Lopsided Suzy with the Baby Fine Hair:
Black Women and Transformed Bodies after Breast Cancer

By

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To the amazing matriarchs I lost along the way, Earline Taylor and Maybelle Wilson

And

Finally, to the most beautiful black woman I will ever know, Genora Taylor Wilson, I do this for you.

I will forever feel your loss.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER I

INTRODUCTION: THEORY AND PERSPECTIVES

How do black women breast cancer survivors make decisions, activate psychosocial resources, and work to achieve wellbeing after experiencing the change and uncertainty associated with life threatening illness? This dissertation uses a qualitative approach to study this important topic in the area of intersectionality and health. My data come from semi-structured interviews I conducted with 49 black breast cancer survivors in three Southern cities: Nashville, TN, Durham, NC, and Atlanta, GA. Black women die from breast cancer at much higher rates than white women do, yet their stories are fairly unknown. Moreover, given the gendered nature of breast cancer, the illness presents a good context for exploring the intersection of femininity and health, along with race and social class, in the contemporary United States.

Breast cancer, like most medical conditions, is both a disease and an illness. As used by sociologists, the term disease refers to the biochemical disturbance that makes an organ or organism unwell (Cassell 1976). The presence of cancer cells within breast tissue represents the presence of a disease. Diseases usually require medical attention. As a disease, breast cancer requires medical treatment to stop the advancement of cancerous cells. The term illness, on the other hand, refers to more symbolic phenomena. As used by sociologists, the term illness takes into account that the whole person is affected by sickness, not just the diseased organ (Cassell 1976). Most importantly, the term illness is subjective in nature, and has come to represent cultural metaphors for what is broadly considered as unfitness (Cassell 1976; Reissman 2003). In America, breast cancer represents a gendered illness with meanings that extend beyond the biological nature of the disease. To speak of breast cancer as a gendered illness is to speak directly to socially constructed constraints on social roles, gender, and the body (Cassell 1976; Reissman 2003; Bird and Rieker 2008; Regher 2012; Sulik 2011). While it affects females more than males due to sex differences, the impact of breast cancer on black women is influenced by more than these biological facts.

Breast Cancer and the Pink Ribbon Culture in America. The treatment of breast cancer in America, however, has implications that extend beyond the biological factors of this disease. The treatment of this illness is influenced by cultural norms about feminine bodies. Hence the adoption of pink, a color that symbolizes mainstream notions about femininity, by activists dedicated to fighting breast cancer. What Sulik (2011) calls pink ribbon culture (henceforth referred to as PRC) arose from a breast cancer movement that advocated for women's health. The breast cancer advocacy movement emerged in the 1970s, following the important women's rights social movement of the 1960s and 1970s. Proponents behind the early breast cancer movement sought to humanize women who contracted the disease. Previously women were demonized for having breast cancer, largely because of the nature and meaning of the organ it affected. This led to aggressive and crude treatment of the disease, which often left women maimed and incapacitated, usually at the hands of male physicians (Sulik 2011; Regher 2012; Olson 2002).

The early breast cancer movement brought public awareness to the nature and causes of breast cancer, and encouraged women to practice medical consumerism, an informed utilization of medical services (for instance, by investigating her treatment options). This movement was successful insofar as it was able to redefine the image of the woman with breast cancer by framing her as a survivor. The survivor held a respectable position within her community, and this identifiable image resonated with the public. The survivor image was important in destigmatizing the disease and normalizing experiences of women affected by this illness (Sulik 2011; Klawiter 2008).

As the movement began to become more popular and its messages disseminated among the general public, this image of the survivor began to undermine women's health advocacy. The 1990s mark a pivotal period in the breast cancer movement, in which the message of advocacy transformed into a culture that concentrated on aesthetic and gendered images of coping with the illness. The growing popularity of programs that came out of this culture, such as National Breast Cancer Awareness Month (NBCAM) and "Look Good, Feel Good" (which was founded by a cosmetic and toiletry corporation), helped facilitate this transition. Also during this period, breast cancer advocacy groups adopted the color pink and the emblem of the pink ribbon to symbolize this disease, and the public followed suit. This color appeals to traditional notions of femininity, which are steeped in hegemonic norms of the goodness and beauty a woman is supposed to represent (Sulik 2011).

In all, this culture of treatment and activism normalizes all experiences of women facing this disease by placing emphasis on coping in ways consistent with pink femininity. So what are the stipulations for survivorship under this pink femininity model? Sulik (2011) writes, "With femininity intact, either through normalization processes or using breast cancer as a badge of honor, the she-ro is a feminine hero with the attitude, style, and verve to kick cancer's butt while wearing 6-inch heels and pink lipstick. She returns from the battle, if not victorious, then revitalized and transcendent" (16). Interactionist theories of "doing gender" can help us examine why this representation of the breast cancer survivor resonates so powerfully with the American public (West and Zimmerman 1987). All women are expected to "do" breast cancer in similar ways, just as they are expected to "do" gender in a male dominated, gender-binary society.

Gender, *Doing Gender*, and the Pink Ribbon Culture of Breast Cancer Treatments

For American women, doing gender according to present-day prescriptions entails enacting such roles as nurturer and includes expectations for a certain degree of passivity when dealing with distress (West and Zimmerman 1987; Simon 2002; Sulik 2011). Additionally, women are pushed to adopt certain feminine body projects, which represent efforts at achieving the cultural standard for a body type considered attractive and healthy (Brumberg 1983, 1993; Merianos et al 2013; Weitz 2010). These prescriptions for doing gender become so engrained that individuals find it difficult, if not impossible, to escape these gendered expectations when dealing with stressors such as cancer diagnoses (Schippers 2007; Courtenay 2000; Charmaz 1994). The image of the PRC survivor reinforces such ideologies, and sometimes depictions of this survivor look a lot like Barbie.

Universalizing breast cancer experiences. The discourse used within the PRC universalizes womanhood by concentrating on aesthetic aspects of treatment that are steeped in notions of hegemonic femininity. For example, the PRC survivor image embodies expectations for feminine body projects as demonstrated by the concentration on breast appearance and head coverings central to contemporary treatments of breast cancer. The concentration on breast appearance coincides with the rise of plastic and cosmetic surgery in the latter part of the 20th century (Merianos et al 2013; Sulik 2011). Reconstruction is as normalized in the treatment of breast cancer as chemotherapy and mastectomies; women may feel pressure to undergo this invasive surgery to be restored back to the ideal feminine image. Likewise, the early and ongoing influence of the cosmetic industry in breast cancer advocacy is a symptomatic of the importance of the feminine ideal in American culture. For instance, women are encouraged to wear wigs to hide the effects of chemotherapy and give off the image of feminine hairstyles.

These are just two ways in which a society-wide emphasis on aesthetic ways of coping invades the lives of women undergoing treatment for breast cancer (Sulik 2011).

As for emotions, PRC also stipulates how women should feel and react to cancer. The image of the survivor is a happy, attractive woman, one who feels resilient and of "good cheer" after her bout with breast cancer and its treatments (Sulik 2011, 103). These prescriptions also mandate a certain degree of prudence in how women react around others when dealing with breast cancer. Emotions like sadness, depression and anger are not acceptable under this paradigm (Sulik 2011; Regher 2012; Lorde 1980). Yet, such a life threatening illness would undoubtedly trigger these stigmatized emotions insofar as many women feel powerlessness and fear in the face of an uncertain future (Lourde 1980; Sulik 2011). The stifling of these negative emotions may not be conducive to well-being among women who experience breast cancer (Sulik 2011).

Many women's lives do not conform to these gendered norms. When women do not embody this model survivor, they find themselves disparaged for not conforming to standards of pink femininity (Sulik 2011; Lourde 1980). These gendered expectations of the breast cancer survivor are problematic in part because, similar to tenets of doing gender, PRC appeals to norms associated with middle and upper class white experiences. As a matter of fact, the women who were first used as images to symbolize breast cancer survivorship were famous and wealthy as well as white (e.g. Betty Ford, Minnie Pearl) and not representative of the general population (Sulik 2011). Current breast cancer advocacy comes from a legacy of high society in which women held luncheons, teas, and other elegant affairs to raise awareness about this ailment. Importantly, these events were for the primary purpose of fundraising; and participating women used their social statuses to leverage financial resources (Sulik 2011; Klawiter 2008).

Traditional notions of femininity are inherent in these high society practices that disseminate messages like prudent behavior, the importance of appearance, and the presumption of heterosexuality (Sulik 2011; Ingraham 1994). Most of these experiences related to the survivor image are unattainable to many women, especially black women who have historically been denied access to economic and cultural resources needed to obtain this social positioning (Craig 2002; Collins 2001).

Yet those who occupy marginalized racial/ethnic statuses, like black women, do identify with the PRC survivor and the pink femininity rhetoric. Why would they? The answer lies in the strategic dissemination of culturally specific materials that draw all women into buying the distorted message of pink femininity (Sulik 2011). In an attempt to reach minority women, physicians and other players within the PRC use the premise of cultural competency to bring the message of pink femininity to black, Latina, and other minority women (Sulik 2011). In this context, cultural competence means that physicians and other health professionals use language and tactics that appeal to minority women and make them buy into the PRC survivor image. Through these tactics, the message of PRC successfully transcends racial and ethnic boundaries by creating a universal frame of femininity. The use of terminology such as “classiness” and “with sass” within the rhetoric of black breast cancer advocacy groups indicates that this marginalized group of women has largely bought into the pink ribbon model for disease treatment (Sulik 2011; Sisters network ref).

How black women are expected to do gender in general is steeped in black middle class norms for being a woman. These middle class norms are especially problematic given the oppressive constraints that prevented most black women from advancing from the lowest rungs of occupational statuses. Individually, within white majority contexts, black women are often held as models or symbols of their entire race. Thus embodying unattainable middle class norms is held as a standard for how well one performs and represents her race (Craig 2002; Davis 1983). I will discuss this issue in more detail below, after addressing how social structures affect the lives and health of black women.

Some of the ideas associated with the pink ribbon culture do resonate with notions of black womanhood. While scholars note that racial paradigms do influence body type and hair style preferences through the use of cultural stereotypes, there is no strong evidence that the significance of certain body markers for gender performances and identity varies by race (Brand; Banks 2000; Weitz 2010; Ulmer). For example, breasts and hair matter across racial lines (even if favored sizes and styles differ), and all women treated for breast cancer may seek out reconstruction and head coverings to aid in appropriately performing and displaying gender (Sulik 2011; Craig 2002; Weitz 2010; Regher 2012; Young 2009).

Barbie bodies: gender socialization and feminine bodies. The importance of breasts and hair for how women display gender results from gendered socialization about normative body standards, which starts early in a girl's life. Toys young children play with socialize girls in particular to accept meanings and expectations for proportionality and breasts before they are biologically mature enough to have natural experiences with breasts for themselves. Barbie—first popularized in the 1950s—is a popular replica of an idealized feminine body. Pleasant-natured Barbie has a slender waist, with thin hips, and large plastic breasts. Initially, Barbie was also white with blonde hair. This type of socialization continues over the lifespan and models ideologies of hegemonic femininity[1].

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[1] Or white, normative, mainstream notions of femininity

Despite the white-washed portrayal of gender and femininity in America, expectations for the curvy, gold standard feminine body transcend racial and ethnic lines. Now, girls of all racial and ethnic backgrounds learn this lesson early. While it took decades, the Barbie brand (and its parent company, Mattel) eventually bridged the racial divide. Increased cultural awareness over the last part of the 20th century led to the coloring of Barbie's skin. Now, she comes in multiple skin shades and colors. Facial features and hair were more slowly adjusted to represent different racial and ethnic groups, symptomatic of the continued cultural preoccupation with white femininity.[2]

The elusive black Barbie and veiled black femininity. When I was a girl, my mother was determined to inundate me with black Barbies (and other black dolls). The replica I played with as a girl did not necessitate that I incorporate white skin into my image of the model of femininity. To me, Barbie was beautiful and she was black; *yet*, she still had curvy, busty body proportions. I was showered with black Barbies every birthday and Christmas, and my mother would justify her extravagance on her unfulfilled wishes from a childhood spent in the 1960s. She *hunted* for these dolls in multiple stores; a pastime I now share when shopping for my niece. It should be easier given online markets like Amazon.com and Target.com; yet still, black dolls, in general, are not easy to find[3].

Our quest for black dolls (across generations now) is symptomatic of how American culture conceives femininity and beauty. In other words, the elusiveness of black femininity and beauty experienced in the hunt for black Barbie translates into *adult* world practices. Black

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[2] The discussion of facial features and hair lie outside the scope of discussion for this chapter. I will discuss hair and black women in Chapter 2. Up until recently, Black Barbie had Caucasian features. Interestingly, Mattel reports having released their first African-American doll in 1968 --a white doll with black hair (Christie). It wasn't until 1980 that she actually had brown skin.

[3] Additionally, black dolls are often more in my experience.

women rarely find their likeness depicted as models in the media or included in dialogues about femininity. That is not to say that there are not more black women in the public eye than there have been in the past. However, the numbers are still relatively few, and black celebrities bear the burden of representing their race and having their unique success being held as a metric of all black progression. This inattention to black women and femininity also applies to academic research. Hence it is necessary to use an intersectional perspective for understanding the experiences with breast cancer for black women.

Intersectionality and Health

Intersectional health scholarship describes the health experiences of individuals who occupy multiple statuses within the US. This scholarship recognizes complexity in that people occupy racial, class and gender statuses at the same time (McCall 2005; Harnois and Ifantunji 2013). In this dissertation, I take an intersectional theoretical and methodological approach to address health disparity issues that affect black women, who by definition occupy multiple marginalized statuses.

When research fails to consider the simultaneous influences of multiple social categories it implies universal womanhood, perpetrates genderless racism (hence the dominance of racial and discrimination scholarship exploring experiences that are more likely to happen to men), and makes the experience of minority and disadvantaged groups, like black women, invisible in academia and public arenas (Mullings and Schulz 2006; Choo and Ferree 2010; Harnois 2013). Intersectionality is one tool by which these marginalized experiences can be situated within academic scholarship. Conceptually, it explains the interaction of multiple statuses—such as race, gender, and class—that shape differences "in individual's lives, social practices, institutional arrangements, and cultural ideologies and the outcomes of these interactions in terms of power" (Davis 2008, 68). In other words, the intersectionality perspective recognizes that people are products of multiple social forces and that symptoms of these complex relationships occur at all levels of human interaction (Davis 2008; Carbado 2009; Collins 2001).

Intersectionality is a framework that includes a variety of conceptualizations and methodological approaches (McCall 2005; Davis 2008). Scholars approach intersectionality using various interpretations, ranging from the call to dismiss all categories to more complex analyses that demand the comparison of multiple social statuses simultaneously. Feminists of color and minority scholars tend to use the intracategorical approach, which is a middle ground interpretation of intersectionality. Intracategorical approaches consider smaller intersections of the population—such as black women—where people occupy multiple subordinate locations (McCall 2005). The implications of race, class, and heteronormative notions of gender for health justify my selection of this interpretive approach for studying black women with breast cancer. Importantly, the intersections among race, gender, class, sexual identity, and age contribute to a great deal of unexplored variation within black women (Moore 2011). In particular, the meanings and effects of social class within black populations are drastically understudied phenomena within the health literature. My dissertation addresses this topic as it applies to black women experiencing breast cancer. By using an intracategorical perspective, I can discuss how gender, race, and class affect black women who have been diagnosed with breast cancer. These effects occur on multiple levels: individual, small group/interactional, and institutional/structural.

Gender. I begin with a discussion of gender given its salience in defining the pink ribbon culture. Numerous feminist scholars theorize that gender is an institution or structure that permeates across all levels of social life (Acker 1990, 2006; Risman 2004; Martin 2004;

Schippers 2007; Bird and Rieker 2008). As an organizing structure, gender shapes the self, interactions in institutions such as family and work environments, national policies, and cultural expectations. Inequality as it relates to gender has effects on institutional, interactional, and personal levels as well (Risman 2004; Martin 2004; Bird and Rieker 2008).

In order to understand variations in health by gender, it must be acknowledged that this social construct maps to a biological component, sex. This particular component makes gender different from the other two master statuses of race and class. Some variations in health conditions are based on sex differences. For instance, conditions such as immunological disorders are more prevalent in females while incidence rates of cardiovascular diseases are more prominent in males, for apparently biological reasons. Females tend to have more intense immunological responses, as illustrated by passive immunology during pregnancy and the health benefits of breast feeding. In the same light, previous pregnancy can exacerbate immunological certain conditions (e.g., lupus) and improve others (e.g. arthritis) (Bird and Rieker 2008). Additionally, being female includes some biological protective mechanisms against cardiovascular diseases, patterns that have not been observed in males (Bird and Rieker 2008; Richardson et al 2011; Crimmins 1981; Crimmins 1994). Similarly, breast cancer as a disease has certain biological risks attached to it, and the biggest risk factor for this disease is being female. Males are about one hundred times less likely than females to contract breast cancer and represented only one percent of new diagnosed cases in 2015. The female sex hormones of estrogen and progesterone and denser breast tissue primarily explain the elevated risk in females (ACS 2015). These facts have little to do with the social components of gender. However, the way the disease of breast cancer is treated is gendered--and socially constructed--as seen in the PRC popular rhetoric for treatment of breast cancer in America.

Doing gender is a popular interactionist theory used by feminist scholars to describe and make sense of how gender is constructed in social interaction. Patriarchy and gender inequality would not be reproduced if people did not embody and enact the social norms of what it means to be a man or woman. West and Zimmerman (1987) describe the process of "doing gender" as creating differences between men and women that are inessential, socially constructed, and not biological. Doing gender requires that individuals take actions, adopt identities, and perform ongoing assessments if they want to be classified as a man or woman. For women, the need to "do" gender inspires certain performances, demands attention to appearance, requires certain emotion work, and insists on adherence to certain roles so that society can deem them as practicing suitable womanhood or femininity (West and Zimmerman 1997; Hochschild 2003). Gender becomes a daily interactional accomplishment (Dull and West 1991), which can have macro level consequences for both men and women. National policies and practices within the work environment reflect the consequences of gendered assumption. For instance, that women get paid less than men rest on the primitive assumption that men are breadwinners, and women's work is traditionally in the home. Moreover, women are more likely to have access to (and longer) parental leave than men, which is symptomatic of gender ideologies that assume women are responsible for childrearing (Bird and Rieker 2008).

In addition, these gendered interactions reinforce the internalization of hegemonic femininity norms, such that they become essential to one's identity. Hegemonic femininity refers to the cultural expectations and qualities women are expected to have and follow to be considered appropriately feminine (in a particular place and time). It is important to note that this ideology best describes the experiences of white middle —or upper —class women in American society (West and Fenstermaker 1995). Like hegemonic masculinity, these standards are based on patriarchal, white, largely middle class notions of womanhood. In other words, "proper" women in the contemporary United States are pretty, passive, nurturing, and love the color pink (Risman 2003; Martin 2004; Ridgeway and Correll 2007; Deutsche 2007; Connell & Messerschmidt 2005).

The social dynamics of gender contribute to health differences between males and females in a number of ways, primarily through pathways of personal behaviors. According to Courtenay (2000), the social construction of manliness or masculinity contributes heavily to elevated mortality for men because in pursuit of privilege and power, men do harm to their bodies. Men are more likely than women to engage in behaviors with negative health consequences such as extreme sporting, infrequent visits to the doctor, refusal to acknowledge pain, and overworking, all of which put them at greater risk of immediate death, injury, or developing severe acute and chronic illnesses (Courtenay 2000; Bird and Rieker 2008). Thus, across race/ethnic categories and at all class levels, women outlive men (Bird and Rieker 2008).

