diagnosed focus their energy on surviving treatment itself. Extended survival is the period after completing treatment when the survivor’s energies are focused on dealing with the physical and psychological consequences of treatment. Lastly, permanent survival is the period where recurrence seems more and more unlikely, however the survivor is continuing to deal with the long-term effects of treatment.

This concept was groundbreaking for those in the medical field and has been widely accepted as the way to define the people who have been diagnosed and undergone treatment. In
1986, Mullan founded the National Coalition for Cancer Survivorship, a survivor-led advocacy organization seeking to change the focus from cancer victim to survivor (Morgan 2009). The NCCS stated “from the time of its discovery and for the balance of life, an individual diagnosed with cancer is a survivor” (Leigh 2007: 10). The term cancer survivor has now been extended to include family, friends, and any others directly impacted by cancer; they are often referred to as co-survivors (Alfano and Rowland, 2006; Bucher et al., 2001; Northouse, 2005, Varner, 2012). With more and more people embracing the shift from cancer victim to cancer survivor, it is important that the experiences of all cancer survivors are taken into consideration when defining them. For African-American women, this includes the intersections of race, class, and gender that impact their experiences as cancer survivors.

Definition of Survivorship

While the term cancer survivor has become more widely accepted in our vocabulary, it is still important to recognize that each person diagnosed with cancer has a different perspective of his or her experience. There is a tendency to interpret a person’s cancer experience separate from their life. In actuality, it is very much linked to the daily lives of those diagnosed with cancer. Many of the women I spoke to shared the following sentiment: “Your life doesn’t stop just because you have cancer.” When discussing the culmination of their breast cancer journey, I ended each interview with the question, “Do you consider yourself a survivor? If not, how would you define your experience?” From this question, each woman provided profound and unique answers, however three common themes were evident: they saw themselves as survivors of breast cancer, as survivors of life, or survivors willing to share as a testimony and teaching tool.
One of the first women I got to know and the first to embrace the title of breast cancer survivor was seventy-four-year-old Phyllis, a three-time breast cancer survivor. I had never met her prior to our phone conversation, yet she spoke to me as if we were long-time friends. Phyllis had a natural cheer to her voice and spoke pensively, revealing a comfort in being a long-term survivor. Phyllis was first diagnosed with breast cancer in 1986. Having never had a mammogram prior to her diagnosis, she noticed an irritation near her left armpit that alerted her that something was wrong. Once getting her first mammogram, her doctor informed her that she had Stage II breast cancer. Phyllis saw this as a mild shock, while her husband reacted more strongly to the news.

After diagnosis, she underwent a lumpectomy, radiation and chemotherapy—a treatment that lasted all of two weeks. In October, after her first round of chemotherapy, she suffered a major setback when her mother died. Despite this loss and adjustment to treatment, she continued with her job as a teacher in the Los Angeles Unified School District. Phyllis shares that in many ways she was blessed because she had the support of her husband, friends, and job, as well as great insurance. In 1998, she was diagnosed with ductal carcinoma in situ in her left breast, an early form of breast cancer found in the milk ducts of the breast. This time, her treatment consisted of five rounds of chemo and a mastectomy. By 2001, she was diagnosed in her right breast and underwent another mastectomy. Towards the end of our talk, she let me know that she had written about her experiences in a book that other breast cancer survivors had contributed to as well. She laughed as she shared the title of her piece, “Three Strikes and You’re Out… Not Necessarily.” Phyllis had let me know that she was not by any means a baseball fan, but in her words, “I have had what I consider three strikes with breast cancer and I’m certainly
not out.” Though enduring some challenges, Phyllis views her overall cancer experience as positive and her survivorship as a message of hope.

I really think I am a survivor. I didn’t consider it like I went through a battle but I know that I’ve come through something. I have survived and I am really, really overjoyed to know that and to say that I am a breast cancer survivor of so many years. Apparently there is some purpose to my life. Not only am I a survivor one time, but three times.

Another survivor, sixty-four-year-old Roberta, reminded me that even the youngest of survivors still grapple with claiming survivorship. As a three-year survivor, she is reminded at each support group meeting that she is not “just” a three-year survivor, but is proudly three years out from breast cancer. She tells me with conviction, “I see myself as a survivor because I went through the process. I went through every surgery, all the things that I had to do, and even though they weren’t chemo and even though they weren’t radiation, I consider myself a survivor.” Other women like Roberta and Phyllis thought positively of their survivorship. Below are their perspectives:

**Lois, 73:** I do define myself as a breast cancer survivor. I don’t put a lot of focus on it. I really don’t. That’s not to say that I’m not appreciative that I’m still here and that I’ve survived. That’s saying that I’ve let it go and I’ve moved on.