Women on the other hand have higher incidences of morbidity. That means that they experience longer periods dealing with chronic illness or they live longer, but sicker lives (Bird and Rieker 2008; Simon 2002). Some theorize that internalizing responses to stress, which women are more likely to do than men are, creates physiological changes in the body that lead to chronic conditions like autoimmune disorders and obesity (Simon 2002; Kowaleski-Jones and Christie-Mizell 2010; +). Women are also more likely than men to report higher levels of psychological distress and mental health conditions. These factors lead to different health experiences for men and women.

Medicalization and gender. Medicine and science treat women and men’s bodies differently beyond what is necessarily prescribed by biological differences. Riessman (2003) defines medicalization as the outcome of two interrelated processes in which natural responses or deviant behaviors become framed as illnesses and therefore subject to medical control (see also Conrad 1992). Medical control is a form of social control; and medicalization processes can be considered therapeutic styles of social control; they commonly serve to uphold hegemonic structures and practices in place in broader society.

All bodies have been subject to medicalization, however women's bodies tend to be under more medical scrutiny than men's. Women's bodies are usually medicalized regarding reproductive capacities, secondary sex characteristics, and natural body responses (Riessman 2003; Weitz 2010). One paradigm for examining medicalization and the female body is childbirth. No specific characteristic of childbirth renders it as inherently medical; and the process is fairly uncomplicated 90% of the time. Prior to the 19th century, childbirth was considered a natural process, occurring in the home, and laboring women were attended by midwives or female family members. Today (in the US, specifically) both childbirth and pregnancy are highly medicalized events; births are commonplace in hospital and clinical contexts. An entire medical field is devoted to pregnancy and labor. Today, *natural* childbirth means that women go through labor without an epidural or other type of anesthetic, yet, the woman is typically still under medical care in a hospital or birthing center. This means that medicine helps to shape what is culturally perceived as medical as opposed to natural—an important phenomenon to remember throughout this dissertation as I discuss breast reconstruction and hair (Riessman 2003; Weitz 2010; Wolf 2003).

Shifts or catalysts in the medicalization process can be attributed to the power of medical professions, the influence of a social movement or cultural change, and because of the ambition of a political or other power organization (Conrad 2005). Similar to the first proponents of the breast advocacy movement, the rise of medicalized childbirth around the turn of the 20th century was due to the interests of white middle class women (and white male physicians). These women sought relief from pain during childbirth and worked with white male physicians, whose interests were to monopolize the healing market and delegitimize other healers like midwives.

Other aspects of reproduction fell under medicalization following the rise of medical childbirth. For instance, as more (white) women began to work outside the home—starting in the 1900s—the scientific field began to pay more attention to menstruation, as it could affect women's work. Taboos around this natural body process arose, as scientists became fixated on the days before menstruation. In 1931, a male scientist came up with the concept of PMS, problematizing this natural body process and upholding stereotypes of different spheres for men and women. In this context, presumed hormonal spikes that affect women's emotional management renders them less productive than men on certain days before menstruation. Against the backdrop of medicalized menstruation, when women display natural responses, such as anger, as reactions to social conditions, these responses are often relegated to hormonal imbalances. Dialogue around PMS/PMT stipulate times in which anger and depression are acceptable, and delegitimized real reactions (i.e. depression) to social stress for women (Martin 2001).

Breastfeeding is another reproductive features that has become subject to medical control. Under the scientific lens, this process is interpreted to be a natural phenomenon which both solidifies the mother-child bond and passes developmental nutrients to the child. Women who do not breastfeed are often seen as bad mothers. This ideology does not take into account that some women cannot naturally breastfeed. Moreover, work schedules also prevent some women from being the sole source of nourishment to infants. Importantly, women can bond with children without breastfeeding (e.g. adoptive mothers and birth mothers who choose not to). This perspective also discounts the fact that women eat genetically modified foods, and thus pass on unnatural chemicals to their babies during breastfeeding (Blum 2000).

The overall movement towards medicalizing the entire female body are important for the breast cancer context because of the nature of the body part this cancer affects. Additionally, medicalization tends to reduce women's bodies to parts, as seen especially in fields such as plastic surgery (Weitz 2010; Dull and West 1991; Merianos et al 2013). With the rise of medical cosmetic procedures and plastic surgery over the past couple of decades, the physical features of women increasingly have become subjected to medical jurisdiction. Plastic and cosmetic surgery procedures mainly target the face, breasts, skin, and body of women (Merianos et al 2013). These features are objective aesthetic qualities, meaning that society places great emphasis on the *prettiness* of physical characteristics for assessing how well a woman is adhering to gender expectations. In this light, "flawed" secondary sex characteristics (e.g. breasts) of women can be *corrected* by medical treatments (Dull and West). Cosmetic surgery is rapidly becoming a normative way for women to effectively perform American cultural expectations of gender--especially prettiness (Dull and West 1991; Merianos et al 2013).

The tail end of the breast advocacy movement that led to the current culture for treating breast cancer, with its focus on aesthetic coping, coincided with the rise of cosmetic medical procedures in the late 20th century. Trends in medicine affected this health advocacy movement, as what emerged as its main frame emphasized aesthetic forms of coping for the treatment of breast cancer. Women are encouraged to maintain the appearance and manner of hegemonic femininity while undergoing treatment for cancer. However, to stop the spread of cancer, which leads to death, medical intervention is necessary. These medical interventions often disfigure the body, especially when they are designed to cut out cancerous legions from the breast. Therefore, the tie between disease (cancer) and cosmetic/plastic surgeries that are aimed at correcting the breast may complicate how breast cancer patients process illness given gendered expectations for appearance (Sulik 2011).

Gender and sexual identity. It is also important to note underlying assumptions implicit in much of popular culture (and some research) which encourage people to interpret gender through a heterosexual lens. Many studies presume that heterosexuality is natural (or at least the default status) in humans, and assumptions that people are heterosexual shape norms for how women should perform and embody gender. This heterosexual norm also influences broad policies that shape career and educational choices available to women, and affects the cultural meanings of womanhood in America. It structures divisions in labor and wealth, for example, insofar as pay structures assume that women's wages are supplementary to those of breadwinning husbands. Assumptions of heterosexuality also shape medicalization processes and how women's bodies are treated when they experience illnesses like breast cancer (Ingraham 1994; Sulik 2011).

The fact that gender is conflated with assumptions of heterosexuality is especially relevant to experiences of black women in America. Throughout history common stereotypes such as the Jezebel or welfare queen appeal to notions of the hypersexual heterosexual black woman, which was an ideology used to justify racial oppression as a whole (Hickey 1999; Davis 1983; Craig 2002). Not only has the assumed hyper-heterosexuality been used to justify the sexual abuse of black women, but these ideas also contribute to the demonization of black men (Craig 2002). Now, I move on to a discussion on the pathways through which race--as it intersects with gender--can affect health and influence women's experiences of breast cancer.

Race. According to the National Cancer Institute (NCI), a disparity exists when incidence, prevalence, burden, mortality, or other adverse health conditions of disease vary by population groups in the US (Anglin 2006). Disparities are often found along the lines of major social statuses, a phenomenon that reflects the structural inequalities found within current society. Along racial lines, we find some of the most persistent and disturbing differences in health. Why? I begin to explain this trend by starting with a quote from Audre Lorde. In her *Cancer Journals*, she describes daily living as a minority women in America, "all carrying within our bodies the seeds of destruction not our choosing." In this quote, she explains how social constructs like race can get underneath one's skin to produce real consequences for health. Consequences of America's racial structure result in trends of poorer health for black individuals. Black women's health is better than black men's, but this difference maps on to traditional patterns in gender where women tend to outlive their (racial other) counterparts by 6-7 years (Bird and Rieker 2008). These trends in racial health disparities have persisted since Africans were forcibly brought to the US. Dehumanization tactics that began in slavery—when race was viewed as a biological phenomenon—have led to disadvantages relative to whites (and most other ethnic groups in America) for black men and women in mortality and incidence of illnesses (Wilson, Thorpe, and LaVeist 2017).

Historically, biological explanations were used to justify inequality in America based on race. Presently, however, scholars find race to be a social construction in which the notion that physical or phenotypical characteristics distinguish humans is accepted to be normative and biological--even though scientific research demonstrates that it is not (Delgado and Stefancic 2012; Bonilla Silva 2004). The resulting racial structure shapes social relations that organize the economic, social, and political opportunities available for different groups in society (Bonilla

Silva 2004, 2006). Racism is the discrimination or prejudice that occurs due to this racial structure. Similar to gender inequality, racism can occur on an institutional level (unequal access to resources and opportunities), a personally mediated level (discrimination and prejudice between individuals), or can be internalized on a psychological level by members living in a racially conscious society (Jones 2000; Bonilla-Silva 2004, 2006).

The consequences of racial structures on resource allocation have been so strong that class and race have become largely intertwined in both practice and ideology. This means that in America, the categories of black and white have not only come to distinguish between skin colors, but also to imply differences in socioeconomic and occupational status (Omi and Winant 1994). This link between race and class is rooted in historical institutional racism. Aside from the first major insult of chattel slavery, the oppressive climate of the late 19th and early 20th century was pivotal in maintaining group status differences between blacks and whites (Davis 1983; Brodkin 2002).

National policies and practices limited access to quality education and diverse employment opportunities for blacks. In the mid-1900s, domestic policies like the GI bill and other government interventions subsidized education and facilitated home ownership for many white Americans. For instance, the GI bill provided 16 million veterans with access to jobs, low interest mortgages, and subsidized higher education. Both de jure and de facto discriminatory practices, such as segregated schools, redlining and steering in real estate, and prejudicial hiring practices fundamentally closed access to these economic resources to blacks. Blacks--even those who had served in the military—were denied access to the majority of higher learning institutions because of segregated college campuses. Banks denied blacks these low-interest mortgage loans, and real estate practices steered blacks who could own to less desirable areas with environmental and infrastructural hazards. Moreover, white employers denied access to well-paying jobs through racist hiring practices (Brodkin 2002; Williams 1999; LaVeist 2005). As a result, stark and persistent disparities in wealth were established between blacks and whites. Some estimate this gap to be as great as tenfold amongst those of a similar income level (Wallace and MaEntee 2010; LaVeist 2005). This wealth disparity has had important consequences for establishing group differences in health and mortality (Brodkin [2002]; LaVeist 2005).

Arguably, the most important mechanism for maintaining racial inequality is residential segregation, which has consequences on individuals' status attainment and physical and mental health (Do 2009; Browning et al 2003; Aneshensel 2010; Williams 1999; LaVeist 2005; Massey and Denton 1993). Since the abolition of slavery—and before the Civil War for Northern states—segregation has been enforced by law and cultural practices (Omi and Winant 1994; Wilson 1978; Massey and Denton 1993). The ghettoization of predominantly black segregated areas has led to the political control and economic subjugation of blacks. Therefore, blacks have little power to improve the infrastructure of segregated areas (Wilson 1978; Collins 2001).

Residential segregation is strongly correlated with the quality and quantity of infrastructure and resources available to individuals within a geographic area. Presently, highly segregated areas tend to have poorly funded public schools, few opportunities for higher education, and very few employment opportunities (Williams and Sternthal 2010; Williams 1999; Bonilla-Silva 2006; Williams and Collins 2001). In addition, these areas have ample access to liquor and tobacco products while providing very restricted access to nutritious foods. These factors along with the lack of infrastructure that facilitates leisurely physical activity make segregated areas hotspots for the production of poor health (LaVeist and Wallace 2000; Williams and Sternthal 2010).

The degree of segregation of blacks from other racial and ethnic groups has not improved much over history, and presently, the overwhelming majority of black Americans still reside in predominantly black areas. This finding is not contingent on socioeconomic status (SES), as high income blacks are highly segregated at levels that far exceed those for the poorest individuals of other minority groups (Williams and Sternthal 2010; LaVeist 1993; Massey and Denton 1993).

Race, gender, and social status/class. Collins (2000) writes that black women have been especially suscepthistory ible to the ghettoization associated with segregation. Since a large proportion of black women have always participated in the labor force in dual or sole earner households, the lack of opportunities for employment and education have had both direct and indirect effects on the life experiences of black women (Collins 2001). Additionally, gendered roles like motherhood, especially in single parent homes, within these areas expose black women and their children to the hazards of segregation more than black men and whites. Moreover, black women are more likely to be members of churches and community organizations within these communities than black men are. While these institutions do provide resources and support to black women, it is important to note that because of poor infrastructure and restricted access to resources, these organizations are usually less well off (financially) than similar ones in predominantly white areas (Collins 2001; Lincoln, Chatters and Taylor 2005).[4]

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[4] The church has been an important institution in black women's lives and has served as a free space in which to strengthen collective identity, fight against racial stereotypes, and rearticulate the meaning of race. The church has also been important in disseminating social support to black women in the forms of tangible and informational aid.

The unequal distribution of economic opportunities within segregated areas has also contributed to differences in social relationships and family structures between groups of blacks and whites. Many times, black social support groups have a sizable proportion of members who are low in education, income, occupational prestige and other socioeconomic factors. This intertwining of low SES with norms of group social support presents challenges in black women's lives that create atmospheres in which black women's lives are more strained than white women's. One notable disparity is observed within the (heterosexual) marriage market, which is highly variable by rates of male un- and underemployment (Wilson 1978; Clarke 2011). Thus, black women who marry are less likely to have, and those unmarried are less likely to find, a partner who can adopt the breadwinning—or even equal earner—role than white women who marry (Clarke 2011). This is important because research finds that various forms of social support from spouses is highly correlated with improved health after cancer diagnoses (Kroeneke et al 2013a,b; Bloom 1993).

Low rates of marriage for black women potentially reflect the emotional and financial strain experienced by this group and exacerbate group differences in SES and health. Importantly, however, the lower marriage rates within the black community do not imply lower rates of parenthood, and black communities are often categorized by high levels of female led single parent households. This creates the tendency for precarious communities in which women

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In all, the church provided cultural and economic resources which racial oppression had closed for the majority of black women. Yet, there is a give-and-take relationship with this institution. Black women have been integral for maintaining the vitality of the church in the black community. They often serve as organizers of events, and are more likely to participate in activities than all men and white women. However, they are less likely to serve in leadership roles like pastors (Robnett 1997; Sarkisian and Gerstel 2004; Craig 2002; Lincoln, Chatters, and Taylor 2005).

are highly co-dependent on each other’s scarce resources (Lincoln, Chatters, and Taylor 2003; Mullings 2005; Robnett 1997; Robbins and Padavic 2007).

Race, gender and femininity. Race has also shaped how individuals experience gender socialization. Womanhood for black women accordingly differs from mainstream (white) forms of femininity. Black femininity is often devalued and typecast as a pariah—or less feminine—form of femininity. This devaluation of black femininity is the result of several historical processes. For instance, chattel slavery in America consisted of coercive, strenuous, genderless work (Davis 1983). Black women and men worked alongside each other in fields, performing backbreaking manual labor, and both genders were equally subjected to whippings as punishment (Davis 1983; Collins 2000). Even after the fall of slavery, less pronounced gendered divisions in work led to the tendency for black women’s work profiles to look far more masculine than those of white women. Black women have been more likely to work outside the home and therefore to experience strains akin to (middle class) white and black men who participate in the male breadwinning role. However, oppressive structures constrained the occupational roles available to black women, who have historically held low wage, undesirable positions such as the domestic worker (Collins 2000; Acker 1900, 2006; Martin 2001).

This strenuous work has also contributed to the stereotype that black women are impervious to distress, as demonstrated by what some scholars call the strong black woman phenomenon. When they internalize the ideology of the strong woman, black women must face strains, such as motherhood and low earnings, while being robust and durable. Powerful images of the mammy signify this stereotype, as the mammy is hardworking, nurturing, and resilient. Such stereotypes contribute to the lower rates of diagnoses of psychological disorders and lower utilization of mental health resources by black women when compared to white women. The physical consequences of this mentality manifest in higher levels of obesity and other forms of stress-induced acute and chronic conditions among black women compared with women from other racial backgrounds (Beaubouf-Lafontant 2003, 2007; Mullings 2005).

The ways in which race and gender intertwine are complicated, because as the asexual mammy has come to represent black women, so has the polar opposite image of the whore. As a group, black women have been disproportionately exposed to rape, molestation, public exploitation, and medical experimentation. Images of the hyper(hetero)sexual black female have been used to justify such treatment and victimization (Davis 1983; Collins 2001; Craig 2002; Roberts 2014).

All women are subject to sexualization, especially busty women, but the history and version that this sexualization for black women takes is extreme and distinctive. For instance, the media celebrates curvy, big-breasted white women (e.g., Kim Kardashian—all the Kardashians, Scarlett Johansson, Christina Hendricks), yet they do not treat black curvy bodies with the same admiration (Davis ; Collins ; Capodilupo and Kim 2014). Body image (and the evaluation of physical signs of femininity) for black women was initially rooted in the commodification of their body parts, which served as a means of alienating women from the body. At the same time, a racialized gender/feminine identity was also born out of this complicated history of subjugation and oppression. This gender identity linked voluptuousness with the black female body: a gold standard for beauty that black men (and the black community) appreciate and the outside world appropriates without accepting the black woman herself.

The history of the treatment of black bodies and femininity. Exploited versions of black femininity are not as elusive as the celebration of the beauty of black femininity. Black female bodies have been subjected to a variety of abuses since Africans were first forcibly brought to the U.S. The hypersexualized stereotype (Black Jezebel, a hoe (i.e., whore), or Hottentot Venus) is depicted as having large breasts, a big butt, and shapely hips. She is dangerously sexual or promiscuous (and fertile). This hypersexualized stereotype has been used to policing black women reproduction and to justify heinous acts of sexual coercion, rape, experimentation, and exploitation routinely practiced upon black women (Hickey 2006; Collins 2001; Davis 1983).

Insensitive treatment of black women and their bodies extends past American borders and describes a strand of Western thought more broadly. The sexualization of black female bodies is best exemplified by a young Khosian woman, named Saartjie Baartman—derogatorily nicknamed Hottentot Venus—born in southern Africa in 1789. As a young teen, Baartman was tricked by merchants into traveling to Europe[5] where, after her arrival, her captors exploited her body in minstrel shows around England and France. She was often paraded around chained and nude. At these shows, white men *and women* ogled at her protruding labia, big buttocks, and large breasts. The public display of her nudity was justified because she represented both a sex symbol because of her gender and an animal because of her race. Eventually, her captors introduced her to opiates, forced her into prostitution, and she died alone at the age of 25 in Europe. While Baartman never touched American soil, her experience represents the universal

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[5] Europeans did not have the same "access" to black bodies as (Southern) whites did in America. For them, the notion of a black woman was still exoticized. Baartman was never legally/officially a slave, as slavery was not a lawful practice in much of Europe at the time. However, after she was lured to Europe, the men who captured her used intimidation, drugs, and distance to keep her subjugated as one would a circus animal. Moreover, she was a woman in a strange land with no resources and access to return to her distant home. In addition to parading her in minstrel like shows—including being dragged around on a chain, naked, while making animal sounds—her captors also served as her pimps. photo taken from bbc.com
Screenshot of google image search for Saartjie Baartman—notice one of them is not Baartman, but a contemporary symbol of black womanhood. And by all practical measures, Beyonce is a slim/small woman.

mistreatment of black female bodies, as many American whites had "Hottentot Venuses" tilling the soil of their backyards.

This type of victimization extended beyond the years of slavery, influencing contemporary race and gender stereotypes (Davis 1993, Roberts 2014; Collins 2001). For instance, in the preface of the second edition of *The Woman and the Body*, Martin (2001) calls our attention to how race and gender intersect to marginalize black women in images of gynecological exams and birthing from medical textbooks. Historically, it was socially acceptable to display female genitalia in textbooks only if the depicted bodies were black, symptomatic of the overall resistance of the general public to acknowledge the vulnerability associated with black femininity and sexuality (Martin 2001; Collins 2000; Hickey 2006).

Baartman continues to be a salient image of voluptuous black femininity long after her death. Until 1973, patrons could travel to a French museum and still gawk at a mold of her body as well as her dissected sexual organs. Today, a google search of her name will render images of that same mold even though her remains have since been buried. Countless other images that exaggerate her breasts and buttocks surface in the search as well. Interestingly, Baartman's name also returns images of another black feminine icon, Beyoncé, a woman both celebrated and critiqued for her curvy proportions. It is important to note that Beyoncé, although deemed curvy, is a size 2 (). Additionally, Baartman's frame was not large either judging by the photos of people standing next to the mold of her corpse. Thus, curviness is exaggerated to make black femininity more pariah than white femininity.

In order to combat these stereotypes, the image of the black woman has been heavily policed within black communities, especially by black men. Black women are highly scrutinized for the way they appear and act, as they are held as symbols for the progress or fitness of the entire race. Expectations about how black women should embody their racial identity are rooted in black middle class norms, which often take on the form of traditional hegemonic white experiences (albeit without the resources enjoyed by middle class whites). Additionally, these norms align with colorism and other racial ideologies that praise Eurocentric notions of appearance and performance. More specifically, the image of the ideal middle class black woman demonstrates preference for lighter skin, straighter hair, passivity, and traditional notions of femininity. This image is also chaste, thus making the sexuality of black women open for public chastisement and scrutiny, especially within the black community (Craig 2002; Collins 2001). Black women are often forced or persuaded to adopt norms for embodying race and *doing gender* that they can neither physically nor socially attain. Women who do not fit these norms are shunned, and often considered low class, masculine, or both (Craig 2002).

Now that the nuances associated with black women's social position have been explained, I wish to explore how these factors play into the experiences of those diagnosed with breast cancer in the contemporary pink ribbon culture. Such dynamics can only be captured in the dialogue of these marginalized women who have faced this life threatening illness. I examine these factors by way of 49 black women's stories who survived breast cancer in a context where survivorship is tenuous because of the color of their skin.

Research questions: Using my interviews, I seek to answer the following questions:

How do black women react to the body transformations associated with breast cancer treatment? Additionally, how do race and class nuance these experiences? In chapters 1 and 2, I explore these questions by looking at how women process breast disfigurement and hair loss. What role does social support play in adjusting to life during and after treatments? How was social support activated to help women through their treatment processes? In chapter 3, I examine the role of social support, with a heavy focus on support from spouses, in helping women cope and survive during their breast cancer treatments.

Before discussing women's stories in the chapters following this one, I provide demographic and historical information about breast cancer to situate women's treatments within a broader national and historical context. Major shifts in medicine and cancer treatments occurred before and during the time that the women in my sample were treated. These changes, mostly advancements, powerfully affected the availability of options women had. These women also experienced this illness within a national context where skin color makes their survivorship more precarious than most other groups of American women.

Black Women and Breast Cancer: History and Epidemiology

During the 20th century, America and other Westernized nations experienced dramatic changes in demographics and epidemiology. These changes included large increases in life expectancy and the replacement of infectious diseases with chronic conditions as the main culprits behind mortality (Crimmins 1981; Crimmins et al 1995; Omran 2005; Oshansky and Ault 1987). Importantly, these shifts were in large part fueled by aggregate gains in social economic status (SES) for most American citizens (Omran 1971, 2005; Crimmins 1981). Inequality in America, however, impeded equal access to these SES resources during this time period, which may explain why we observe major health disparities for chronic conditions today. For example, when compared to white women, black women suffer from both greater incidence of, and mortality from, most chronic conditions like diabetes, cardiovascular diseases, and autoimmune disorders. In fact, for some cardiovascular conditions, black women's mortality is higher than that of white men, challenging the assumption that sex is universally protective against these diseases (Richardson et al 2011; Bird and Rieker 2008; Crimmins 1981; Crimmins et al 1994).

There has also been a dramatic improvement in mortality from many forms of cancer, including breast cancer, over the latter part of the 20th century. Innovative medical technologies have contributed significantly to lower cancer mortality rates. Most cancers are now diagnosed at early stages, and treatments for advanced cancers are so sophisticated that many cancers are now widely treated as chronic instead of fatal conditions (Crimmins 1981; Crimmins et al 1994; Zeng et al 2015; Aizer et al 2014). It is important to note that these improvements in cancer mortality align with the demographic, epidemiological, and economic shifts that occurred throughout the 20th century.

Previously, black women had lower rates of breast cancer incidence than white women did; however, the most recent reports show that black-white disparities in incidence no longer exist. Moreover, overall incidence rates hide patterns by age among black and white women with breast cancer. Black women are more likely to be diagnosed early (prior to age 55). However, black women have higher mortality rates from breast cancer, a fact that has remained consistent across decades. Although white women have experienced significant gains in survivorship over the past four decades, black survivorship has remained fairly stagnant while black women's risk for the disease has increased (ACS 2013; Komen 2016). Breast cancer survival rates for black women (around 75%) have not improved at all over since the breast advocacy movement began, while they have improved to above 90% for white women (Sulik 2011; Aizer et al 2014). At all ages, conservative estimates find that black women have about a 40% greater mortality risk than that of white women (ACS 2013; Walsh-Childers et al 2012; Williams et al 2010; Markossian and Hines 2012).

Several explanations have been offered to explain the higher death rates from breast cancer for black women. These reasons include biological explanations that find black women more likely to be diagnosed with basal-like—or triple negative—cancers (ACS 2013; Williams et al 2010; Markossian and Hines 2012). These types of breast cancers typically are harder to treat, have less positive short-term outlooks, and have higher rates of reoccurrence than other types of breast cancer. The greater incidence of comorbidity with other illnesses for black women is another offered explanation for observed disparities (ACS 2013; Grann et al 2006; Funch and Marshall 1983; Funch and Mettlin 1982; Eli et al 1992; Williams et al 2010).

Variations in health behaviors also make a difference, however not in terms of screening (Mishra et al 2012; Williams et al 2010; Gran et al 2006). Some research shows that black and white women undergo routine mammography screening at about the same rates at around 80%. Thus, detection is not the main reason behind differences in mortality (Sulik 2011; Salant and Walsh 2012). Less frequent utilization of screening services by black women often stems from issues related to socioeconomic status and constrained access to resources that affect all women (Kaiser 2008; Mishra et al 2012; Williams et al 2010; Gran et al 2006). However, black women experience longer delays between diagnostic screening, doctor diagnoses, and during and after routine treatment than white women (ACS 2013; Walsh-Childers et al 2012; Williams et al 2010; Whitman et al 2011). Research shows that black women are more likely to be diagnosed at more advanced stages of breast cancer even when controlling for SES variations. The pattern of advanced staging could be a symptom of the aggressive nature and high proportion of premenopausal cancers that describes breast cancer incidence in black women (Levine and Venoroso). Stage of diagnosis is a reliable predictor of survivorship and mortality consistently across studies (ACS 2013; Funch and Marshall 1983; Yarboff et al 2003; Markossian and Hines 2012).

Similar to its relationship to other forms of wellbeing, higher SES is associated with improved survival rates for breast cancer. Variations in SES among women diagnosed with breast cancer leads to differences in access to care, the ability to fit routine treatment into schedules, the ability to pay for routine treatment, and levels of role strains, which often are high among low status women (Anglin [2006]; Bird and Rieker 2008). The SES argument is important for explaining disparities between black and white women given that group levels of SES are significantly lower for black women.

While the consideration of socioeconomic resources is fundamental to any study of health, other types of resources make a contribution as well. In particular, examining the role of psychosocial resources is equally important for understanding variations by outcomes for breast cancer. Breast cancer treatments have been described as “traumatic, invasive, […] harshly visible,” (Regehr 2012, 753), and isolating. Thus considering the roles of identity, personal resources, and support from others is crucial to research on cancer and health disparities. These differences may provide additional insight as to why black women die from breast cancer at alarmingly higher rates than other women.

What makes breast cancer treatments “harshly visible?” This next section will walk you through the surgical treatments of breast cancer and the history behind the “harshly visible” scars left behind after treating cancer. This section can also be used as a guide when reading chapters (like Chapter 1) that heavily reference the types of treatments women received.

Breast Cancer Treatment in America: A Surgical Model

Before contemporary breast cancer treatments. Breast cancer is not a modern illness. The fear of this body part becoming plagued by disease has haunted women for thousands of years. There are records of Egyptian queens being treated for conditions that resembled what we know as breast cancer. In ancient times, treatments included lanceting of protruding malignant and benign tumors, the application of herbs, and spells. While incidence of breast cancer has gone up in modern times (due to global and regional demographic shifts that improved life expectancy and spawned changes in lifestyle), breast cancer is an old disease (Olson 2002; Crimmins 1994, 2005). Its treatment, however, has evolved over time.

Prior to the late 1800s, few, if any, effective or humane treatments of breast cancer existed. Before the rise of hospitals, surgeries, and anesthesia, women suspected of having cancerous tumors (which usually meant there were lesions protruding or poking from the skin) endured painful and horrific treatments. Male physicians performed surgeries in which they used crude tools like sharpened forks/forceps and razors, and sliced the breast away from the body. Sometimes surgeries included scraping cancers off bones once breast tissue was removed. Such procedures were then finished with the cauterization of the wound with flat hot irons that had been cooking on a nearby fire. The woman patient was conscious throughout the surgery and held down by straps or other people. Perhaps if this woman did not hold too tightly to traditional gender norms, she entertained the use of alcohol as an anesthetic. For many of these women, removing the breast was a last effort to save her life, and the pain—like that of childbirth—was seen as a badge of honor. This was the early mastectomy, the procedure that resulted when physicians and other stakeholders decided that breast cancers should be medically treated by amputating the breast (Olson 2002; Uroskie and Colen 2004).

Women who survived this heinous ordeal were often psychologically traumatized for life—which was usually short due to high risks of infections or the fate of an already far advanced disease—and severely physically impaired. These surgeries were only performed on women whose cancers were so advanced that they were visible (now we know that likely means it was an advanced Stage III or Stage IV). It is also important to note that the first recorded surgeries of this kind were all performed on rich white women (e.g. President John Adams' daughter) (Olson 2002; Uroskie and Colen 2004; Klawiter 2008).

William Halstead and the radical mastectomy. The rise of anesthesia, aseptic treatments, antiseptics, and pain medication paved important roads for advancements in the technologies of breast cancer around the turn of the 20th century.[6] (Olson 2002). In last decade of the 19th century, when William Halstead performed the first anesthetized mastectomy, he became a medical icon. Since the woman was unconscious, Halstead could take his time and his surgery was strategic in the removal of muscle and flesh. He could sew up his incisions instead of burning open wounds with hot coals. Halstead is considered to have fathered the modern mastectomy (Olson 2002; Sweeting 2016).

The Halstead radical mastectomy has been described as a revolution but in fact it came about through a multi-stage process and represented more than just surgical advancement for amputating breasts. During this process, we begin to see the rise of cellular pathology; scientists were looking under microscopes to understand the nature of the conditions they were treating. They could determine if tumors were benign or malignant. This advancement alone was paramount as it stopped the dangerous removal of noncancerous lesions. Advancements in

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[6] While advancements like anesthesia existed prior to this, they were not widely available. Therefore, I am acknowledging the rise of anesthesia and other advancements and not their invention.

cellular pathology allowed physicians and scientists to target only cancerous tumors and to treat these tumors more effectively and precisely. Moreover, it offered palliative therapy to women who were suffering from obtrusive cancerous lesions of the breasts (Olson 2002; Sweeting YEAR).

Halstead also recognized that cancer cells mutate and spread even beyond the boundary of the breasts. He believed that he could be doing harm by if he left too much breast tissue behind. He was very concerned with contaminating other areas with cancerous cells. For this reason, the Halstead (radical) mastectomy included not only the removing of breast tissue, but also removing axillary nodes and both chest muscles. He believed that removing a lot of the flesh around the breast reduced the possibility of reoccurrence because the area had essentially been decontaminated (Olson 2002; Uroskie and Colen 2004).[7]. He could also treat earlier stage women, so for that group, survivorship (or the incidence of no reoccurrence, as he framed it) went up drastically. Before, only women who presented with advanced stages and protruding lesions were treated. Now, with anesthesia and a better molecular understanding of breast cancers, early staged breast cancers could be detected and affectively treated. Lower staged women were surviving at rates of higher than 80 percent. Halstead did note that advanced stage women, especially those with metastasis, were "doomed" and survivorship was below 40%. However, these improved rates from before in which women presented mostly advantaged staged cancers for treatment and survivor rates were less than 10% (Olson 2002).

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[7] Interestingly, the development of the Halstead mastectomy can be linked with broad processes of medicalizing the female body, especially in relation to pain. Prior to industrialization, the pain of mastectomies where seen as a badge of honor for all women, even wealthy white women. Similar to the medicalization of childbirth, wealthy women first enjoyed the privilege of a torment free, anesthetized mastectomy. Today, research supports that disparities still exists in the treatment of pain. Blacks, other minorities and low income individuals are more likely to experience pain when at hospitals (Baea-Hernandez; er study). This history of pain and treatment is yet another reason why mechanisms of class and race are important in the discussion of breast cancer treatments.

The Halstead radical mastectomy dominated surgical treatment styles for breast cancer for about 50 years after he performed the first surgery. During the mid-20th century, the popularity of the Halstead method began to diminish as physicians sought out less invasive (and disfiguring) means to treat breast cancer. Additionally, this time period begins to coincide with major social movements, like the women's and breast cancer advocacy movements, in which women sought more agency over their bodies. Some physicians also wanted to open up the possibility of reconstructing breasts, which the Halstead mastectomy rendered impossible. Mastectomies gradually came to be less radical (Olson 2002; Uroskie and Colen 2004; Klawiter 2008; Sulik 2011).

My participants' diagnoses of breast cancer spanned a range of time during which treatments for breast cancer also shifted. While the disfigurement associated with the Halstead radical mastectomy was not relevant to women in my sample, some women did have more drastic forms of mastectomies because they were treated decades ago. For example, one of my interviewees had a radical form of mastectomy that is no longer practiced today. Florence, who was diagnosed over 30 years ago when she was in her early 30s, described the consequences of her Halstead procedure. She even showed me the disfigurement left in place, and I was shocked at the amount of her body that had been removed. I could see the shoulder and breast bones on her right side, because there was no muscle or any sort of tissue there. It looked like skin and bones. She had absolutely no front shoulder muscle, such that I could see the ball and socket joint of her arm. The lower part of her right arm was also disfigured and she had developed lymphedema over the years. Not only were her breasts maimed by this surgery, but also this woman experienced drastic changes to an entire side of her body. She showed me her range of motion in her arm, which was not much. She could not lift her arm up or attempt to put it in a 90 degree angle. She talked about how she even had to modify the way she dressed. She always would have to start with the right arm, by putting that arm in the sleeve using the assistance of her left. The right arm lacked the flexibility for her to dress normally.

> Florence: It took all of that rotation out of that arm. So you just have to know everything you do, it's going to have to go that way. And at first, after I went through treatment and stuff, I broke a lot of dishes and stuff, because I would forget about [my arm]. I'd [try to use my right arm], and I'd drop and [break a lot of stuff] – but I'd laugh about it (laughs), you know, what – whatever, the alternative, push up some daisies out there. If you're not pushing up daisies, this side of the grass, you're doing good.

While the type of procedure Florence underwent is outdated, her case is important for understanding how cancer treatment can affect lifestyle, quality of life, and impairment long term. Moreover, many women in my sample complained about the loss of mobility in the adjacent arm (granted, less extreme than Florence's case) after surgeries on the breast and lymph nodes. I will discuss this more in Chapter 1 on breast loss and reconstruction.

Contemporary breast cancer surgical treatments. The 1970s mark important shifts in the surgical treatments of breast cancer. The mastectomy was greatly improved. Physicians started to practice more breast conserving surgeries, which meant they did not take away as much muscle and tissue from the treated area. In many cases, physicians found that it was unnecessary to remove the entire breast. In the mid-1970s, studies found that lumpectomies plus radiation treatment showed equivalent survival rates to the mastectomy for lower staged cancers (ACS 2014; Sweeting 2016). Over the last few decades, medicine as a whole has also moved towards less invasive types of surgeries, including for breast cancer treatment. Presently, most breast surgeries to treat cancer are lumpectomies or other forms of breast conserving surgeries.

Physicians target cancer cells and localize cutting to small diameters around those cells. They attempt to leave as little evidence of surgery as possible.

Of course, breast conserving surgeries are only possible because of the advancement of cellular pathology, which now allows for the very early detection of disease (Sweeting; Olson 2002). Improvements in understanding the cellular pathology of cancer have been the trend since the 1980s. Importantly, scientists have been able to distinguish between cancers by the hormones to which they respond. This has led to the development of hormone therapies to treat and prevent reoccurrence of hormone receptive cancers. Even so, the style of cancer treatment in America tends to favor surgical remedies for cancerous diseases. Under the American medical model, techniques that involve directing radio waves and manipulating physics may appear far less "sexy" to the American public than skillful cutting and removal of tumors. However, some cancer biologies do not stipulate any sort of mastectomy or surgery due to the likelihood that cancer cells have already been released into the blood stream (Olson 2002; Conrad 1992).

In America, we also favor surgical approaches to disease. This preference is symptomatic of the same social structures that facilitated the rise of white male physicians as the dominant healers after industrialization (as discussed in the section on medicalization and gender). The European and American treatments for cancer began to diverge around the time that Halstead's popularity began to rise. American medicine has favored hospitals that promote surgical approaches to treating disease. For this reason, the American surgeon is far more prestigious than other physicians in America and surgeons in many Western European countries. The prestige of the surgeon—again traditionally a white male—shapes the medical model through which we treat breast cancer (Olson 2002).

Surgical breast reconstructions. While there are records of early reconstruction-like surgeries around 1900 in Europe, in this section I focus on modern breast reconstruction in America. The first cosmetic (in-hospital) breast augmentation occurred in 1962. A year later, the first reconstruction using silicone implants was performed by American physicians. For about 10 years, reconstructions were only performed in separate surgical procedures after the mastectomy. In 1971, the first immediate reconstruction was recorded. This means that the reconstruction process began during the same surgery in which the breast was removed. Many advancements in reconstruction followed over the next 40 years (Uroskie and Colen 2004).

*Types of Reconstruction***.** Women today have several options available for reconstruction after surgical treatments of breast cancer. Women also have the option to choose no reconstruction. Selecting which option is not only a matter of personal choice, but can depend on a number of other individualized characteristics like body composition (especially fat distribution), health status, personal history, and availability. Women can select to have a saline or silicone[8] implant to replace the amputated breast. If they select this option, a tissue expander is put in place where the breast was removed during the same surgery as the mastectomy.[9] This expander preps the area for the insertion of the silicone or saline implant, which takes place weeks later after healing. In the time between surgeries, women routinely visit doctor's offices to have solution injected in their expanders. These injections expand the skin and tissue of the chest so that the

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[8] There was a medical ban on silicone during the 1990s, so this option was no available to all women treated in my sample.

[9] Women have several years to decide to do reconstruction. Reconstruction does not have to start at the time of mastectomy.

area can accommodate the size of the saline or silicone implant. After the reconstruction process, these breast implants require routine care typical of cosmetic augmentations[10].

Women can also elect to have autologous flap reconstruction surgeries. Autologous means that the tissue for the reconstruction comes from the woman's own body. These surgeries are done and completed[11] at the same time a woman is anesthetized for the mastectomy. I will discuss two types of autologous surgeries that women in my sample reported having. Women can have a transverse rectus abdominis muscle (TRAM) flap surgery, where the breast is constructed from tissue, skin and muscle removed from the stomach area and repositioned on the chest. Latissimus flap surgeries are another type of autologous flap reconstruction in which the repositioned tissue is taken from the upper back.