**Agnes, 60:** I think of myself as a survivor because there are so many women that don’t survive and don’t have a positive outlook either. Even though I was diagnosed, I have a positive outlook. You either progress or move back and I intend to move forward instead of backwards.

**Evangeline, 68:** I see myself as a survivor of 24 years. I’m a survivor because I’ve lived through breast cancer. Breast cancer has made me see myself in a better way, taking care of me first and helping whomever I can along the way that needs help in any way.

**Lydia, 55:** Breast cancer survivor means that for me you went through something that a lot of other people went through and some people didn’t even survive coming out. Some people had a break up because of that. Some people was alienated because of that. I survived all those things and let me help someone else get through and survive through it. It’s more emotional than physical. If you can survive anything emotional and get over it, you have survived. The only survivor that I say I am is a breast cancer survivor. I
remember some said to use something else and I didn’t even hear what they said because I’m gonna say that I’m a breast cancer survivor. I survived childbirth too. If you can get through the emotional part, the physical part will heal itself and that’s the survival of it. I did and I’m proud of it.

Debra, 73: I consider myself and define myself as a survivor. I have traveled the journey and I consider myself a survivor from the day I completed my treatment because they told me that I was cancer free. It doesn’t mean I don’t have cancer genes in my body. I’d like to believe they’re dormant. I’m in awe that the time has passed so fast and that it’s been ten years. In many ways, that’s a victory. I don’t think I’ll ever lose track of the years because my mom died the same year I was diagnosed. Those two things stand out; they’ll be with me for the rest of my life.

Carmen, 54: Survivor for me is one who is outside of treatment. While you’re in treatment, to me you’re a fighter. I think for everybody, once you’re diagnosed, you’re aware that you’re a survivor. It’s a matter of recognizing your phase in the process because everybody is a survivor. I just happen to think you’re a survivor from the moment you find out.

An additional perspective of survivorship identified is that being a survivor means that you are a survivor of life. For these women, it was not only about surviving breast cancer but also surviving all the other challenges in their life. Many of their viewpoints draw from the strong black woman image that recognizes the challenges that occur on a day-to-day basis. They state:

Bessie, 71: I see survivorship as a way of life. It’s like eating. I know when I’m overweight, okay? So I’ll go somewhere to take my weight off. As you get older, it’s not about surviving. It’s about longevity.

Gladys, 65: I am a survivor. I was a survivor before breast cancer. In my life, different things, I was a widow at 26, so many things, so many hardships that I have overcome. I am a survivor, but this is just another thing that I had to survive. I’m happy to be a survivor and I’m happy in a way not to have gone through it but to have made it through it. I didn’t turn inward or strike outward. I didn’t become an introvert or become very angry and very hateful. I just rolled with the punches, so to speak, and tried to think about the best thing to do.

Francis, 54: I see myself as a survivor of life. I see myself being a survivor of life at 54 just being a black woman, being a single mom. The cancer is a part of the mix. I’ve survived racism, gender discrimination, being an executive in a white male dominated world. How could I not be happy to make it to 54 after all of that?
Lastly, a few women did not identify with being a breast cancer survivor at all. Many viewed their experience as a testimony or teaching tool. Their rejection of survivorship is reminiscent of the breast cancer survivors in North Carolina that rejected the clinical structure of support groups, instead creating their own model of support groups (Mathews 2000). These women shared:

Carolyn, 69: I don’t see myself as a survivor. I see it as God left me here for a reason. He left me here to educate and talk about where He brought me from with breast cancer. And to see how He can take me from a third stage breast cancer and still be a strong woman, still be independent, still know how to take care of yourself and survive and work and raise a family and take care of a husband or a dad that was sick that everybody told me “Don’t do that. It’ll make you sick. Your cancer gonna come back.” I’m like you don’t know that. He kept me here to show you that if you believe in [Him] then you can do it. So that’s why survivor… I never put myself as a survivor. I’m at peace with my life.