Nipple restoration surgeries and procedures are another component of reconstruction. Women can choose to have a nipple reconstructed after the original one was removed during the mastectomy. Not all mastectomies require that the nipple be removed (nipple-conserving mastectomies). If women do have their nipple removed, during this surgical procedure, the physician uses pieces of skin to create a nipple on top of the (healed) reconstructed breast. After, women can then choose to use tattooing services to complete the nipple restoration by giving it color and the appearance of an areola. Likewise, sometimes, women select tattooing services as their only nipple reconstruction procedure.

All women who are covered by insurance are legally eligible for reconstruction after experiencing a mastectomy (or other disfiguring surgical treatment from breast cancer). This

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[10] Implants that burst or rupture require replacement, and some physicians advise routine replacement every 10-15 years anyway ().

[11] By design, surgeries don't always render successful results on the first try.

right was enacted by the Women’s Health and Cancer Rights Act (WHCRA) passed in 1998. Only two of my women were diagnosed and treated prior to 1998 (Florence and Beatrice). This legislation stipulates that for all group or individual plan holders, women have rights to 1.) reconstruction at the mastectomy site, 2.) other surgeries needed to achieve evenness of both breasts, 3.) be covered for any complications that may arise from the mastectomy process, and 4.) have prostheses provided (Center for Medicare and Medicaid Services 2017).

CHAPTER II

METHODS

Qualitative approaches to research, such as the semi-structured interview, allow researchers to capture internal dynamics and processes that are unique to the respondent and difficult to capture with survey techniques. In interviews, the researcher can pick up on respondents' perceptions and the feelings, reactions, and thought processes their experiences evoke. Often these realms of experience lie outside the researcher's own biography and knowledge. Additionally, each interview can be tailored based on the respondent, which contributes to greater depth, breadth, and coherence in the recounting of one's past (Weiss 1995). At the same time, the researcher does maintain some control in capturing desired responses by using a consistent set of questions in semi-structured interviews rather than allowing for free-flowing narrative common in unstructured interviews (Bell 2009).

Some feminist scholarship speaks to the utility of this method when interviewing women. Most standard social science instruments use language that in "itself reflects male experiences, and that its categories are often incongruent with women's lives" (DeVault 1990, 96). Open-ended questions in semi-structured interviews allow women to verbalize processes in their own words instead of trying to fit experiences into the words of a likely more educated, and often male, survey researcher (DeVault 1990). Thus, open ended questions are especially important for capturing experiences of marginalized groups of women, including women of color (DeVault 1990; Neighbors 2002; Weiss 1995).

Semi-structured interviews have proven to be especially effective for the study population selected, because some research suggest that they are more valid than formalized and structured survey techniques for black populations (Neighbors et al 2003; Harnois 2013). For example, the experiences related to racial discrimination and oppression have multilevel consequences, including how individuals internalize and interpret these experiences. Often researchers do not identify with these narratives making these experiences difficult to capture using the limited words associated with surveys (Neighbors et al 2003; Krieger 2012).

Finally, qualitative approaches are less restrictive in terms of analysis than their quantitative counterparts. Qualitative data lends itself to standardized as well as the researchers' interpretations of the data. Specifically for this dissertation, I used an issue-focused thematic approach to understand the dynamics of holistic breast cancer experiences for an understudied population of women (Weiss 1995). This is a study of illness, in which I learn from black women about the physical, mental, cultural, and psychosocial consequences of an invasive disease. I have chosen to study black women because their experiences are little known, and their survivorship is far more tenuous than that of white women.

Data. The primary data source for this dissertation comes from 49 semi-structured interviews with African American women who have received diagnoses of breast cancer. I conducted interviews at three sites: Nashville, TN, the Durham-Chapel Hill Metropolitan Statistical Area (MSA) NC, and Metropolitan Atlanta, GA (including the city of Atlanta and the surrounding counties). Originally, I planned to conduct interviews only in Tennessee and North Carolina, and the Georgia site was added several months after the project started. I chose the sites because Southern states have both higher overall mortality rates and larger racial mortality gaps from breast cancer compared to other regions of the US. I also expected to find large scale class variations among the locations, especially since Atlanta has a more sizeable and prominent black middle class. Moreover, the North Carolina area has gained medical notoriety for being a place where breast cancer aggressiveness is especially high among black women, young women in particular.

Mortality rates from breast cancer are especially high in Tennessee, and the black-white contrast in mortality is alarming, approaching 12 lives for every 100,000, which is one of—if not the— largest gaps in the country. In Tennessee, black women have slightly higher incidence rates of breast cancer than white women, which is not the trend nationwide. Until the most recent report released with 2015 data, white women had higher incidence of breast cancer (that is, except among the young, which are women diagnosed before 40). North Carolina, on the other hand, has a smaller mortality difference and white and black women in North Carolina have about equivalent incidence rates of breast cancer. Still, black women in this state die at higher rates from breast cancer than whites do. In Georgia, black and white women have basically equivalent rates of breast cancer (white women have higher incidence by 1 person per 100,000). Black women in Georgia have higher mortality rates from the disease than white women, which is about the same as in North Carolina. Thus, Tennessee is a bit different than the other sites in terms of breast cancer incidence and mortality gaps between black and white women. However, North Carolina has the highest incidence rate of breast cancer for black women among the three states. Georgia has the lowest incidence rates of the three states. Tennessee has the highest and Georgia has the lowest mortality rate for black women with breast cancer (ACS 2015).

All three cities have large academic research hospitals with specialized breast cancer centers that serve a wide area in the region. The North Carolina center includes one sector that focuses specifically on research on black women with breast cancer. Nashville is also home to several historically black colleges and universities. This has important implications for the development of a strong black middle class in Nashville. Not only have many black Nashvillians graduated from these institutions, but these colleges and universities also recruit and attract significant numbers of highly educated professionals of color. Atlanta has the largest and strongest middle class of the three states (and some argue the nation). This city is bigger than both Nashville and the Durham-Chapel Hill MSA, which means there are more research centers and hospitals in the area. Also, there is a significantly higher proportion/number of black physicians in Atlanta. Almost all of the women I interviewed in Atlanta had at least one black physician—and for many it was the same one[12]. This particular physician is notable in her commitment to breast cancer interventions over her career. She has established resources, support groups, and affiliations that can be accessed by many in the Atlanta area. Diagnosed women in Atlanta sought her out,[13] therefore I am not surprised that so many women consulted her even though I did not recruit from her clinic or an institution she was affiliated with. There are far more resources aimed at black women in Atlanta than in Nashville or Durham-Chapel hill, and it is easy in Atlanta to access specific health promoting services (like fitness class for breast cancer survivors) and support services (like a choir of black breast cancer survivors).

While all cities have higher than national average proportions of black residents, the three cities are demographically dissimilar. For example, Durham-Chapel Hill and the surrounding area have a far greater proportion of black residents than Nashville. Over a third of the population in this region are African American. Nashville's percentage of black residents is smaller, but the city's population is twice as large. The two areas also have very different labor markets and economic structures, as the North Carolina region is premier for bioengineering and

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[12] There is a very influential, high-profile black woman physician who specializes in breast cancer in Atlanta. She has started outreach programs, screen programs, support groups/activities. Many sought her for their treatments given her reputation in Atlanta, and the surgical oncology community as a whole. A catalyst like this undoubtedly changed the landscape of resources available to black women in Atlanta.

[13] She reminds me of the doctor on Sex and the City, in the episode where Samantha camped out for days and bribed the personal assistant to secure an appointment with the oncologist.

medical research. Nashville’s economic industry is more diverse, while the largest sector is in healthcare insurance and products (U.S. Census 2015). Atlanta is different for many reasons. The city (or MSA) is about 5 times larger than Nashville and ranks number 9 in the country. It boasts one of the highest rates of college educated individuals in the country. It has a very diverse economic base, and this employment mix makes Atlanta special and diverse compared to other areas of the country. Atlanta’s black population is the largest of all the sites (at around 36%) however this proportion has dropped dramatically over the last couple of decades (the city used to be majority black) (Atlanta Regional Commission 2017; Georgia Power 2016). Findings from the study may not be generalizable to all black women in the US South, but the variability these sites provide does lead to greater diversity in the sample especially in terms of SES, utilization of health services, and stages of diagnoses.

The collection of data for this study was funded by a pilot-project mini-grant awarded by the Robert Wood Johnson Foundation. The grant proposal was a joint collaboration with Professor Laura Carpenter and Raeshell Sweeting, MD. Dr. Carpenter, a sociologist, served as the faculty sponsor of the grant and as my advisor. Dr. Sweeting is a surgical oncologist who, until recently, was employed at a research university in North Carolina. She facilitated contact with the Sisters Network (which I will explain below) at the Durham location, and acted as a medical consultant during the process of this project. I recruited participants, conducted all of the interviews and undertook the data analysis independently. Interviews ranged from 40 minutes to nearly 3 hours in duration, and took place in participants’ homes, work locations, public spaces, and my campus office. Women were provided with $40 or $25 gift card[14] incentives for interviewing with me. A copy of the interview guide can been found in the Appendix.

At study sites, I use snowball sampling techniques to recruit participants (Biernacki and Waldorf 1981; Noy 2008). I began with members of the Sisters Network in Nashville and recruited both group members and non-member women who participated in community outreach functions sponsored by the group. The Sisters Network is a national outreach organization, "committed to increasing local and national attention to the devastating impact that breast cancer has in the African American community" (Sisters Network Inc. 2014). Both the Nashville and Durham chapters use free community-based facilities to hold meetings. In Atlanta, I began recruiting participants from a large church in the area (my uncle is the pastor). Women then referred me to others who were willing to participate in the study. I had no contact with the Sisters Network in Atlanta.

The chapter meetings and member characteristics of the Sisters Network vary at each site. The meetings of the Nashville chapter included a very strong religious undertone. I attended several meetings and events of the Nashville chapter over a six month period. In this setting, the president led the meetings and provided programs for the meeting's agenda. The Nashville chapter opened (and ended) with a prayer, then a quick birthday celebration with cake for that month's "birthday girls." After, officers would take turns discussing upcoming events and affairs for the chapter, such as fashion shows, luncheons, and frequently the need to raise money. Sometimes guest speakers would come to talk about health related therapies. When there was no agenda, some women would engage in informal conversations or group sharing. Many times

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[14] I changed the amount of the incentive for budget reasons and given that many women said they would have been willing to do the interview for free. Other colleagues conducting interviews were not offering that much money either.

these conversations as well as the subject of the prayers centered on the health of members' husbands and children.

I attended only one meeting at the North Carolina site. The meeting of the NC chapter focused on the dissemination of medical and health information. In this medically centered chapter meeting, a small board led a focus group style meeting where participants could ask questions, share experiences, and give advice. The president of this North Carolina chapter is a health professional. At one point in the meeting, a chapter member discussed nutrition and sold locally grown produce to members. At another point in the meeting, the vice president discussed the logistics of an upcoming annual tea, complete with borrowed and very expensive fine china. Participants in this meeting were survivors and affiliates of survivors. This meeting had about four times as many people attending as the Nashville chapter meetings, and included a few women of ethnic backgrounds other than African American. In comparison to Nashville's chapter, a greater number of younger participants attended this meeting.

I also recruited participants from local black churches and church-based support group organizations in Nashville. I could easily access these groups, given my ongoing relationships with pastors in the area. With that said, the majority (basically all) of women in my sample practice religion (albeit at varying degrees of participation). However, my predominantly religious sample is not completely off the mark when it national statistics. Based on Pew Reports, blacks are the most religious racial/ethnic group in America. About 80% of African Americans say that religion is very important in their lives, and even for individuals unaffiliated with a specific church or organizations, the majority say that religion and spirituality are important to them. Importantly, nearly 90% of black Americans believe God exists. Slightly more than half of black Americans report going to church every week, and three-fourths of the population pray on a daily basis. Black women tend to be more religious (in theory and practice) than black men are (Pew Research Center 2017; Barnes 2009). Similarly, there was variation in the amount of religious participation in my sample. Many women did not attend services regularly. Everyone I interviewed said they prayed daily, a routine that was likely influenced by the uncertainty related to cancer (Woodell and Hess 1998).

Recruiting participants from outreach programs performed by the Sisters Network ensured that the sample was diverse in terms of social class. Interestingly, within the Sisters Network chapters, social class diversity was quite high; however I would like to point out that lower status women were likely to report that they did not participate in these groups on a routine basis. One woman even told me that she felt ostracized and as if the middle class women of the group were less likely to offer assistance to her than they were to middle class participants. Also in North Carolina, many of my participants told me that the meeting where they met me was the first and only Sisters Network meeting they attended. Social class diversity also tends to be high among large mega-churches, which would describe the churches I used as recruiting sources (Barnes 2014; Robnett 1995?). With that said, I recognize that my recruiting technique likely exposed me to a higher than average proportion of middle class women.[15]

While I attempted to maximize diversity, I may have missed individuals who tend to be more socially isolated, do not affiliate with religious institutions, or those who may not identify or find solidarity in a black group identity. I also did not specifically recruit for sexual minorities, though I do have one woman who identified as a lesbian in my sample. The rest identified as heterosexual.

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[15] It should also be noted that lower class survivors are likely fewer in number. It sounds grim, but breast cancer survivorship maps on to class like many other conditions.

I analyzed interview transcriptions using Atlas-TI software to look for patterns in narratives and responses (Muhr and Friese 2004; Muhr 1991). The rich data I collected lends new insight into the experiences of an understudied population and context. Therefore, I incorporated modified grounded theory into my analytic strategy. In grounded theory research, scholars recognize that the particular case or subject they are studying may not be well situated in existing literature and theory. Thus, the data informs theoretical approaches. In traditional grounded theory the theoretical framework solely comes from the data. My approach is a modified version of grounded theory in that I recognize that while respondents make meaning of their experiences, my own biography and knowledge help shape both interactions with interviewees and interpretation of the data. Essentially both the respondent and I shape the knowledge that will emerge from these interviews, and this knowledge is a result of our interactions and locational positioning in the social world. (I discuss this more in my reflexivity statement.) This approach incorporates an interactionist and constructionist approach to data collection and analysis, which also aligns with the broad theoretical lens of this dissertation (Charmaz 2003; Charmaz and Mitchell 2001; Glaser and Strauss 2009).

In the appendix are figures and tables summarize the demographics of my sample, explain how I created class categories, and show the specifics of women's treatments I interviewed. I also include short descriptions of each participant in the appendix, which include information about their sociodemographic characteristics and the nature of their diagnosis. The majority of my sample were married and most had children. The high marriage rates make my sample unusual in comparison to the average rates of marriage for black women (Clarke 2011).

I decided on women's class by using a multi-step system. I began by dividing women into two groups to differentiate between women in middle class and low class statuses. The first metric I looked at was homeownership. I also considered the description of this home and location. Then I moved on to consider educational status and occupational type/status of the participant and her spouse if relevant. I then considered insurance status. If participants scored high on three of the indicators they were considered middle class. To differentiate among the middle class and lower class statuses, I considered stories about financial difficulty, types of treatment, daily life during treatments, speech patterns, and some characteristics of social support.

A handful of women did not fit neatly into class categories because of individualized experiences. For instance, for a few women there were mismatches between level of education and the occupational statuses achieved. These women often had access to fewer resources than their education status would imply. These women got their advanced degrees more recently (a later stages in life) or their service oriented degrees were in fields that were not high paying. For instance, one woman with two master’s degrees qualified for welfare. For the most part though, women were easily placed into class categories based on the indicators I described. See the table and descriptions of my participants in the Appendix for more detail.

CHAPTER III

WHEN RESEARCH COMES ‘ROUND AND SLAPS YOU IN THE FACE: MY REFLEXIVITY STATEMENT

Slap me in the face? Yep, that is exactly what it did. In May 2015, my research came in my room, woke me up, and slapped me in the face. Hard. I got an early morning call from my mother crying. Four days previously I had accompanied her to a biopsy. I knew why she was crying, I just didn’t think it would be so bad. On October 23, 2016, it came back and slugged me again. Six months later, I sit here and reflect on what it feels like to be a researcher and study the thing your mother just died of. I must reflect on how it feels to have started a project in response to my mother surviving cancer and to end it by dedicating my work to her memory. It feels like someone slaps me in the face every time I see or hear the word “cancer,” and then I realize I say, read, or type this word 100 times a day. So before I tell the stories of the women cancer survivors I interviewed, I must acknowledge that this experience has been an undesirable immersion in my research. I gained an insight into the context of breast cancer that I resent. I do not want to be this closely connected to my research. I would gladly have my insider status revoked.

I am both an insider and an outsider in reference to my research and the subjects I chose (Baca Zinn 1979). In addition to being unwillingly immersed in all things breast cancer because of my mother's illness, other characteristics afford me insider status among these women I studied. Like all of my participants, I am a black woman. As an insider, I understand the subtext and body language that accompany the actual words of these women. These dynamics of our conversations were crucial. Sometimes, I would swear so-and-so said X, but I did not find these words in my transcriptions. Most of these instances centered on nuances of race. I spoke the language (verbal and body) of these black women. Some reminded me of my great aunts, aunts, my mother and my grandmothers. Some of the younger ones were like my friends, like me. I could vibe with them in interviews, because we could sometimes understand each other without really articulating words. These instances do not translate well when you contract out transcription services. Some of these visual interactions and cues are lost. Therefore, at some times in my chapters, I may seem to infer more than you see from quotes. This happens because when I read each transcribed text I can remember the dynamics of that interview. I can remember her face. Sometimes we gave each other side-eyes, or winked, or giggled and grunted, because we had insider knowledge that the rest of world didn’t know. These women felt comfortable with me because I was a black woman. On top of that, I was personable and determined to share their invisible stories. Some of my participants were proud of me, in a motherly way, because I was pursuing a PhD. Some women offered words of comfort and some gave me little gifts if they were aware of my mother’s status.

At the same time, I am an outsider, primarily, because my experience with cancer treatments is not direct. Additionally, I was younger than the women I interviewed, and younger than all but two of my participants when they were diagnosed. Beyond my chronological age, my status as a student kept me young in experiences relative to most of my women. I have yet to have my family and my career. I also possess a unique set of knowledge that makes me an outsider researcher. I attempted to keep my knowledge from derailing my interviews. I have close ties with people in medical communities. Two of my uncles, an aunt, and my sister are all practicing physicians. At the time of my mother’s first diagnosis in 2012, my sister was a surgery resident specializing in Oncology in North Carolina. She consulted a supervisor and renowned oncologist for advice on the next steps to take with my mother's treatments. This physician became personally involved and reached out to her colleagues and friends here in Tennessee. My mother's surgeon was hand selected by a group of informed parties, which included her own daughter who was specializing in treating cancers. A few years later, my mother's oncology surgeon and medical oncologist were not only my sister's colleagues, but also her friends. The surgical oncologist wept with us at my mother's funeral, that's how invested she was. I have no qualms with her medical care and my mother was given the Cadillac of treatments.

As a researcher, I can stand back and recognize that my mother's level of social support was extremely high, especially in terms of her medical ties. This may have made her experiences with breast cancer atypical, especially for black women diagnosed with breast cancer. I wanted to explore social support when I started this project in 2014, because then my mother was a survivor, and her social support networks seemed beneficial. She also had a good circle of friends—some of them medical professionals—who would check in on her and offer her food. Friends offered gifts, including home improvements one friend installed to help as my mother's mobility began to decline. My mother was also deeply religious, a characteristic she shared with many in her social networks. My sister and I sometimes joked that the prayers of her friends and family were keeping her alive when she seemed tired and ready to be physically defeated. Despite all this social support—a variable with consistent positive associations with psychological and physical well-being—she still died. As a researcher, that kind of fact is hard for me to wrap my head around. Yet, she was privileged to be able to activate so many resources around her during her last years on earth.