Martha, 72: It’s best to get it taken care of and move on. My survivorship is to make sure men and women are aware of the disease.

Dot, 63: I’m here living my life. I had it and I’m here. Nothing’s really changed other than me really trying to say I wanna make this count because I feel like I’ve been given a second chance. What is it that I really really want to do. I feel like I want to get things done. I look at things more intentional. I think for me a survivor is doing the things that I’ve always wanted to do and didn’t take the time to do them.

Each woman provides a unique perspective that brings complexity to the identity of a breast cancer survivor. From their own definitions, it is apparent that no woman has the same idea of what it means to be a survivor. Therefore, the larger image of the breast cancer survivor can be of disservice to women. For the black women who incorporated race into their survivorship, they highlight the importance of an intersectional lens when analyzing the dominant breast cancer culture. By moving away from the narrative of a single breast cancer story, those looking to create change can do so by incorporating the diverse stories of all women diagnosed with breast cancer.
Another important influence on survivorship is religion. Every single survivor interviewed mentioned faith as one the greatest influences, if not the greatest influence, on their journey. Religion influenced the participants’ perceptions of survivorship in two ways: survivors saw their experience with breast cancer as a second chance and survivors relied on God to navigate their cancer experience.

In order to better understand survivors’ reasoning for incorporating faith into their care, it is important to understand the role of the church in the African-American community. The institution of church has played a significant role in the lives of many African Americans. Prior research indicates that African Americans exhibit greater religiosity than other ethnic/racial groups, which is seen through practices including regular church attendance, reading religious materials, and engaging in church activities (Holt et al., 2008). During the time of slavery, attending church was one of the few opportunities where African Americans could freely communicate and organize. This distinctive space allowed for their sole control of the church and the ability to set the institution’s norms, goals, and practices (Frazier, 1974). Since any practice relating to their natal culture was discouraged, congregations allowed people to continue their traditional practices in a modified space. Evidence suggests that African ritual behavior is maintained in a modified form in African-American congregations today, especially through the incorporation of ecstatic, participatory worship (Pitts, 1989). Most importantly, the church provided African-Americans with leadership positions that they may not have had while enslaved or in the work force. Black women especially benefited from this environment, taking on leadership roles and creating the foundation for community organizing. The church has been
seminal in creating a space for black women to emotionally and spiritually heal, as well as have the opportunity to be leaders in their community.

The first way in which religion has influenced African-American breast cancer survivors’ perceptions of survivorship is through the belief that God gave them a second chance to live out their purpose. A common theme seems to exist where those who face life-threatening illnesses speak of making a change after overcoming illness. They were at death’s door but the chance at a new life inspired hope and gratitude. Oftentimes this feeling is paired with religion. In the case of the survivors I interviewed, this was a reality. Evidence suggests that African American women are more likely than any other racial or ethnic group to depend on spirituality and religion both during and after cancer treatments (Henderson et al. 2003).

While interviewing these women, many held the highest regard for the role God plays in their life, but they also spoke of how it inspired them to take a more active role in their life. Carolyn touched on this when she discussed how going through breast cancer while dealing with a lot of stress is a teaching tool to those who do not understand the power of God. She argues, “The man upstairs knows who can endure it. You can’t be weak and go through cancer.” Carolyn asserts that breast cancer survivors owe it to God for keeping them strong, therefore they must do His work by become active in breast health education. Other survivors spoke of the second chance as providing the opportunity to fulfill goals and reshape their life in a way that removes negativity and puts their needs at the center. For many survivors, a second chance was their wake up call to take care of themselves.

Another way in which faith influenced survivors is through the belief that God navigated their breast cancer journey. Survivors believed that their close connection to God and their faith
allowed them to relinquish control to God, therefore allowing a higher power to guide them through the process. This demonstration of faith can be perceived as the deconstruction of the strong black woman. Health care providers may view this mindset as fatalistic, but this does not mean all feel powerless (Phillips 1999). To many of these women, God was the answer to their decisions and their survival. Black women are known to draw upon their religious and spiritual heritage in determining their health care decisions (Gullatte et al. 2009; Kinney et al. 2002; Peek et al. 2008; Roff et al. 2009). It is not merely about prayers but a full incorporation into the treatment and survivorship. Francis described it best when she said:

God is the great physician. He'll cover you even when everybody around you is making mistakes, yourself included. So just like I accidentally got poked in the bowel, got that infection—that was a mistake. But God covered me through that. Even when a doctor forgot that I was supposed to be back on my chemo and so for four months I wasn't on it, who do you think covered me for those 4 months? The Lord.

Many other survivors spoke of the influence that God had on their cancer experience, often claiming it was “always up to Him.” A vivid example of this faith is seen through the story of Lydia. Lydia was diagnosed in her left breast with ductal carcinoma in situ in July of 2003. Her doctor recommended she have a lumpectomy given the early stage diagnosis, but she was adamant about having the entire breast removed. Her doctor still tried to convince her to have the lumpectomy, so Lydia decided to think about it. One night while asleep in her bed, Lydia experienced what she perceived to be a sign from God. She recounts:

God had showed me. I was asleep one night and worried and God was talking to me and He said, “I’m going to show you a picture.” In my reality, I don’t even call it a dream, these things came up. They were like these little black round things, like a Pacman. One of them woke up and said, “It’s been ten years. They think they got us all, but they don’t. We’ve just been sitting here. Maybe we should just move to the other side. She should have took us when she had the chance.” Then they just started eating up my breast. They went to my right side and were eating up. They were going into my organs. It was like, “We got her now.”
After this encounter, Lydia decided to have a mastectomy. A few nights before her surgery, Lydia prayed to God, requesting that a touch lamp she had be the vessel for her deceased parents (her mother, father, and a cousin that served as a second mother) to communicate with her that she would be fine in surgery. All three nights before her surgery, the lamp turned on on its own—a sign to Lydia that her parents were watching over her and that she would be fine. Lydia and Francis’ stories reveal the immense amount of faith that African-American women have during their breast cancer journey. In their eyes, God is not merely a huge influence—he is the reason for all of their breast cancer experiences.

Religion is an important aspect of survivorship for many black women. For the participants I interviewed, two main aspects of religion shaped the perception of their survivorship. The first is that God gave them a second chance to live and their survivorship should serve as a teaching tool. The second is that God made all of the decisions regarding their care. With every single woman being religious, faith cannot be ignored when accounting for these women’s journey. In many ways, when physical and emotional support failed, God was the support they needed.

_Sasquatch and the Survivor_

Appearance can be a huge influence on how women diagnosed with breast cancer view their survivorship. The survivors I spoke to had divided feelings about appearance and breast cancer. Some women felt that breast cancer changed their perception of beauty while others felt no change. Other women who had negative perceptions of their body did not relate it to their identity as an African-American woman; they instead viewed their body as less because of disease as something unnatural in relation to their body. In this section, I explore how
appearance relates to understandings of survivorship among breast cancer survivors and to non-survivors.

For many non-survivors, women who have gone through breast cancer cannot help but be compared to the standard image of the sickly survivor who is close to death. Dot gave a stark example of this expectation. Prior to becoming active in breast health education, she remained relatively quiet about her diagnosis. Always a private person, she did not feel the need to share and therefore only told her immediate family and close friends. After talking to her doctor, she decided that she wanted to open up more about her diagnosis. She reflected, “I felt I wasn’t being authentic.” Dot decided to become more active in breast health education. One day, while tabling at an event, she ran into a former friend that she had not seen in years. Dot noticed that the woman kept looking at her closely, but she ignored it. Towards the end of their conversation, Dot revealed that she had undergone treatment for breast cancer. She reveals that the woman perked up and said, “Oh, I figured because I have never seen your hair that short.” The woman’s words were hurtful to Dot because she had been struggling with the change in her hair breaking off from taking Tamoxifen. This insensitive remark is a reminder of how preconceived notions of what a survivor should look like can make survivors feel unsupported.