That is not to say that my mother's experiences was free of any sort of racial bias. The one event I recall that honestly infuriates me to this day is when she met with a psychologist. We begged my mom (for years) to see someone other than a minister to talk about dealing with her illness. She was strong, yes, but trying to be impervious during cancer treatment seemed like self-torture and unnecessary. Sometime in late 2015, after her reoccurrence (and upgrade to Stage IV), my mother met with a psychologist, an old white man probably 20 years her senior. In this appointment, he told her he could not understand why she was so upset. *She has lived a good life for a woman of color;* her children were doing well and accomplished, she had a husband, and according to him 60 years was a pretty good life. He suggested she record things she wanted to say to us—like what she would say to me at my graduation and other major events—because she wouldn't be around (*but she would be in spirit*). Of course, she never saw another psychologist after that.

I tried to explain to her that he was the wrong pick and it was not uncommon to have to try out different therapists. I tried to use my own personal anecdotes. At the very least, I told her, they should gender match, but she was done with this type of service. Honestly, I couldn't blame her knowing how apprehensive she was about seeking out this type of help in the first place. While one goal of this dissertation is to spawn interventions that increase mental health services utilization by black women, I can understand why black women wouldn't seek out this type of help. I write about my mother's appointment to show that a trained professional could be this insensitive to my mother, a patient, and to bring to light the insensitivity black people **often** experience in physician's appointments. Words can harm, especially when they come from a medical professional.

According to an older white man, my mother's life was long enough--though she was only 61 when she died. My mother was a woman of color. My mother was a woman who was a wife, mother, friend, and beloved (and only departed) sister (the youngest girl and the 5th of 6 children). She left just four years after her own mother, who lived to the age of 84.[16] Another woman of color that came before her, her own grandmother lived to the age of 91. To me she was a mother whose life was not long enough, whose children are not fine because we expected her to be around longer. She left before I finished this dissertation. I rubbed her black and blue skin that covered the broken clavicle and hip that cancer ate through when chemo stopped working. I saw her age dramatically in weeks such that she looked like my grandmother when she was dying. I felt the lumps under her skin from the tumors that had grown off the bones of her arms. I cannot put into words how horrible it sounds to hear moaning from someone when every inch of their body is in pain. So as I write these chapters, her death affects my research—I think that is an understatement.

My mother's death is painful, but at the same time, it validates my research. Breast cancer is a lethal disease and dying from it is agonizing. I was unaware of the severity or potential fatalism of this disease before my mother was diagnosed. Like many others, I bought the pink paraphernalia. I had pink jewelry. Frankly, I liked the color, and did not think much about the cause. At that point, I did not understand what breast cancer was. Now I understand how *not pink* breast cancer is, not only because of my personal experiences but because 49 women shared their stories with me.

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[16] Of her 7 siblings, the youngest death was in the 70s and one great aunt is still living

Sometimes, I heard horrendous stories from women about mistreatment from physicians, other professionals, spouses, family and friends. Additionally, some women were unaware of the mistreatment or misinformation they were given in physician appointments. This was especially troubling for me. I struggled to keep wearing my objective research hat. My mother also had great insurance as a state employee. Some procedures she experienced were missing from some of my other participants' stories—especially women with low income and low education. Other differences in care emerged simply because of differences in insurance formularies and schedules.[17]

As I now prepare to dedicate my dissertation's work to my mother and my grandmothers—all women I lost during graduate school—I realize how much I did not expect to write a reflexivity statement like this. I didn't expect to encounter or experience my *research* like this.

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[17] For instance, there is a shot given to patients after chemo to protect bone health and prevent infections. Some (and major) insurance formularies do not cover this treatment procedure. One shot out-of-pocket would cost patients thousands of dollars (and I mean close to $10K). Many women could not access that level of economic resources. [Some women's chemo treatments are multiple times a week for weeks if not months. What does each denied shot do in this situation?]

Table 1: Quick Reference Guide for Breast Loss and Reconstruction

	Lumpectomy	**Mastectomy**	Reconstruction
Brielle	L		
Doreen		M	N
Florence		M	Y^{f}
Pearl	L		
Ramona		M	Y^{f}
Shaunte		M	Y^{i}
Simone		M	Y^{i}
Terrin	L		
Vivian		M	Y^{fi}
Beatrice		M	Y^{f}
Bebe	L		
Bethanie	L		
Brandy		M	Y^{i}
Catherine		M	Y^{f}
Drita	L		
Essence	L (2)	M	Y^{f}
Keisha		M	Y^{f}
Monique	L		
Naomi	L		
Olivia		M	Y^{f}
Andelle		M	Y (special case)
Angela		M	Y^{i}
Dominique	L		
Esther	L		
Kerrie	L		
LaToya	L	M (double)	Y^{f}
Marie		M	Y^{i}
Monica*	L		
Thomasina		M	Y^{f}
Cassandra		M	Y^{f}
Eden	L	M	Y^{f}
Gretchen	L		
Jesse		M	N
Lena	L		
Sheree	L		
April		M	N
Cora	L		
Deanna	L		
Farrah	L		
Gina	L		
Irene	L		
Jorie		M	Y^{fi}
Lenore		M	N
Mary Jill		M	N
Miriam			
(Monica)		M	N
Shelita	L		
Shonda		M	N
Sue		M	Y^{f}
Yolanda	L		

*This is an abbreviated version of the Treatment Basics table in Appendix II

CHAPTER IV

LOPSIDED SUZY:

PROCESSING BREAST DISFIGUREMENT AND RECONSTRUCTION

Breast size and type have been important for distinguishing men and women for millennia (Young 2009). On average, women have larger and denser breasts than men due to biological sex differences between females and males. For women, breasts also have significant social meanings that tend to represent two idealized versions of womanhood: the sexual and the maternal. Evidence for the dual meaning given to breasts dates back to ancient times, when small breasts represented fertility, beauty, and youth whereas large breasts signified power and nourishment. In ancient Greek paintings, small breasts were associated with youthfulness, virginity, and fertility (e.g., Venus), while powerful and matriarchal figures like Athena were portrayed to have larger breasts and fuller figures. Similarly, the form of women's breasts implies certain meanings related to womanhood, motherhood, and attractiveness (Young 2009; Lorber and Moore 2010; Millsted and Frith 2003).

The sexual meanings of breasts in Western cultures are generally framed in a way that assumes heterosexuality. Women's bodies are evaluated based on their ability to attract the attention of men. Scholars call this concept of gendered evaluation the male gaze (Gervais, Holland, Dodd 2013 ; Mulvey 1989; Millsted and Frith 2003). While small breasts may have once been desirable or signalers of potential mates in Greek times, cultural influences on these stereotypes have dramatically changed in modern times. Larger, fuller breasts have become the normative cultural standard for women of all ages who adhere to hegemonic femininity and body projects (which entail that women be slim otherwise) (Merianos et al. 2013; Millsted and Frith 2003; Goodman and Walsh-Childers 2004). In American culture, large breasts are deemed most attractive on a curvy thin woman, whose physique enhances her secondary sexual characteristics (Dixson et al 2010).

The curvaceous thin woman has been lauded and recreated countless times within institutions like the media, pop culture, and even the medical industry. In popular culture, she is described with measurements to the tune of “36-24-36”, proportions of a woman with a large bust, skinny waist, and thin thighs (Richie et al 1977). Practically speaking, these proportions describe a woman whose top/torso is a size 10, her waist a size 2 and her hips a size 4, proportions that the fashion industry has never chosen to favor. Academic literature describes this curvaceous woman in a bit of a different fashion. She has an hourglass figure with a low waist-to-hip ratio (WHR) and large breasts. She is a woman whose proportions make her the most distinct from typical male physiques. In most cultures, this represents a woman with a relatively thin middle/abdomen such that the circumference of her chest and hips are each several inches larger than that of her waist. In the United States, women with WHR around .70 are considered most attractive based on evidence from male gaze studies (Dixson et al 2010; Millsted and Frith 2003).

American culture is preoccupied with the aesthetic and sexual nature of breasts, and breasts are an important component for defining and signaling one’s gender or femininity. In popular culture, the feminine idealized body—proportionate with large breasts—became the American paradigm of white femininity/womanhood beginning in the 1950s. Large breasts came to be fetishized as *Playboy* and hypersexualized caricatures like Marilyn Monroe and Blaze Starr--the topless performer with the jiggle-free enormous breasts—solidified the tie between the sexual nature of breasts and the “appropriate” performance of femininity. This decade also ushered in the rise and validation of mainstream porn featuring white women. Playboy was the first to commercialize and make widely available what were then considered pornographic images of white women's breast and buttocks. The accessibility of magazines like Playboy and the competitors that arose after set the tone for the rise of erotic pornographic videos of the 1970s (Olson; +). Thus, the new growing popularity of this sexualized image racialized the American feminine paradigm as well.

Prior to the 1950s, white women's bodies were covered by conservative clothing. Specifically, the breasts were covered in public for *white* women in traditional and agricultural communities that defined the landscape of the country around the turn of the century (citation). However, as the country increasingly urbanized, hem lines for white women began to rise and collars began to lower, placing more of the body within view of the male gaze. Strikingly, in these same communities, black women were seldom afforded this same protection under conservative garb in public. During slavery, black women's bodies were exposed at public auctions and other events. For decades after, images of nude black women could be readily viewed, at public libraries for example, as scientific texts frequently used faceless black bodies to show female anatomy. This sort of spectacle-making of black women's bodies demonstrates that Americans had a preoccupation with curvy feminine bodies well before the 1950s, however, race conditioned the way these feminine bodies were treated and perceived (Davis 1983; Collins 2001; Lorde 1980; Martin 2001).

In contrast to the experiences of white women, black women's breasts and bodies were rarely afforded the same protection under the law or dominant cultural practices. In addition to being evaluated for their capacity to perform manual labor, black women were simultaneously assessed by their sexual attractiveness, as they were often used as sex slaves (Hickey 2006; Davis 1980). Black female bodies have been subjected to a variety of abuses since Africans were first forcibly brought to the U.S. Stereotypes that arose from slavery reduce black femininity to polarized forms similar to the dual meanings associated with breasts. Black women are either sexual or motherly--stereotypes rooted in slavery for which black women are defined by their sexual parts. Black Jezebel, a hoe (i.e., whore), or Hottentot Venus are representations of this hypersexualized black woman, one that is proportional and voluptuous. Black women's breasts and bodies were critiqued, prodded, and groped to assess potential fitness as a female slave.

These practices of subjugation emphasized the importance of breasts and body proportionality for assessing the attractive qualities of black women. (Recall the discussion of Saartjie Bartman in the Introduction.) The disregard—or lack of respect—for black bodies was conducive to creating a dominant, American culture where black women were highly vulnerable to being perceived as sexualized spectacles, marked by their female sexual characteristics. Black communities have tried to combat sexualized stereotypes by endorsing behaviors that promoted black respectability (e.g. modesty and conservative dress), a topic I discussed in the introduction (Jones 2009; Craig 2002).

In this chapter, I will focus on how the sexual meanings for breasts affect the ways women cope and make decisions about transformed bodies after breast cancer treatment. While most women in my sample were mothers, no participant was nursing or had plans to nurse children in the future. Therefore, the reproductive meanings for breasts arose infrequently in my interviews. However, women perceived their breasts through the lenses of gender and heterosexuality, and both were salient throughout the processes of breast loss and reconstruction. There are mixed messages about black femininity that come from notions of black respectability and racialized stereotypes, and using this qualitative approach, I capture how black women process and interpret their own bodies.

When researchers use qualitative, inductive tools they allow marginalized groups like black women to express how they feel about body image using their own words (DeVault 1990; Neighbors and Jackson 1998). For instance, Capodilupo and Kim (2014) conducted focus groups with educated black women about body image to address methodological gaps in this area of research. This study (and a few others) found that there is an expectation for black women to be curvy—although this ideal feminine body is not always naturally attainable by all. Additionally, these focus group women, and participants in my study, emphasize that big breasts and large butts appeal to the desires of black men. One could conclude that black women are more susceptible to the ideology of the proportionate, hourglass, busty feminine standard than white women are. Essentially, being proportional (or thick, or curvy) is one way black women can show that they embrace their racial identity and that they are performing gender correctly. Moreover, participants also emphasized that, in addition to size and proportion, other aspects like skin tone and hair texture[18] are very salient for how women interpret their body image. Thus, what we can take away from extant research is that black women have body image concerns.[19] How they come to interpret their bodies is shaped through the perspective of being both black and a woman.

Breasts and defining womanhood: the PRC and gender norms in practice

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[18] I will discuss hair texture and race in Chapter 2. I do not include any in depth discussion about skin color, race, and its effects on health. For references on this subject, refer to Verna Keith's work on skin color and health.

[19] It's important to note that studies that find that black women are less affected by body image than white women still find that the majority of all women are concerned with and disciplined by issues of feminine body paradigms (citations?).

In my interviews, women repeatedly articulated the importance of breasts for defining womanhood and femininity. Inherent in these discussions are notions of attractiveness predicated on the assumption of heterosexuality and based on the belief that (black) men are looking at (black) women's bodies. Breast cancer treatments transform an important feature of the feminine body that is linked to attracting male attention. This perceived connection between breasts and gender identity came to affect women at all stages of the cancer treatment process.

Some women told me that the fear of breast loss was instrumental from the onset and influenced their decision-making about courses of treatment. A few of my participants decided against certain procedures like mastectomies or double mastectomies in order to maintain their gender identity. It was almost as if they were staking claim to this part of their body over cancer. When Shaunte's doctor suggested a double mastectomy, she was apprehensive. Shaunte (MY^{i}C) was 33 when she was diagnosed (and 38 at the time of interview). She told me about her decision not to have a double mastectomy. "I'm not married yet, and things like that, I still wanted to feel like a woman," she said. "[…] so I ended up keeping one of my breasts."

Similarly, other women grappled with (life-saving) decision-making while facing the threat of losing this part of their feminine identity. Essence, 44 and unmarried, chose to have multiple lumpectomies to avoid the total removal of her breast (mastectomy). Essence (LMY^{f}R; 40 at the time of diagnosis) was diagnosed at Stage 0 and could not fathom how such a low stage cancer could require more than a lumpectomy. Essence's physician initially advised her to get a mastectomy to treat her cancer. This is how she recalled this decision making process:

> And so he [the breast specialist] told me then, he was like, trying to talk to me about having a mastectomy, and explaining to me that so much – he had to take so much tissue out – I was in denial about that. I wasn't in denial that I had cancer, I was in

> denial that I was going to have to have my breast removed, because you know, I'm thinking like, I'm stage zero, you know, I'm early stages, why do I have to get my breast removed? You know, and so after the second lumpectomy, cancer was still present, and at that moment, he had me to have consultations with a variety of doctors that I actually – are part of my care team now, and that was part of my care team then. And after the second lumpectomy, cancer was still present, so I had to have the mastectomy.

Essence told me that her physician (breast specialist/surgical oncologist) recommended a mastectomy before the first lumpectomy and again before the second. However, she was determined not to lose her breasts. Stage does not necessarily determine the aggressiveness of the procedures to treat the cancer--and despite its low stage, Essence’s cancer was a rare type and widespread. After her second lumpectomy, with the cancer still present, she had the mastectomy, along with radiation treatments.

Essence was not the only woman diagnosed who could not understand why the stage and size of her cancer would lead her physician to recommend a mastectomy. Kerrie (LCR), who was 48 at the time of our interview and a 1 ½ year survivor, was determined to keep her breasts before the initial oncological surgical consultation. While she wanted to choose the option that was best for life-saving, she needed this choice not to mean losing what she called a “healthy” breast.

> So after I did the bracket test, then – and it came back negative, that's when I decided I would have a lumpectomy as opposed to the mastectomy because it was like, you know, why risk losing a perfectly healthy breast when all they can do was – you know, I mean, when all they had to do was remove the lump, and good enough for me, it hadn't spread to any of the lymph nodes. So then when I was talking to the surgeon, I was asking her, you know, what was the chances of the cancer coming back if you had a mastectomy versus a lumpectomy, and she was like, well, there's

> nothing that's 100 percent guaranteed, but the ratios were so close – it was maybe like, 22 percent versus 20 or something like that. So when I heard those odds, I said, okay, well, do I want to go through all this when, you know, it's so close? So, you know, of course, you know, I relied on my faith, so I prayed about it, and like, one day I was just laying in the bed, you know, I was reading, and it like, came to me, you know, go for the lumpectomy, why do you need to ruin a perfectly healthy breast when you can just have the lump removed, and that's why I decided to go ahead and do the lumpectomy as opposed to the mastectomy.

Kerrie refers to her breast as “healthy” twice, which to her means not in need of a mastectomy. Importantly, she is *not* referring to her *undiseased* breast, but the breast where cancer was detected. Similar to Essence, Kerrie had a hard time understanding why the small size of her tumors and low stage cancer would even make the physician suggest a mastectomy. To her, that meant that her breasts was perfectly healthy aside from a small (removable) spot. To an oncologist, the biology of her cancer meant that the cancer could spread, regardless of its size. I also speculate that she may have underestimated the difference between the two survival rates for each procedure. Kerrie reported that her cancer was classified as triple negative. Triple negative cancers are more aggressive than hormone responsive cancers and have higher recurrence and death rates within 5 years across all stages. These types of cancers are more likely to spread to other areas of the body despite the stage[20]. The biology of triple negative mutations is fairly unknown. Kerrie's physician’s knowledge about the biology of Kerrie’s cancer influenced the treatments she recommended.

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[20] Take my mother’s own triple negative case for example. In 2012, she was diagnosed with the lowest stage cancer 1A. She barely made it into stage 1. Yet, three years after her first diagnosis, cancer (many tumors) were found in her spine, on her hip bones, on her lungs, and around the original site. This was a damning Stage IV diagnosis. A year and a half after this diagnosis she was dead—less than a year shy of her own 5 year survivorship anniversary. She also had routine mammograms after her treatments. Triple negative cancers are enigmatic.

It is important to note common characteristics shared by the women I just discussed and other women who avoided mastectomy despite medical recommendations. They were young—especially to have received a breast cancer diagnosis—and, for the most part, unmarried. April (MNC), 64 at time of interview and 62 at time of her diagnosis, told me she could understand why younger women would be far more distressed. She said, “You know, I’m at a stage in my life where I’m not defined by what I have physically. When I was your age or younger, or thirties—you know my daughters’ ages--that might have been a different story. But now, I decided I didn’t want to have reconstructive surgery not just yet.” April said that her age influenced how she interpreted her newly transformed body. She opted not to pursue reconstruction. Because she was older, she explained, her gender identity was no longer as heavily defined by having feminine physical characteristics like breasts. April shared this sentiment with other older women in my sample, as women (only 5 out of 25) who opted out of reconstruction were more likely to be older when diagnosed. She felt that she had moved past the age where she needed to be defined by her feminine body.