The appearance of breast cancer survivors also ties into the damaging image of the strong black woman. The strong black woman image is dependent on black women consistently appearing put together and not in need. When considering the strong black woman as a breast cancer survivor, a healthy appearance can be perceived as black breast cancer survivors not struggling with any issues related to cancer or not needing any help. Some survivors spoke of the challenge of appearing healthy and being perceived as not needing help. Carolyn and Francis
both mentioned how some people told them that they appear as if they never had a struggle in life. For both of them, this came as a minor insult considering the difficulties they have had in life. As Francis protests, “Why does someone have to look bad before you'll give them support?” Therein lies the problem with the hyper-visibility of breast cancer. With the increase in awareness and funding, people believe that all issues related to cancer have been solved. As Claire, an executive at an organization that helps those diagnosed with cancer navigate the job market, describes, “People think that the problems with breast cancer have been solved because people have raised so much money, but we still have so much work to do.” One of the glaring problems is that survivors’ support needs are not being recognized. The idea that a person must look bad to be in need is also shared among women diagnosed with breast cancer. Dot admits that she finds herself saying how good certain women look despite the underlying suffering that women show. The idea that survivors need to appear sickly in order to receive help is problematic. Many breast cancer survivors must mask pain, but African-American breast cancer survivors have a unique challenge of battling this myth when taking into consideration the damaging stereotypes that are inherent to the strong black woman image.

As we continued our conversation, Dot and I discussed how most people still have difficulty interacting with survivors. I made the comparison to a mythical creature. Each person has a different idea of what Sasquatch looks like. Some people claim to have met the mythological figure and tell grand stories about the creature. They go into detail about what it looks like and happily share with others. As time goes on, the description of the figure changes significantly with each person. If by chance you one day met Sasquatch and the figure was the opposite of how someone had described it, then you may be confused but fascinated. Is this
creature real? Did you really encounter this being? I explained to Dot that I felt many people were still unsure of what to expect when they met a survivor. This made Dot roar with laughter and she agreed that this is often the case. She explained:

I was telling people how off putting it is when people react to me being a survivor. It’s like, “I want to touch you. You’re a survivor!” It’s just really odd. They say, “You’ve made it personal, you’ve made it real.” There’s a person that they have met and can actually talk about it.

Breast cancer has become hyper-visible in society, yet the majority of people are still uncomfortable interacting with breast cancer survivors. Within the African-American community, part of this can be attributed to the silence that exists around the disease. Many in the community still view cancer as a death sentence, so how would a person approach another they view with a fleeting lifespan? If a woman diagnosed with breast cancer appears healthy, then how does her appearance fit with the image of the sick cancer patient? Our continued belief that cancer equates to death confirms Sontag’s argument that cancer as a myth is not helpful in getting people to understand illness. With a lack of understanding, survivors like Dot encounter moments where people cannot comprehend their existence.

While those outside of the community may not fully grasp the correlation between breast cancer and self-image, survivors within the community have a clear definition of how they see themselves. One perspective survivors have is that breast cancer has not changed their perception of beauty. When I asked Debra if she felt breast cancer had changed her, she calmly answered that it had not. She then rummaged through her purse, pulled out her wallet, and retrieved two drivers’ licenses. One picture showed a youthful woman with curly shoulder length brown hair and a beaming smile. The other revealed a more mature woman with closely cropped wavy hair and the same radiant smile. She lowered the licenses and stated, “Either way, I’m happy.”
I asked the same question to Evangeline, she mused, “From having breast cancer, I have a scar but that’s my beauty.” Many of the other survivors had the same sentiment, with some saying that they looked better than before their diagnosis.

The other view from survivors focused on disease affecting what they felt was womanhood and not strictly beauty. Roberta vocalized her grievances with her post-treatment body when she stated, “Surgery leaves you mutilated. I never had a perfect body but now I’m deflated and have a keloided breast.” While Roberta did not have a mastectomy, her words coincide with Audre Lorde’s argument that mastectomies are a form of amputation that should be regarded as traumatic--just as one would be outraged from a war soldier having a limb amputated. Lorde asserts, “Any amputation is a physical and psychic reality that must be integrated into a new sense of self” (14). Carolyn also expressed the hardship in accepting her new body. She states, “Breast cancer is an invasion of your body and womanhood. It can really take away from you as a woman.” What makes Carolyn’s views of breast cancer more troubling is that she had a mastectomy without her consent. Her view of breast cancer as an invasion draws parallels to what Sontag describes as the perception of cancer as a disease of space and cancer cells as alien. With her breasts connected to her perception of womanhood and for those breasts to be taken so aggressively, Carolyn’s view of cancer invading her body and changing her perception of beauty carries much more weight. Breast cancer survivors who have gone through surgery and other harsh treatments experience the struggle of body acceptance in a pressured environment. Women are expected to be grateful to still have their bodies, mutilated or not. Survivorship changes meaning among women diagnosed when the body changes significantly due to treatment. The expectation for women to always be positive about their experience is
problematic when one considers how women like Carolyn underwent certain treatments beyond their control.