That is not to say, however, that older and/or married women did not experience similar internal dilemmas when faced with breast loss. For instance, a handful of women who were in their 60s said that they felt uncomfortable letting their husbands see their bodies after invasive breast cancer treatments. One woman waited until our interview was over, and the recorder turned off, to tell me how she avoided letting her husband (of 40+ years) see her body because she was self-conscious. Jorie (MY^{fi}CR, 71 and 6 years out from her diagnosis) told me this about her apprehension of letting her husband see her body after she described her reaction to her mastectomy:

> Well, actually, I never adjusted to the mastectomy scar, because every time you would change your clothing, it was there for you to see, so it was a little bit – you know, I didn't like the way the scar looked and the fact that my body was altered the way it was. So I decided to go ahead and get the reconstructive surgery, and I feel so much better about having done that.
>
> Me: Okay. Were you comfortable with letting your husband see your body?
>
> Jorie : Not at first. Not at first. But, you know, we had a discussion, and my [inaudible 16:24] is very old-fashioned, and he said it was not a big deal to him. You know, he had been in – he had been in Vietnam and he had seen a lot of things much worse, even though this was his wife. So he was very encouraging and everything. ”

I suspect that even some women who said they were not uncomfortable showing their husbands their bodies may have been somewhat apprehensive. Take Shelita (LCR) for instance. Shelita, in her 60s, stated that she was not self-conscious about letting her husband see her body, and insinuated that her husband's body had changed over the years too. However, she finished her statement by mumbling that his reaction to her body is "Only what I let him see," suggesting that she still hid her body from her husband. Moreover, she talked about not being self-conscious, "And [my transformed body] don't stop me from wearing no swimming suits, you know, as long as I don't wear nothing that's like low cut. I mean, I'm just not going to advertise my scar, but it's there. I'm not going to just advertise it, but I'm not ashamed of it." She did not feel ashamed of her scar, yet she did not willingly show people either. She no longer wore the swimsuits or low cut clothes that she used to because of the scar. Therefore, might this appeal to age and marital status be a way women cope with body loss?

The presence of a (long-term) partner did not mean that women adjusted to breast loss easily, a pattern that cannot be better demonstrated than by Monica (LR, MN). Monica—unmarried but cohabiting with her boyfriend of 17 years—told me a distressing story about the fear of male gaze. The first time her partner saw her body after the surgery, Monica told me, “that was the hardest thing in the world, to have him look at me like that, and I was all swollen out to here, and it was – I was so ugly. I think that was the hardest part of it this year. No woman wants a man to see her look like that.”

Why wouldn’t a woman want her man to see her breasts maimed? Brandy (MY[i]CR), who was 40 and married during her treatments, offers an explanation. She discusses conversations she had with a distressed, unmarried friend undergoing treatments. She says, “[S]he just feels very hurt, depressed a lot. […] And even though you’re not your breast, [it is so important] to our physical, our sex appeal, our, you know…whatever. That’s missing from her, you know, and it’s hurting her.” Brandy tells us that breasts are an important physical attractive characteristic that gives women sex appeal and describes how this connection to sex appeal could be troubling for another woman. She told me earlier in the interview that she did not feel this way because she was not her breasts. However, notice the change in subject in her quote. She begins by talking about her friend’s distress, then transitions into using the ambiguous “you” to ending with “our sex appeal.” Throughout her interview, though she told me she was not distressed, she often nostalgically recalled her large breasts.

This connection between *feeling like a woman* and the presence of breasts was a common theme in these interviews, regardless of women's age. This idea included considering how men would respond to their bodies. That said, however, my younger participants emphasized that the sexual meanings for breasts and womanhood strongly influenced their treatment choices more often than did women I interviewed who were diagnosed at later stages in life (after 55). Some women saw their youth as the very reason why reconstruction was a vital part of their treatment process. For instance, Simone (MY[i]CR) said she arrived at her decision to reconstruct because, “Well, I knew that since I was considerably young, that I did not want to wear prosthetics and if that -- if reconstruction was an option for me, because they did it all at the same time, then I wanted to just get that done. I didn't want to have to revisit it later.” Simone was only in her late 30s when diagnosed and treated for breast cancer.

So, why are you here?: the expectation that women must buy into plastic surgery

In addition to pressures to attract the male gaze, science and medicine have adopted practices that reinforce norms about proportionality, especially the appeal of proportional feminine breasts. Currently, plastic surgery is a multi-billion-dollar industry and its largest revenue source comes from *correcting* breasts (Merianos 2013; Dull and West 1991). Such success hinges on the cultural preoccupation with ideal feminine bodies in which breasts are highly scrutinized. Studies on body satisfaction find that women are most often dissatisfied with their bodies because they are displeased with the shape, size, and form of their breasts. Large and perky breasts are not the biological norm for how women’s bodies look (Forbes and Frederick 2010; Dixson et al 2010; Dull and West 1991). In other words, most women cannot naturally attain the hourglass, voluptuous, Barbie body; yet, the busty standard still holds as gold. Medicine can address the aesthetics of breasts, treating dissatisfaction as a medical problem remedied with cutting, saline, silicone, pills, lifts, and reconstructions.

When a woman showed any reservation about reconstruction or rejected all together, her response was not always condoned. Before I formally interviewed her, I remember talking with my mother about her first consultation with the plastic surgeon. She was not happy. After leaving the appointment, she felt annoyed and a bit hurt; she was insulted. She felt that the threat of death that she faced from a cancer diagnosis was trivialized in this consultation. She felt condemned for refusing the service of reconstruction, as if her decision to opt out of reconstruction was paramount to refusing to undergo a mastectomy. In our interview, when I asked her to recall that experience she tells me the following:

> *He talked to me about [reconstruction] but he was not very convincing. I mean, I don't know what quality or level he was as a doctor. He could've been a good plastic surgeon, but he had no pictures of his past work. When I told him I did not want to do reconstructive or have breast implants, he was not very, I guess, nice. He was like, well, why did you come here? And basically I said because they told me to come here.*

My mother's justification that "they told me to come here" signaled how quickly women must confront decisions about restoring their bodies in the cancer treatment process. It also shows the strong assumption, even by medical practitioners, that all women want or should have reconstruction. Typically, after being diagnosed by a breast specialist (usually the surgical oncologist), a woman was referred to a team of doctors for initial consultations regarding treatment options. Depending on the severity of the cancer, this team of doctors consisted of a surgical oncologist, a medical oncologist, a radiation oncologist, and a plastic surgeon. Even women who were not candidates for mastectomies—the most severely body altering of the breast treatment procedures—were often referred to a plastic surgeon.

Ramona (MY^{f}C)—who did elect to do reconstructive surgery—also had an uncomfortable experience with the plastic surgeon to whom she was first referred. She tells me: "But that one—that one plastic surgeon in particular, because I was so emotional about it, he just basically said, you need to get over it and – I was like, really?" Ramona was 29/30 at the time of her diagnosis and treatment. Despite choosing another plastic surgeon to perform her reconstructive surgery, the feeling of insensitivity she experienced during this initial consultation lingered with her throughout her treatment process (and still today 15 years after).

Other women talked about feeling pressure in physician's appointments to conform to ideal feminine body proportions. Proportionality was often a subject raised within physician's appointments. For instance, Bethanie (LCR), a 41 year old cancer survivor, describes the consultation with the plastic surgeon that her medical team suggested.

> Bethanie: I know he talked about taking like some belly fat and putting it in my breast or what have you, yeah, and then a breast reduction too, and I just decided against all that.
> Me: Why did he recommend the breast reduction?
> Bethanie: Because I'm top heavy anyways, and you know, they were just saying that one breast was going to look different than the other one or bigger, you know, one would be bigger than the other, but—My surgical oncologist didn't think that I needed either, so we just didn't do it. […] I felt that he was just trying to make some money, so he was very insensitive to what was going on.

This excerpt with Bethanie revealed that her plastic surgeon evaluated the proportionality of her breasts relative to her body. She had large breasts, but to the plastic surgeon, they were too large in proportion to the rest of her body frame. The disproportionality of her large breasts was now a treatable condition. Both of her breasts became subject to fixing via medical procedures, not just the diseased breast. The unaffected breast was eligible for an insurance-covered reduction because disease was found in the other breast *and* her breasts were too large for her body. Later in her interview, Bethanie told me that she was unaware that reconstruction was optional until she and her husband did more research. The veiling of the optionality of reconstruction highlights the integral role this procedure plays in cultural understandings of breast cancer treatments. While Bethanie decided against any sort of reconstructive procedure, other women did use reconstructive procedures to fix the other breasts or the proportionality (and size) of both with breasts lifts and reductions.

Attention was called to the proportionality of women's breasts and their waists during many women's consultations with surgeons. The legal rules about reconstruction procedures (for insurance purposes) opened up other options to women in addition to restoring the diseased breast(s).

You'll have perfect little breasts: breast lifts, reductions, and eveners.

Reconstruction and treatment consultations were not always about restoring the diseased breast(s) that would be maimed by mastectomy or lumpectomy. Instead, women told me that physicians (and not only plastic surgeons) often commented on the other breast or the proportionality of the set. Gretchen (LCR) described an early consultation with the breast specialist (her surgical oncologist not plastic surgeon), where she found her other breast scrutinized.

> And she [the physician] said well Gretchen did you notice that your left breast is larger than your right breast? I was like no. (laughs) No one ever told me. And she said, well, by the time we remove this [cancer mass]…She said you'll probably have perfect little breasts.

I am not so sure that Gretchen did not think that her breasts were not perfect already.

"Fixing" the undiseased breast was quite normalized in some women's experiences. For instance, Angela explained that her left breast was reconstructed after its mastectomy to treat the cancer and that "the plastic surgeon included the reducing of my right and giving me a lift." One woman, Cassandra (MY^{f} C), even talked about how she was somewhat happy that having breast cancer surgery gave her the opportunity to augment her breasts as well—something she had always desired since her breasts were small (even though she ultimately decided against doing so). Cassandra tells me that after her mastectomy:

> Well, it looked horrible, for one. It looked like – I mean, I've always had small – I've never had big breasts, and I always used to tell myself, I'm going to – I'm going to get breast – [like big breasts]– whatever, you know? And because [my plastic surgeon] asked me, he said, do you want me to do the other breast and give you a cup size larger? I said, if it means you have to touch the other side, where you have the right side open, no. Just make it back the same small little breast that I had before. And he kept laughing – I said, I don't think it's funny, because I mean, as far as I know, somebody could slip up and hand you the same one, and then there goes the cancer in that side. Kind of silly, but I didn't want it – I didn't want it then.

Cassandra decided against the larger breast implants because she was afraid of further complications. However, she did have the opportunity to get larger breasts—something she always wanted. Apparently, she had voiced her desire to go bigger to her plastic surgeon at some point because he suggested adding a cup size to the otherShe also remarked that her reasoning behind not wanting larger breast at the time was “silly,” for believing that cancer could accidently be transferred to the other breasts. Was it silly that she bypassed an insured chance to create larger breasts?

Brielle (LCR), who had a lumpectomy and did not have reconstruction on her diseased breast, had a cosmetic procedure done to the unaffected breast about a year later. After I asked her if she opted for reconstructive surgery, she told me, “I didn’t. At the time, I didn’t need it with the lumpectomy. The only difference was that after the radiation and then the lumpectomy, the right breast was a little bit tighter, firmer than the left breast was. So I did receive a breast lift on my left breast, the non-affected breast. I did get a breast lift[21] a year later."

Breast cancer treatments offered women the chance to *fix* the undiseased breast, the ability to optimize breasts' proportions, and the opportunity to restore the self—as the maiming treatments for breast cancer feel unnatural to many women. In some contexts, it also provides an insured way to fix proportionality flaws of the body.

Tummy tucks. Breasts and issues related to breasts' proportionality were not the only conditions eligible for fixing and reconstruction. In addition to making women feel that reconstruction was necessary and that its refusal was somewhat unacceptable, some plastic surgeons pointed out other aesthetic uses for the TRAM flap reconstruction in particular. A handful of women said that plastic surgeons promoted the TRAM flap procedure by selling it as a tummy tuck. For example, Beatrice (MY^{f} C) said, "Actually my doctor called it a free tummy tuck. […] We are going to give you a free tummy tuck and everything. (laughs) So I said, all right." Florence (MY^{f} R), who was treated over 30 years ago, did not even refer to her TRAM flap as reconstruction but instead said, "Back then it was called, I guess, the tummy tuck, they pushed the fat up to where the breast was." Florence implied that the procedure changed names with her assertion that "Back then it was called a tummy tuck." Essence, age 44 and 4 years out from her treatment, also described her flap surgery as a tummy tuck. This discourse of the tummy tuck turned attention away from the diseased breast to perfecting the proportionality of a woman, an adherence to the curvaceously feminine standard (Dixson et al). The women who chose to do reconstruction and selected flap surgeries did not express negative feelings towards

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[21] A breast lift is a surgical procedure used to "correct" drooping breast tissue. See the figures in the history section for a more comprehensive description of breast reconstruction procedures.

having belly fat removed or feminine proportions enhanced. However, the tummy tuck or autologous flap procedures did come with other side effects that many women did not anticipate (more on which below).

Natural procedures, disability, and reconstruction. Women who seek augmentation for cosmetic reasons expect to have a foreign object in their body, and it is their choice to have something “unnatural” implanted to enhance their bodies. The women I interviewed did not choose the context that put them in plastic surgery consultations. Many women in my sample felt uncomfortable with a foreign agent inside their bodies. Thus, many of them maximized their power to have the most natural and unaltered body by choosing options for reconstruction that did not require the implantation of foreign objects. This need to feel natural is not something that women likely share with cosmetic consumers of breast *enhancing* surgeries. For instance, while people might want or expect cosmetic breast augmentation to look natural, the women who undergo it actively select to use saline or silicone implants—foreign entities unnatural to the body. The women in my interviews frequently expressed that cancer already introduced something unnatural (even foreign) into their healthy bodies--and they didn't want to add anything else unnatural. (I will discuss the link they draw between foreign agents and cancer more in Chapter 2 on hair loss.)

The majority of women in my sample who opted in to reconstruction chose a flap procedure. In this surgical procedure, physicians take fat and muscle from other parts of the body (the stomach or back) to reconstruct breasts. Some women who chose this option implied or directly related their choices to the need to be natural or free of outside agents/bodies. Keisha (MY^{f}C) said, after I asked her about her reconstructive surgery:

> I elected for the TRAM flap, and because I was doing the TRAM flap, and it was my own body tissue, nothing—no artificial being put in there—the breast that I have are from my own body. […] better than me getting implants or doing some other things.

Essence also reported selecting the TRAM flap surgery for the immediacy of the procedure, which can be done and completed at the same time as the mastectomy. Implants cannot be placed at the same time as mastectomies are performed. Instead, a tissue expander is put in place to prepare the chest area for the implant procedure that usually occurs several weeks later. Essence told me, "So I had the mastectomy with the TRAM flap breast reconstruction. That surgery was about nine hours. Yeah, so I told them—I said, you're taking away a boob, when I wake up, I want another boob!" Essence's youth at diagnosis likely played into her demand for a new breast quickly. Recall that she also avoided the mastectomy in order to preserve her breast.

Eden (LMY[f]) presented another perceived benefit of the TRAM flap surgery when I asked her if she selected an implant or a flap procedure. She said she chose the flap "[b]ecause I didn't want – I had heard so much about the saline[22] that I did not want that, and then the flap was – they was going to go into my back or something and bring it around, and I didn't want that. So I just wanted a *simple* thing that I could get, and I was a candidate for the reconstruction that way." Autologous flap surgeries, such as the TRAM flap, are not without their risks, and many women seemed unaware of—or better yet, unprepared for— the consequences these procedures

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[22] I assume that Eden is actually talking about hearing negative things about silicone, which was banned for much of the 1990s. Often women misspoke and were misinformed about procedures and treatments that they "heard about." This information did not come from physicians. I should have probed more in this instance when she gave the misinformation about saline.

entail. Despite that fact that surgeons use one's own body tissue, flap surgeries are long, *complex*, and dangerous, and these patients are far more susceptible to infections than women who elect to do implant reconstructions. The recovery process from flap surgery is months long, and the loss of feeling in the stomach or back is often an unavoidable side effect. Many women I interviewed complained about this loss of feeling.

The numbness after reconstruction for some was likely permanent. The loss of sensation associated with these types of surgeries was first brought to my attention before I started this project. During a graduate field methods course, we were instructed to select a space to do participant observations. I selected the Gilda's club[23] and started frequenting some of the classes. One class I enjoyed was the quilting club, a space where cancer survivors—predominantly white breast cancer survivors—came together once a week to work on sewing projects and to gossip. I recall one conversation between two breast cancer survivors—one an 18 year survivor—who joked about the lingering consequences of flap reconstruction. One woman joked that she could feel nothing in her abdomen area. This area used to be a sensual hot spot for her and her husband but since her treatment, *he can rub down there all he wants, and I won't feel a thing*. The other woman joked that when a male coworker accidentally brushed her breasts, she told him not to worry because he was really touching her stomach—and she had no feeling in either area.

Women in my interviews shared similar experiences of body sensations with the women in my quilting club. For instance, Beatrice, also 18 years out from her diagnosis, talked about her experience with numbness following her "tummy tuck." After she told me the area below

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[23] The Gilda's club is a non-profit cancer organization that specializes in providing free counseling, activities, and information to cancer survivors and their families/significant others. Membership is free.

her breast down to her abdomen was numb after surgery, I asked her if the feeling came back. She said, “It took a long time, because some areas now, if a pin sticks me, I don’t know there’s a pin in there.” Similarly, Essence described the change in sensation in her abdomen area after the flap surgery: “Certain areas—because see, the TRAM flap is more like a C-section scar, and so certain areas, I can feel myself touching my skin, but I can’t feel myself scratching—you know? And then certain areas, I mean, I can have a little pin, and the needle prick is just, I mean, it hurts really bad. So that sensation, those nerve endings and stuff there, it’s something.” Based on Essence’s account, the numbness from flap surgeries could coincide with sharp, sporadic pains or overly sensitive spots in affected or transformed body parts/areas. Recently, scholars have become interested in the consequences of flap surgeries, especially changes in sensations. Some research finds that numbness in the abdomen area in particular can be potentially harmful or dangerous to overall health (Paus et al 2010).

I make no assumptions about whether women are typically warned of the loss of feeling prior to surgery; however, most women I talked to were unprepared for this sense of loss and found it hard to cope with new body sensitivities (or lack thereof). Perhaps they were told but found this threat of sensory loss to be just another piece of information to process after being overwhelmed by the initial news that they had cancer. The pain from sensations left Olivia (MY^{f}C) to regret her reconstruction all together. She told me:

> And if I could go back, I wouldn't have anything done under my breast, because I'm having more problems out of my breast than I did before, you know, I had it. I wouldn't have reconstructed the right breast, because now I got to go every six months, because the scar tissue, they don't know if that's going to grow or not. So I think in my instance, I wouldn't – I would not – I would not have – I wouldn't have the breast whole reconstruction thing. I – I wouldn't do that. Even the pains that you

> have in your breast, you know, the skin that's hanging over to the side and – I just think it was better before.

Olivia’s claim that her body was better before reconstruction was a bold, and often uncelebrated, claim. Women were expected to buy into reconstruction to rebuild diseased breasts. Reconstruction also could present the opportunity to fix other aesthetic flaws; and in this offering was the implications that women’s pre-cancerous bodies were flawed. But for some women, the reconstructed body was worse rather than better.

I still need a prosthesis?: body critiques after reconstruction. Even after reconstruction, some women in my sample found that they still faced evaluation, even criticism, of their body proportions. Sometimes the first critic was the woman herself. Women were often critical of themselves because the visual and sensory results did not meet their expectations, or map onto the memories they had of their body.

Some women I interviewed expressed that the root of their disappointment stemmed from visual results that did not meet their expectations nor map onto the memories they had of their body. For instance, Brandy fondly remembers folding clothes and resting them on her large breasts. She cannot do this anymore because her surgeons could only reconstruct a smaller set of breasts than she had naturally. Catherine (MY^{f}CR, 13 years out from her diagnosis) tells me about how she visualizes her transformed body: “I don’t know if this affects everyone but I can tell you people in my [support] group, it’s two distinct characteristics. They would probably never identify this. The first thing is their hair. If you looked at before and after pictures, which I hope we never do that because we would all be like, what, because all of us gained weight, you know, from the medicine and stuff. But also from the breast. You know, your hair is different and our breast is different. The one that was operated [with either a] lumpectomy or a mastectomy, is always smaller than the regular breast, your other breast." Catherine had reconstruction 18 years ago and she said that she still has some numbness under the arm near her reconstructed breast. Catherine's also mentioned about another feminine characteristic that can be transformed, sometimes permanently, by cancer treatments: hair.