Real Survivor

The last aspect of the survivor identity that influences women’s perceptions of their breast cancer experience is what it means to be a “real” cancer survivor. Within the breast cancer community, some people feel that if women have not undergone intensive treatment or have been cancer free for a certain number of years, then they are not a “real” survivor. This idea can be understood through theories of biosociality and biological citizenship. By creating a community based upon a biomedical diagnosis, women are able to restructure concepts of identity and belonging.

Biosociality is a term credited to Paul Rabinow. He explains that after the rise of biomedicine and the increase in technology, social relationships could be tied to biology and understandings of vulnerability, suffering, genetic risk, and susceptibility as it relates to the body (1996). These perceptions of the body changed relationships between communities and institutions. People who are a part of the community also incorporate ideas of support, activism and education. Breast cancer survivors looking to take part in support groups are a clear example of biosociality. Conversely, biological citizenship constructs citizens through conceptions of identity and affiliation in biological terms. Adriana Petryna (2002) constructs this idea of biological citizenship in her study of post-Chernobyl Ukraine. Citizens associated themselves and distinguished themselves from others in biological terms. These biological views of identity allowed people to make demands on themselves, family, community and institutions. As Heath, Rapp and Taussig (2002) have highlighted, citizenship in the contemporary age of biomedicine is
presented through struggles over self-identity, ideas of community, demands for recognition, access to knowledge and claims to expertise. The participants I interviewed revealed how theories of biosociality and biological citizenship are present in the breast cancer survivor community.

One of the most evident examples of how women determine survivorship is through perceptions of suffering. Many women noted that they assessed their cancer experience by comparing it to other survivors. If they had less harsh treatment than others, then they felt that they were luckier compared to others who they perceived as suffering more. Roberta confirmed this perspective when she talked about how being in a support group with women who have had aggressive cancers or multiple cancers helped her to realize that her experience “was not as bad” as other women’s. This outlook among survivors perpetuates the idea that suffering and pain is inherent to the breast cancer experience. The other argument about suffering is that some survivors feel that women with early stage breast cancers do not have the right to claim the survivor identity. Francis identified this problem, stating:

Women who've gone through chemo and radiation and other things will say, “Well you didn't really have cancer. You haven't gone through the full cancer experience.” Things like losing your hair, having your hair thin out, throwing up, wound healing problems, etc. So they won't consider you “down” with the cancer experience unless you've had some organs missing or some heavy-duty therapy. They'll consider it kind of lightweight in comparison. I hate to say it, but you haven't suffered enough to be considered going through a cancer experience.

Francis, a long-term survivor, believed that this mentality was damaging because it excluded women from the community that have gone through the same terrifying process of diagnosis. Lydia agreed with this sentiment and told me how invalidation of the emotional trauma she suffered from being diagnosed is very hurtful to her. She shares:
It’s like being in a plane crash and it’s a lot of people. Some people just get a bump on the head, which would be me. Other people got the big scars and have blood gushing out. Does that make me less? I was in that accident with you, but because I didn’t have blood all over me does that make what I went through less than you? We both survived. We were at the same place at one time, which is getting that news that you have breast cancer.

Through this breast cancer survivor community, women must navigate ideas of the self and their community. While some women are opposed, a hierarchy appears to exist in the socialization of survivors. In order for women to be “real” survivors, they must endure the harshest treatment and have the most aggressive staged disease. I argue that this idea aligns with the Darwinist idea of survivorship: only the strongest and toughest are the true survivors. As Barbara Ehrenreich argues, “It is the “survivors” who merit constant honor and acclaim. They, after all, offer living proof that expensive and painful treatments may in some cases actually work” (48). This perception of true survivorship brings into question the women with early stage diagnoses and the women who have died from breast cancer. Have they not been affected by breast cancer? Have they not suffered in some way? Through this navigation of the self and the community, the importance of acknowledging different views of survivorship yet again becomes evident.

As these women have highlighted, survivorship has many definitions according to breast cancer survivors. Considering that these women come from many different backgrounds, survivorship can be in relation to their breast cancer experience, other hardships in their life, or their relationship to a higher power. Regardless of how women identify as survivors, it is important that they have the choice to define their own experience and navigate how to heal themselves. Much of this growth is integral to improving the quality of life among African-American women diagnosed with breast cancer.
Conclusions

While in the midst of writing this thesis, I had an encounter with a colleague whose words reminded me of why I wanted to write about black women’s experiences with breast cancer. In typical stressed out college student form, we had both shared our struggle of writing on a topic that we feared might not be understood. Enough people had asked me how African-American women going through breast cancer relates to cultural anthropology—never mind having to explain the field of medical anthropology. With what they felt were words of encouragement, my colleague informed me that regardless of how well I argue my thesis statement people would be interested because I had “buzzwords” such as black women and breast cancer to keep audiences interested in my thesis. These words validated my reasoning of why it is so important to analyze breast cancer through an anthropological lens.

At the start of this project, I mused over the question of why black women die at the highest rate of any racial group from breast cancer. Many medical breakthroughs have occurred and the public health initiatives to increase breast health awareness have been strong. In this pink ribbon society, a person cannot escape words like early detection and phrases such as “knowing your risk.” However, for black women who have gone through breast cancer, saving the community from poorer outcomes means more than buzzwords like early detection.

Some survivors I spoke with identified how early detection was not enough to change black women’s relationship with breast cancer. A large part of this change would require breaking the silence and the silencing of the black community, as well as furthering investigating silence. With health disparities affecting the outcomes of black women diagnosed with breast
cancer, breast cancer has been viewed as the disease that will surely kill black women. This idea of cancer equating to death has stopped many from having conversations about breast cancer. Moreover, black women feeling like they are not being heard as a person and a patient by the larger medical system breeds a distrust that can disrupt the relationship between patient and doctor. I have learned that this sentiment of not being heard extends beyond the exam room. Black women play an important role within their families and communities, therefore it is essential that they are heard as not only patients but as human beings so they can be reminded that their voice matters in experiences that have an impact on their life.

Considering the pressures that black women have to be emotionally and physically available for people in their life, looking after their own health can be a chore instead of a form of self-care. With the expectation to be the strong black woman and the good patient, African-American women diagnosed with breast cancer are faced with the challenge of balancing both identities and being receptive to outside influences controlling their life. Looking at the larger narrative of the breast cancer survivor in the United States, many women recognize the paradox of being a survivor. They are celebrated for beating the odds and outliving their fellow survivors, yet they are still living with the consequences of being diagnosed with breast cancer. As many women have noted, breast cancer never leaves their lives. Whether it is through a check up or recurrence or family history, these women will always be reminded of their time with breast cancer. When we celebrate survivors, it is important to recognize that support extends beyond treatment.

Survivorship symbolizes many different things to women who have been diagnosed with breast cancer. Some are proud to call themselves breast cancer survivors, while others are not.
There are many women who credit their survivorship to God and treat their experience as a testimony to others. To these women, their life after breast cancer is viewed as a second chance and a sign to help others understand their risk of breast cancer. While they cared about maintaining their health, they put a larger emphasis on educating younger generations about the importance of breast health awareness. By vocalizing the disparities in their care, they call out the actions that need to be taken to change the discussion around breast cancer. The role of the other mother that grows from their experiences illustrates how African-American female breast cancer survivors are returning to their roles as leaders of the health movement in the African-American community.

I admit that my original reasoning for writing this thesis was personal. I grew up in this Pink Nation and never had the opportunity to be an expatriate. I know of too many women who have either died from breast cancer, have survived breast cancer, or do not want to hear about breast cancer. At the height of my involvement in breast cancer activism, I recognized that there was no sense in leaving because there is still so much work to do. Once I learned I was gene positive, I officially became stuck in Cancerland. My status as a BRCA 1 gene carrier is stained on my medical records like a stamp on my passport. While I have not been diagnosed with breast cancer, I am now expected to look after my health as if I were a survivor.