Unfilled expectations for surgical results and concurrent cancer treatments cause great distress for women and move them further away from the body they knew before breast cancer. Such a journey can be observed in Essence's account of why she now calls herself Lopsided Suzy.

> When the breast is radiated, you know, that radiation shrinks the breast tissue, even though I didn't have breast tissue, I had fatty tissue. However, it held up better than an actual breast with breast tissue, and it just—you know, shrunk a little. Yeah. So, but I can tell, you know, the difference. I call myself Lopsided Suzy, so yeah. [I went on to ask her if she had a prosthesis] I actually do have a prosthesis. I have a thin one that I can wear so I can, you know, be even.

Essence perceived her own unevenness. However, many women were goaded by others into seeing their bodily imperfections after surgery. For instance, some women told me that plastic surgeons voiced their dissatisfaction with results during follow-ups. In this way, unsatisfactory results sometimes presented doctors the opportunity to sell more services, almost as if it should be an expectation that the body would not be perfected in just one try. LaToya (LMY^{f}CR) nonchalantly told me about her consultation after seeing her surgical results:

> The reconstruction went fine the first time and the doctors was very pleased, but at a course of time, in months, for some reason it didn't set right with him or me, so we had to go back and reconstruct again.
>
> Me: What was – what do you mean it didn't –

> Latoya: It didn't – the way the breast was – the way the breast looked, the way the breast – the way the surgery went, and then it was a little puffiness in it – in it that he didn't like, so neither one of us was pleased, so he said we going to have to go back and correct that, and then we had like, extra meat hanging – you know, some extra stuff hanging, and so I definitely wasn't pleased with that. So that's why he had to go back and reconstruct [about a year later].

Latoya was seemingly unbothered that the physician was unsatisfied with the results initially. She acts as if she did not expect to be completely satisfied with results, as both she and the physician were interested in fixing results to move her closer to the optimal female body. Instances like these speak to the normalization of cosmetic surgeries as a means for women to display more ideal feminine bodies.

In addition to physicians, other outsiders critiqued women's body post-surgery. Angela tells me the following about an interaction she had with a woman in a lingerie store that specializes in services for women with breast cancer. I asked her how she felt about her reconstruction and she replies:

> Angela: I'm glad I did it. Good. A little tiny bit disappointed when I went to go get fit for bras and the lady said to me, well, *you know you're a little imbalanced and you really should do one of the silicone*—you know they just stick to you type of things—*to make you balanced and fill out your bra evenly*. And I'm like I just paid all this money for this plastic surgery, what do you mean I need a…But I did and I did look better. So that kind of disappointed me
>
> Me: So you went back to get you right breast done or what do you mean?
>
> Angela: When I went to get my bras. I went to the cancer center over at [research hospital with cancer center] just because I knew the lady over there who helps you fit and to get fitted for bras for women who have had mastectomies. Now I was trying on the bras—they really work with you very well—and she said, "*Angela you really need a prosthetic." I was like, I've had plastic surgery*. What do you

> mean…*Oh, and the plastic surgery included the reducing of my right and giving me a lift. So that was a little surprising to know that I still needed a prosthetic to be balanced.* But I also believe there's not perfection in anything. But that was *still surprising to me that I still needed a prosthetic* to be really balanced because she reduced my right and so I felt like that left more option to get me balanced correctly. I said well just make this one [the diseased breast] this size. I think I barely filled in a C cup. I wasn't a big woman. But she said no that would be harder to do and she reduced me. So I felt like I should have been able to be balanced since you were going from big to small and increasing this one but ended up needing the prosthetic.

The woman at the bra shop not only told her she was uneven, but also suggested that she should have had implants and not the flap to look optimally feminine. Angela internalized these evaluations of her body. As we talked, she seemed to be rationalizing why she had procedures done to both breasts. She was disappointed that she was left unbalanced. She talked about the memory of her old breasts, as not being big, and the disappointment that the plastic surgeon could not match the mastectomy breast to her original one. Her narrative demonstrates the high expectations women have for the body after plastic surgery. Angela's story also underscores the assumption that plastic surgery can fix any aesthetic attribute that is undesirable. Similarly, Cassandra told me that her breasts did not look the way she wanted after her surgery. "[M]ine looks like a football. That's all there is to it. Plain and simple. […] You shouldn't have to wear a prosthesis if you've had reconstructive surgery." In the case of breast cancer treatments, however, it is unlikely that breasts can be restored to exactly as they were pre-treatment.

Some women talked about issues related to the nipple reconstruction that caused dissatisfaction with overall look of the breasts and body after maiming procedures. Nipple restoration is usually a separate process from the reconstruction and cannot be undertaken until the reconstructed breasts have healed. However, nipple reconstruction is not always successful. For instance, Angela (MY[i]C) told me, “I tried nipple reconstruction and it failed twice. And I think me being diabetic contributed to that, being a poor healer.” Similarly, Cassandra said that the piece of her skin the surgeons used never “made a good nipple.” She did not continue the process of tattooing the areola because of complications with the nipple restoration procedure.

Breasts without nipples do not match the undiseased breast that was either unaltered or enhanced during reconstruction. Normal or natural breasts have areolas and nipples that are distinct in color and shape from the rest of the breasts. For women in my sample, the nipple was an important aesthetic feature of their breasts. For instance, I asked Essence to recall her initial reaction to her body after her mastectomy and TRAM flap procedure, she told me: “I was amazed, because I had what you call the nipple sparing mastectomy, so the outer skin was still mine, my nipple was still my nipple. So I just looked and was just like, oh my, you know, they did a really good job.” The nipple and skin sparing amazed Essence and the reconstructed breast still looked like her actual breast.

Beatrice’s difficulties with nipple restoration also had what appear to be racial implications. This is what she told me about her nipple restoration process:

> Beatrice: Oh, another thing on my reconstruction, when they did the areola – areola – I forget how you pronounce it, but the nipple area – it was never like it was supposed to be. It's not like a real nipple.
>
> Me: What is it?
>
> Beatrice: They tattooed and they tried to make a nipple, but around it – you know, where the brown is, but that fades away. And I had it done twice, but I haven't done it anymore.
>
> Me: Did they warn you about this before?
>
> Beatrice: No, that – that the tattoo was going to fade?

Me: Mhm.

Beatrice: No.

Me: Did you get the tattoo like, immediately after?

Beatrice: After the reconstruction of the –

Me: Mhm.

Beatrice: Yes.

Me: And when did you have to go get it redone?

Beatrice: I would say about four years later. But it's faded now, so I just leave it as it is. And I guess back then they didn't have the technology to match the color of skin.

Me: So it didn't match your skin?

Beatrice: No.

Me: Tell me about that.

Beatrice: It didn't match the other breast, and that's what they were supposed to do, match the same, but it didn't.

Me: Have you ever been self-conscious about actually showing your breast?

Beatrice: Yes, I have.

Beatrice’s story about nipple reconstruction also points to an important racial nuance in restoring aesthetics to diseased breasts. Only the color pink was available at the medical facility where her tattooing was done. While Beatrice’s tattoo sessions happened several years prior to the interview, she was not the only one to talk about nipple fading. Sheree also said her nipple faded and did not pursue getting it redone. Of the women who did not have nipple-conservation mastectomies (or lumpectomies), many did not complete the nipple restoration process long enough to reach the stage of tattooing. Therefore, I wonder if the availability of colors is still an issue today. It may well be, because the first black man to have a successful penile transplant/reconstruction will have to have his new penis tattooed with pigments intended for white men because of the colors available at his treatment facility (). I speculate that many of these women see actual tattoos as stigmatized, as a couple of women giggled or looked at me funny when I asked where their tattooing was done. “No, not one of those tattoo places,” Beatrice told me right before she laughed. Again, women who were eligible for nipple-reconstruction often told me they were unaware of color availability because they did not complete the process long enough to reach the tattooing stage. So many women had just had enough of the cutting.

Sheree and Beatrice’s stories about nipples may hint at potential pathways by which black women may experience breast cancer in distinctive ways. Up to this point, I have shown how the Pink Ribbon Culture in practice can affect how women process breast loss and body transformations. Black women, however, experience this disease in a time where race still matters for health in many ways. While the nipple color issue was not raised enough among my women to be more than a speculative finding at this point, it is important to note that even 15 years ago (when Beatrice’s got her tattooing) making brown shades of ink available at the facility would not have been a technologically difficult or expensive intervention. The lack of nipple colors then signaled to women like Beatrice that breast cancer interventions are not necessarily designed with black women in mind. The PRC and its treatment practices emerged from a movement that focused on white women, and thus reconstruction treatments are also heavily influenced by white, middle class gendered norms--and with the assumption of white, middle class, female bodies. This sort of approach to understanding how women processed breast loss and reconstruction ignores the fact that white medical establishments often fail to recognize racial diversity.

Raced And Classed: Variations In Experiencing Feminine Bodies In The PRC

The ugly black scar. Sometimes the stories women I interviewed told me hinted that medicine's practices did not necessarily recognize these race-specific concerns that women have about their the aesthetics of their breasts. Sometimes, along the course of treatment black women receive little hints that they occupy social locations outside of normative femininity. This can come in the form of inattention to side effects that are more likely to happen to black women. For instance, some women talked about keloiding (puffy scars), yet they felt that the proper attention to this scarring side effect was not present in their breast cancer experience. While scarring is not unique to them, black women have a much higher risk of keloiding after deep lacerations like surgical cuts than their white counterparts (Kelly 1998; Marneros et al 2004 2004). Keloiding occurs when fibrous scar tissue overgrows the incision. It can also occur underneath the skin to produce protruding knots. Sometimes keloiding is minor, and in other instances, it can result in balloon-like growths that must be removed to prevent spreading and discomfort. Often keloids grow back and require additional procedures (Marneros et al 2004). Monica , for instance, had to have keloids removed several times to alleviate issues of pain and aesthetics. For Monica, this keloiding prevented further progression in the reconstruction process.

Keloiding could also affect other parts of women's treatment. Angela (MY[i]C) talks about how she used her knowledge about her tendency to keloid after cuts to help doctors determine where her port[24] should be placed. Angela tells me: "And I also got it positioned very low on my breast because I knew I keloid and I keloid slightly with large discoloration in

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[24] A port is sort of like having a surgical and semi-permanent. It is a medical device that has a catheter. This device is used to aid with chemotherapy infusions, as medicines can be administered through the port instead of securing an IV line in the arm each time a woman has treatment. The frequency and number of treatments as well as the health of one's peripheral veins determine whether or not a doctor recommends this device. Also, the removal of lymph nodes may also inform eligibility for this procedure. Recall that women who have had lymph nodes removed under an arm cannot be pricked on that arm.

comparison to my skin complexion so they were always a little surprised when they found my port down here when I went for infusion treatments." Angela asked her doctor to position her port lower on her chest to avoid the keloid that formed because of her mastectomy. Angela was also an embryologist so likely had more medical knowledge about the body than most other participants. Oncology nurses—the medical professionals that usually access the port—were often surprised that her port was placed in a different area than where the device was typically found.

While there is no known cure[25] for this condition, there is an abundance of evidence that black people (and some Asian populations) are more likely to experience keloiding than members of other racial groups (Marneros et al 2004). However, women did not say that this form of scarring was discussed in physician appointments. Shelita describes issues with keloiding after her lumpectomy in the following interaction:

> Me: Is there something you would go back and say to your doctors?
>
> Shelita: I'd probably—Well, like I said, everything has changed so much, so what I know now I didn't know 11 years ago, and plus the treatments have improved, the medicines, the surgeries. It's like now they can just zap it out with a laser. I personally, I don't like this scar tissue that's left behind. It's kind of like a knot. I don't like the scar tissue, but the keloid, that's just the way Black people do. I don't know if they can remove that. I used to worry about that. It's nothing you can see with the naked eye. Only I can feel it.
>
> Me: So would you -- What would you tell them like to warn you about it or remove it or --

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[25] Conditions that affect minority populations receive far less research attention and funding. I speculate that keloiding is still *just something uncontrollable that happens,* because it doesn't happen very often to white people.

> Shelita: I would say if—I guess it was the location of the cancer. I don't know if they could have went like under instead of going on the top of my breast, so I guess it all depends on where it's located, because you know, some people just might be on the side, so it could be –Mine was on the top of my breast, so of course that limits you to wear low cut. I wondered if they could have made the incision somewhere else. I never inquired about it. I never even thought about it.

In addition to the lack of attention to keloids at doctor's appointments, Cassandra talks about how information about this side effect is missing from other resources black women may use that promotes self-care after breast cancer. When an agent from a cancer resource organization visited her home, Cassandra was not impressed. She told me: "You know, she didn't find out anything, you know, and you couldn't ask her if you were – what is it when your keloid – if that would happen, because she's not black, you know, and so she wouldn't know that." Cassandra felt that the breast cancer survivor who was sent by the cancer organization could not identify with her or her needs because this agent was not black. This volunteer was trained to provide useful information, yet did so without considering how black women's experiences might be different. Cassandra was not the only woman to demonstrate a feeling of disassociation from white breast cancer survivors; but, I will reserve that discussion for chapter 3 on social support. Next, I will move on to discuss how class variations contributed to differences in breast transformation events among the black women I interviewed.

Implications of Class: Creating Barriers to Restoring Femininity

Let's revisit Monica and the disconnection she voiced between her new disfigured body and her feminine, sexual self. She routinely hid her body from her partner. That there is such a strong tie between femininity and breasts is somewhat disheartening in cases such as Monica's treatment, because she told me that she was not eligible for reconstruction. Monica described how cancer changed her: “Yeah, I’m going to say emotionally I’ve changed. I feel less of a woman than what I used to be.” The impairment of breast cancer had come to define her, and the loss of her breast became synonymous with the process of grieving for a part of her feminine identity. Monica went on to tell me that for her partner the breasts “were always his thing,” and she often caught him looking at the breasts of other women and celebrities after her mastectomy. I will be discussing Monica and her partner more in Chapter 3 on social support.

At this point, it’s important to acknowledge that I cannot quite decipher why Monica was not eligible for reconstruction. She was not able to explain why in detail, even when I asked her directly. I did not have access to her medical records. She hinted at some comorbid conditions during our interview that can affect women’s eligibility for reconstruction. A handful of other women talked about comorbidity (or the presence of other chronic conditions like diabetes and heard disease) as obstacles to reconstruction. In general, black women have higher rates of chronic conditions than white women do (Geronimus et al 2006, 2010), and black women within lower socioeconomic statuses are more likely to have comorbid conditions than well-off black women. Moreover, health experts suggest that BMI is also an important reconstruction eligibility criterion. Black women are more likely to be obese than white women, across socioeconomic statuses (Beaubouf-Lafontant 2007; Wilson, Thorpe, and LaVeist 2017; Christie-Mizell et al 2003; Nicholson and Browning 2012). Given the patterns of obesity by race found in the United States, weight and BMI may confound determinations of a woman’s eligibility and the choices women have for reconstruction (Sanderson et al 2015). However, I do not have to capacity in this data set to assess that dimension.

At the very least, among the women I studied, class came into play by way of affecting how information was delivered and understood, affecting how a woman perceived eligibility for reconstruction. For instance, Monica told me that she thought she was ineligible because of the scarring from her second breast maiming surgery, which followed a second, recurrent cancer diagnosis. If she had had the reconstruction the first time, she believed, ineligibility would not have been an issue. She did not attribute her ineligibility to years spent struggling with diabetes and other chronic conditions. Yet, Monica had a low income and a low level of education, and she was on public insurance. Throughout her interview, I often felt that she did not have all the information she needed about her body and her cancer. She perhaps was not provided with certain information or perhaps did not understand what physicians were saying to her. Therefore, mechanisms of class—via increased likelihood of comorbidities and barriers in communication between physicians and patients—produce variations in how women experience breast loss given the limitations of medicine to restore only eligible bodies.

Botches and infections: class and reconstruction results. Nuances associated with low status contributed to variations in how satisfied women were during the breast reconstruction process. The most disturbing story I heard was told by Andelle. During her experience with reconstruction, she experienced maltreatment with conspicuous class implications. Andelle (53 and 8 years out from her diagnosis) was on disability-based public assistance at the time of our interview but she had worked as a nurse's assistant when she was undergoing treatment. She had public health insurance (Medicaid) coverage, which limits the number of doctors a woman can see and offers fewer services relative to private insurance (Robbins and Padavic 2007; Cubbins and Buchanon 2009; Williams et al 2010). Andelle recalls an uncomfortable encounter with her plastic surgeon on their first meeting.

> I tried that [reconstructive surgery]. But the doctor at the time, the plastic surgeon – he – for some strange reason, when I went in to see him, I could have sworn I smelled alcohol on his breath. […] But I thought it was just me, you know, because most of the time people try to cover up stuff with peppermint, but peppermint really exposes a lot of stuff, and I thought it was just me.

Andelle's story highlight several disadvantages in access to care that lower status individuals tend to experience. First, Andelle alerts me that she felt her doctor might have been inebriated. Yet, she did not feel that she had the power or agency to refuse his services. Agency within professional encounters, like doctor's visits, varies along socioeconomic status lines. Ramona, middle class and from a middle class background, also got a bad vibe from her plastic surgeon but decided immediately that she would not use him. After she and her mother did not like the interaction with the first plastic surgeon they consulted, "You know, he talked to me like that [telling her to get over her distress, and choose reconstruction], and my mom was like – she didn't say anything, but she said, what you think? I said, I'm not using him. She said, okay. She said, I didn't like him, either, but I just wanted you to make your decision." More advantaged, educated individuals were more likely to question physicians during encounters, to know and ask about their options, and--in the case of my interviewees--be affiliated, by kin or friendship, with a medical professional who could provide guidance.

As it turns out, Andelle was right to suspect that her physician had a drinking problem. Months later, she discovered that this plastic surgeon nearly lost his practice and was sent to a drug rehabilitation center in an attempt to save his license. However, she found this out after he operated on her. Andelle described her experience:

> So I had got the tissue expander placed and everything, started going to see him, and he was feeling it, and I was in the mall one day and I noticed people kept

> looking at me – didn't even realize all the fluid that he had put in on this side had leaked out on the blouse. Plus I got a real bad infection. I found a hematoma on it, and I had to go in his office and he had to put me in the hospital to – to cut it, to drain it. So I told him, since I had had so many problems, just take the tissue expander out. But eventually, I found out that they had to put him in rehab because he really was drinking. So that wasn't my intuition, I was really right about that. And when I saw some of his work, I really didn't like it anyway. Now, I would really love to do that now. I would really love to do the reconstruction. I just haven't found a good plastic surgeon that I would really probably want to go through all that again, you know?

She went on to tell me more about how these interactions with the surgeon made her feel and why she was averse to pursuing further surgeries:

> I would have not chose [sic] the plastic surgeon that I had, because I had to deal with a lot with him, too, because it left a hole in my incision right there for a long time, and I had to have home health care to clean that up, because it was infected. And then, you know, I had to go back in and have it sewed up. So you know, I had to go through a whole lot of that simply because of something he was not doing right, and I trusted him, as far as being the doctor, to you know, do – do – give me the best care possible, and he failed to do that. I shouldn't have had to go through home health. I should have never had to experience leakage like I did out in the community, and you – this is your profession. You know, I should have never had to do that. So that's why, you know, I just gave up on it. And had he done everything he should have done from the beginning, I probably would have been passed all that and had my reconstruction and everything would have been over with years ago. But because he didn't do what he was supposed to do and was negligent, I had to stop it and I just gave up on it, because I didn't want to keep going through that, you know? I got tired of them wanting to go in me, open me up, close me up, open me up. I didn't want to keep going through that. So the old saying is, if it ain't broke, don't fix it, so I just let it close and I've been good, and I haven't had to worry about any more infections or anything like that.