Thinking back to the conversation I had with my mother when I first learned about being a gene carrier, her words of comfort hold greater weight as I navigate my position in the breast cancer community more clearly. As she reminded me, she gave me both the cancer gene and the survivor gene. While I am aware that, medically speaking, no survivor gene exists, I believe that the gene my mother speaks of is the generational strength that has been evident through the
women in my family. Like many other black women, these women have survived slavery, wars, Jim Crow South, displacement, and so many other trials. They were mothers, business owners, teachers, community change agents, and so much more. As this thesis highlights, the strong black woman image comes with faults, but it also reveals the humanity in black women. We are strong, vulnerable, emotional, carefree and so much more. Above all, we are complex. When adding breast cancer to the story, our complexity becomes more visible. Breast cancer is a disease that has a huge impact on the lives of people from all walks of life. No single story exists from this experience. As the concept of breast cancer activism changes and support for those diagnosed becomes more comprehensive, it is important that we recognize that breast cancer awareness is more than a race or a ribbon—it is an awareness of the changing environment, technologies, laws, systems, ethics, and outlooks that affect the lives of the brave women diagnosed.
References


Pitts, Walter. ““If you cain't get the boat, take a log”: Cultural reinterpretation in the Afro-Baptist ritual.” American Ethnologist 16, no. 2 (1989): 279-93.


West, Carolyn M. "Mammy, Jezebel, Sapphire and their homegirls: Developing an "oppositional gaze" toward the images of Black women" 4th New York *Lectures on the psychology of women* (2008): 286 – 299

Appendix A

City of Los Angeles & Communities

Place names in BLACK represent communities that lie within the City of Los Angeles.

Place names in RED represent communities adjacent or near to the City of Los Angeles but are not part of the City of Los Angeles.

Los Angeles County Outside City of Los Angeles
Ventura County

Copyright 2004 - Los Angeles Almanac / Given Place Publishing
All Rights Reserved
Appendix B

Questions for Breast Cancer Survivors

**Background Questions**
1. What is your name?
2. How old are you?
3. When and where were you born?
4. Where did you grow up?
5. Describe your family background and your community.
6. What is your highest level of education?
7. What is your occupation?
8. Do you have a family of your own? (i.e. children or spouse/partner)
9. What values and ethics have you tried to establish throughout your life?
10. What have been your experiences, both positive and negative, as a black woman?

**Diagnosis/Treatment Questions**
11. When were you diagnosed with breast cancer?
12. Do you have a history of breast cancer in your family?
13. Tell me about the story of your diagnosis. (What stage of cancer, emotions, where were you when you were diagnosed, etc.)
14. What treatment plan was provided to you? Which options did you go through with?
15. Did your occupation or lifestyle change after treatment?
16. What were some of the challenges you faced while going through treatment?
17. Did other women previously/currently diagnosed with breast cancer help you during this time?
18. What kind of help did you have during your treatment?
19. Did you utilize any community resources during your treatment?
20. What sort of things got you through this time? (books, shows, hobbies, etc.)

**Survivorship Questions**
21. What emotions/feelings did you have after completing treatment?
22. Did you ever fear having a recurrence?
23. Do you feel you got the best treatment available? If not, why?
24. Did you become more active in any breast cancer awareness activities?
25. What are your thoughts on the marketing and awareness surrounding breast cancer in the United States? Your community?
26. Do you see people like yourself represented in breast cancer awareness promotion?
27. Have you seen any organizations reach out to your community to increase education?
28. What changes would you like to see in the community attitude towards breast cancer s/what would you like these organizations to know?
29. How did/do people react to you having gone through cancer?
30. How has your perception of beauty changed with this experience?
31. Do you see yourself as a survivor? If not, how do you define your experience?
Appendix C

Questions for Community Organizers and Others

1. What is your name?
2. How old are you?
3. What is your occupation?
4. Where did you receive your education?
5. How did you get into your occupation?
6. What demographic/community do you primarily serve?
7. Describe your method of incorporating health promotion into your dialogue with breast cancer patients.
8. What has been your experience with African-American female breast cancer patients?
9. How have black women responded to your participation in breast health promotion?
10. What challenges have you faced helping black women with their journey?
11. What successes have you achieved with them?
12. What challenges have you experienced within your organization to help black women?
13. Have you experienced any cultural barriers in speaking with African-American women?
14. Do you see any differences in the needs of African-American women compared to other demographics you serve?
15. Do you think there is room for improvement in breast cancer awareness and research?
16. What are your thoughts on the marketing and awareness surrounding breast cancer in the United States?
17. Do you think more African-American breast cancer survivors should be included in breast cancer awareness initiatives?
18. What has been your role in breast cancer awareness in black communities?
19. What changes would you like to see in the community attitude towards breast cancer?
20. How do you think knowledge about breast cancer has changed since you first came into your profession?
21. How do you think this knowledge will change in the next 10-15 years?