Andelle's experience also shared a striking and disturbing similarity with those of other low status women that I interviewed. These women were far more likely to experience dissatisfaction with or obstacles to reconstruction because of infection. Seven women reported that they experienced a severe infection after surgery (usually the one to remove the cancer). I noticed a pattern in that these women were not (typically) of middle class status. Four of the women, including Andelle, I categorized in the lowest SES category or poor. (Two of the women were working class, and the other middle class.) Similar to Andelle, Irene (LR) experienced infection after returning home from surgery. She gave me the following time line for her procedures:

> I went [to my follow-up appointment] Wednesday and [the doctor] came in and explained to me what she saw – what they saw on my mammogram, and they did a biopsy, and then on that Friday I was in the hospital having surgery. They sent me home, which I think they should have kept me in the hospital after – they sent me home Saturday. No, they sent me home the same – they did the surgery and they sent me home that evening, and when I got home, I don't know what happened, I wasn't responding on Saturday. Sunday, I wasn't responding good, and it took three of them to get me to the bathroom and back, and my daughter called [911], Then I don't know what else happened, but when I woke up, I was at Durham Regional with three IVs sticking up out of my arm – my right arm. I had caught an infection and I was dehydrated, and I stayed in Durham Regional for five days right after the surgery.

Both Andelle's and Irene's infections occurred after they left the hospital. However, in Andelle's case it is easier to speculate the presence of malpractice since (according to her account) her physician was later treated for alcoholism. The reason for Irene's infection is more ambiguous. Irene had a lumpectomy and did not pursue reconstruction because of the minimal difference produced by her breast conserving surgery. Similar to Andelle, LaToya experienced an infection that affected her reconstruction process. LaToya, however, was able to complete the reconstruction process. This is what LaToya told me about her infection:

> The reconstruction came after I got a bad infection and I got a severe burning in this spot of the cancer, and it was so painful to touch, and I went and they said, you got a bad infection. So they cut it out. Well, first they drained it. They thought they had it all. Less than a couple weeks, I was back in pain again. They didn't get it all. And that's when they decided to cut this big old hole in me and get it all out. They got it all out that time, but then I had to change them bandages every day and put this solution they gave me in it, and stuff it, and then bandage it. That went on for months. It was tiring. It was tiresome, and it was – and so because the doctor said, okay, [LaToya] by now your hole should have closed up, and because they see it wasn't, they said it's because of your cancer cells is not like normal – my cells weren't like normal people cells, because the radiation burned me so bad I couldn't – they won't – it wasn't healing properly, and so he said – he said the only thing we can think of, we're going to have to cut it off, and that's when I decided, well, you know what, if you've got to cut it off, cut them both off, because I can't deal with this no more. So that's when I decided to have the double mastectomy, and then he said, down the road, you can have reconstruction, and I decided to just go on and do it all at one time, and that's when they did it – took the fact from my stomach and reconstructed my breasts again.

I must confess that I am not quite sure when LaToya's infection happened. Her interview was more free flowing than most of my others, and I found it difficult to ask follow-up questions. I assume after radiation, if the doctor suggested both radiation and chemo before her breast surgeries. Her infection could have been a result of poor health behaviors while caring for the skin after radiation.

Shaunte, of working class status, also experienced infections which caused her to delay reconstruction for years. She said: “I just had a lot of stuff going on. I mean, it was just like – like, too much going on. It was just a lot of stuff, a lot of infections, and a lot of – you know, it was just too much going on to – and I thought it was like, the best decision, but I really don't think that now, and I don't really recommend anybody – you know, I told them do what they feel, but I don't – I don't recommend it. I mean, it's unnecessary, to me, surgery, and you're never going to feel the same, so it's – you know, it's kind of like, unnecessary to me.” Shaunte’s “stuff” also included the presence of another chronic condition. During her treatments she found out she had lupus. Andelle, Irene, and Cassandra also reported having another chronic condition that altered their treatment available. That is not to say that only the poorer women reported having chronic conditions.

Cassandra (working class) experienced an infection before leaving the hospital as well. Here’s how she remembered her mastectomy and flap reconstruction:

> And then I got an infection. And I had had my mastectomy done at [the private hospital] and [the doctor], I'll never forget him, and he had come in to look at me, you know, look at the bandage, you know how they make their rounds, once I was in my room. And he came in, he took all the bandages off, and you're still in a groggy state, okay? And he said, everything's coming along fine, and then I remember him saying, *oh, the nurse will fix you back up,* and he covered me up. And that day, like, the children would take – [my] two nursing [student daughters]– the nurses were taking turns coming and staying with me. So my daughter came, and I don't know what time of day it was, you know, because you don't know what's going on, and you hurt so bad you can't, you know, sit up or anything like that. And back then, they didn't get you out of bed that fast. And [my daughter] came in and looked at me, and she said, *why are you bleeding?* I said, *I don't know, I'm not*

> *bleeding*. She pulled my sheet down – nobody had ever come back in to cover me up, you know, to rewrap my breast and the – that line and all that stuff.

Cassandra fell between the classifications of working and the precarious lower middle class. Similar to Andelle, Cassandra believed her infection resulted because of bad treatment.

While some of these experiences may be partially due to personal behaviors and errors in self-care procedures, it remains notable that variations in treatment did occur along class lines (and happened to black women). Shonda who got an infection was included in the lower middle class category. However, unlike the other 6 women, Shonda pointed to her own behavior as the source of her infection. She said she continued to stay busy by gardening, caregiving and doing household chores. Her physician told her she likely caught a virus from overexerting herself and exposing her wound.

While most of the women's infections had ambiguous causes, Cassandra and Andelle experienced forms of malpractice. Yet neither pursued legal action for wrongdoing. Recall that Bethanie (middle class) immediately pursued legal action after she was terminated from her job. I followed up with Cassandra by asking how her daughter (a nursing student) reacted to her undressed wounds. Cassandra said: "Oh, she – she raised Cain and Abel. I wrote the hospital, I never got a reply. They said I should have got a lawyer and done something, but you know, when you have cancer, all you're thinking about is Lord, let me live, let me live, let me live." While Cassandra's access to resources may have determined the ease with which she could find a lawyer, her appeal to the Lord was a common theme in women's stories. The "doing something" that Cassandra talked about could be interpreted as an aggressive form of action. Pursuing a lawyer could imply anger during one's treatment. Yet, Cassandra used her spirituality to justify why she did not pursue filing a complaint against her treatment center. Instead, she just wanted to live. Many times women turned to spirituality as a means of accepting and coping with experiences associated with breast cancer. In chapter 4, I will discuss spirituality in more depth.

In addition to infections and the pain that resulted from them, women experienced dissatisfaction with results because of a number of other factors. These factors were rooted in universalized notions of femininity and the promises of surgery to restore women completely

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Conclusion

Many women were distressed by the loss or disfigurement of breasts. Moreover, their distress negates the image of the impervious black woman—a (masculinized) stereotype which implies some sort of unbreakable mental resilience in black women. That is not to say that all women I interviewed were devastated or even distressed by breast loss. However, the majority of women who experienced significant disfigurement were troubled (psychologically) by the threats to physicality and existence that breast cancer imposes.

I want to make it very clear that my intentions are in no way to condemn breast reconstruction. I believe that reconstruction can be an integral part of helping women heal from breast cancer and its treatments. What I do find problematic is the urgency with which it is sold. Women are pushed into plastic surgeons' offices within hours or days of diagnosis. Ironically, psychologists and psychiatrists are not present within these initial consultation teams despite the psychological toll a breast cancer diagnosis entails. Under the current model of treatment, women have to process the impending loss of their breasts, then soon after they are subjected to society's need for them to fix their breasts and restore their bodies to the feminine ideal. Additionally, some women may really want reconstruction to correct breast disfigurement after breast surgeries. However, restoring one's body back to its original state after cancer treatments is likely always impossible, because reconstructed bodies can never be fully restored after surgeries to treat breast cancer disease.

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CHAPTER V

HAIR, HAIR LOSS, AND CHEMOTHERAPY

In this chapter, I aim to explore how personal beliefs and cultural forces shape the ways in which black women process hair loss from chemotherapy. Here, I am committed to writing a story about femininity and hair from a seldom explored perspective: that of black women facing breast cancer. I want to iterate that black women face dilemmas about hair similar to those faced by white women, as hair possesses power in relationships—especially romantic ones—across social domains like race and class. Yet black women's experiences are nuanced because of how expectations for hair fit within dominant racial ideologies. All the while, these women face the impending threat of death for which the loss of hair serves as a precursory, damning omen. By sharing the experiences of my mother and other black women throughout this chapter, and presenting images of relatable survivors, I hope to elucidate issues of black women's health and beauty.

I must begin by situating my own body within my research. That said, I do not necessarily like discussing this topic. I have always felt the need to explain my hair's texture, and more recently (with the new "natural revolution of the 2000s[26]") my choices for hairstyles. My hair is fluffy, full, and wavy (sometimes curly). Growing up, my white classmates frequently touched or asked to touch my hair. I am often asked about my hair texture perhaps because many people do not expect someone with my skin tone, which is darker, to coincide with hair texture like mine. Today, I like my hair in natural hairstyles and straightened with the help of a flat iron. When I have it one way for too long, I tend to prefer another style. I interpret my

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[26] This is not an official term, but instead one to mark a time where wearing one's hair natural is accepted if not expected in certain contexts within the black community.

changing hairstyle as a personal choice. I frequently ask myself the following questions: Why does straightening my hair automatically mean that I am attempting to conform to Eurocentric standards of beauty? Why is it that black women's hair cannot be seen as a beauty aesthetic with no implicit political or identity implications? White women change the texture of their hair with curlers and flat irons, apparently without becoming the targets of intense cultural critique, so why can't I without automatically implying that I am not comfortable with myself? I appreciate my hair, and I owe this gratitude to my mother. I hate the political and status assumptions made about my hairstyles. I get sick of people—especially those who are new to the natural hair revolution—trying to shame or condemn me for wearing my hair straight sometimes.

Around my family, I feel totally comfortable with this part of my feminine body, primarily because my mother always had long hair—longer than most women I know of many nationalities. As a child, I used to play in it, style it, comb it; and she always loved when her children combed her hair. Unconsciously, she knew that her hair made her stand apart, but the one who knew it the most was my father. My father was possessive of this part of my mother's feminine body. They are a heterosexual couple and, in some sense, he felt that her hair was representative of him, a phenomenon that was intensified given the racialized status implications that are projected onto black women with long, loosely curled hair (Weitz 2010; Craig ; Ingraham). He loved her long hair, and would get upset if it was ever modified. When I was a small child, my aunts came to visit and cut my mother's hair to stop a few inches below her shoulder and permed it. He was furious. This sentiment also translated to the treatment of his daughters' hair, which he preferred untouched—no perms, no relaxer, no cuts. When I cut my hair into a short bob after college, I asked him if he liked it and his response was dead silence. I knew that meant no. So, when my mother was faced with cancer the first time, which meant she would have to part with her long hair at age 57, this reality deeply troubled her. While my father accepted the loss of her hair—and was more concerned with her being *alive*—I believe that she unconsciously knew that hair loss was a threat to her feminine and attractive identity. Some of the loss that she felt is associated with the power hair gives women in sexual and other social relationships (Weitz 2010).

I incorporate my story into this chapter because my own experience with hair has been salient throughout this research process, as has the milieu in which I live. First, writing about this topic forced me to confront and define my own meanings for hair as a black woman. Secondly, participants' perceptions of my hair influenced interactions during the interview, mostly in ways I was unprepared for. Most importantly, writing this chapter has been a way of reacting to the painful experiences of watching my mother's bouts with cancer. In the last year of her life, when she knew that persistent chemo would prevent her from ever seeing her hair again, my mother told me having hair was a blessing. I realize that her statement to me was loaded with many meanings.[27] In part, she meant that I have the choice whether or not to conform "appropriately" to standards for gender, race, and class expectations about feminine hair. Moreover, I am lucky (or blessed) because the presence of hair serves as an indicator of health and a signal that I am cancer free. My mother and the women I interviewed had no or

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[27] She also went on to tell me that I should take care of my hair because it was a blessing from God, which has implications for religion and spirituality that I chose not to address in this chapter. I emotionally unload in this chapter more than others. I think that it is because of the tie to hair I share with my mother. While I am especially attached to my breasts, I am the only woman in my immediate family that naturally has large breasts. My mother nor sister were ever really attached to their breasts when they were growing up. They were both A-B cups before birthing children. Breasts were not a salient part of their identities as they are for mine (I don't think I could ever where a B cup and manufacturers don't sell my letters in the average lingerie store). My mother did not need to start wearing a bra to after birthing her children, so when I sprouted boobs larger than hers in the 4th grade, it was unfamiliar territory for her. Her mother had large breasts, but always hid them. My mother told me she didn't realize grandmamma had large breasts until she was undressing one day at a doctor's appointment when she was in her 70s. On the other hand, my mother was always meticulous in the care of our hair—something she learned from her mother.

little choice when it came to hairstyling while they were being treated for cancer. Nor could they escape the meanings for identities that expectations for feminine hair (or its loss) project.

Health in a Culture of Feminized Hair: Gender Norms and Feminine Hair

Hair is a social indicator of health for women. Specifically, the absence of hair on a woman implies sickness or impairment of some kind. Moreover, this visible sign of illness or disability poses a threat to women's gender identity (for more on gender, illness, and identity, see introduction). For men, baldness does not have the same meanings for health, and tends to be a marker of age (Charmaz 1999; Weitz 2001, 2010; Schippers 2007). (And almost no one will interpret baldness in women as an aesthetic preference, although they will in men.)

Chemotherapy and hair loss: why women had no choice. While there is some speculation that radiation can affect the hair, chemotherapy has the most ominous reputation associated with hair loss. Chemotherapy is a drug or combination of drugs used to treat any disease. Commonly the term, shortened as chemo, refers to the chemical agents used to treat cancerous diseases. Unlike surgery and radiation, which are designed to target disease locally, chemo can kill cancerous cells throughout the entire body via intravenous infusion (IV) or pills (less common). Chemotherapy drugs are used to cure, control, or palliate individuals with cancer based on the severity of the disease. A fixed set of chemo drugs to treat all breast cancers does not exist; instead, one or a combination of drugs can be used to target different characteristics of cancer cells. Disease and other biological characteristics help determine how oncologists select the chemotherapeutic agents which best target specific cancers.

Many, but not all, of these chemo drugs produce the side effect of hair loss. The agents damage hair follicles and interrupt hair follicle cycles to create patterned hair loss that can occur on the scalp, face, and body. The biopathology underlying hair loss from these drugs is complex; therefore, the mechanisms behind why these agents cause hair loss remain unclear. Consequently, women have little to no option for effectively managing or preventing this usually temporary form of alopecia. Chemotherapy also has the power to change hair shafts, which can cause an overall change in hair texture. For example, some research shows that chemo can change straight hair follicles to curly, for reasons that are relatively unknown (Paus et al 2013; Weitz 2010). The extent of hair regrowth and any changes in texture depend on the severity of hair follicle damage, which varies by type and duration of chemo treatments as well as behavioral, nutritional, and biological characteristics of the patient (Paus et al 2013). These threats to hair are such a distressing and dreaded side effect that a small percentage of diagnosed women decide to forego chemotherapy each year for this reason alone (Paus et al 2013). Only one woman in my sample decided to forego chemo because of its potential effects on hair. Yet, she did adhere to physicians' recommendations for chemo about a year later, after her cancer had advanced two stages.

Women I interviewed demonstrated they were aware of the implied meanings between hair loss and health, which for some was very distressful. For these women, hair loss indicated to the world that something was different or wrong with a woman—that the woman was likely sick with cancer. Olivia, age 49, highlighted how illness becomes visible with hair loss:

> It's probably unbelievable to people, but that was…that was my biggest problem, was letting go of my hair. […] I mean, it was—I think it's about what someone can see. Cancer, you know, really nobody can see that. But with my hair falling out, I don't know, it was the worst thing ever to me. I really got depressed when my hair fell out. But before then, the breast [mastectomy] and all of that, everybody was like, oh, you're taking it well. But when my hair started falling out, I got a

> little crazy there for a minute.

Hair loss was an easily visible side effect that signaled illness and that something was unfit about or wrong with Olivia. This highly visible side effect was more distressing for Olivia than her mastectomy.

In addition to being affected by what others could see, some women associated visible physical changes to hair with their own sense of experiencing illness. According to Naomi, who was 46 at the time of interview, “I think it makes you somewhat—to a degree, if you don't focus—it will make you *feel* sick because you *look* sick, because it's such a different look, you know?” Naomi’s quote (2 years after her diagnosis) showed that distress from hair loss can become physiological stressors when women internalize visible signs of cancer. Naomi associates looking sick with actually feeling sick from cancer or its treatments.

Less than a year and a half after her diagnosis, Gretchen’s hair had just begun to grow back. Now age 53, she described when her family helped shave her head when her hair began falling out from chemo. Her emotions during our interview demonstrated the trauma hair loss can cause for some women.

> We were actually laughing, and we did a little prayer, and so [my oldest son] smoothed it out [with clippers], and my granddaughter got the coconut oil, and she rubbed and buffed my head, and they said you look beautiful, and (cries) I looked in the mirror, and I was shocked. But all I saw was my eyes, and I saw that I did look beautiful, you know, that it was going to be okay. Now the next morning when I woke up, (laughs) and I looked in the mirror, *I had a meltdown*, because when I looked in the mirror and I saw the baldness, and *I saw what I looked like, I saw cancer*. (cries) And it was one of the first times -- So at that point, that *it kind of*

> *hit me that I do have cancer*. So it was a journey. So I do go through the, okay, I'm going to do this, to the shock of oh my God, I *look* like I have cancer, I'm sick.

Women without hair *look sick*, to themselves and to others, especially since it is well known that chemotherapy treatments for cancer cause hair loss as a side effect. If transitioning to adopting or embracing baldness occurred for women, it was difficult. As Gretchen's treatment continued, she internalized this visible sign into her identity. She transitioned from despair "to the embracing it [the baldness], you know? That I'm bald and I am beautiful, and it shows that I am chosen, and that I am a warrior." Gretchen had to accept that she could be beautiful without hair. She also used religious affirmation[28] to support reconstituting her identity to include baldness. Importantly, she talked about being able to still look beautiful despite not having hair—as if hair possessed a special power for making a woman attractive.

Gender and hair. Hair has other social meanings that operate in conjunction with the associations people make about hair and women's health. In *Rapunzel's Daughters: What women's hair tells us about women's lives*, Weitz (2010) writes that hair and hairstyles serve as important social cues, especially upon first meetings. Hairstyles are used as markers of gender and distinctions between men and women. Observers make assumptions about character, status, sexuality, and femininity based on women's hairstyles. Also, for women, hairstyles are an important metric for displaying beauty or attractiveness (Weitz 2001, 2010; Craig 2002; Banks 2000).

People often perceive baldness on a woman as a sign of masculinity or a rebellion against gendered or feminine norms. Even religious doctrines support gendered distinctions insofar as

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[28] Her discussion about being chosen (by God) and even that she said she was a warrior have religious undertones. Gretchen was a very spiritual person.

hair is often framed as being a covering or crown and (beautiful) symbolic markers of godliness and womanhood. These tenets likely influence women's appearances across cultures, especially among black women, given the strong tie between the Christian church and the black community (Barnes 2009; Sarkosian and Gerstel 2008). Catherine, 53 but diagnosed in her mid-30s, told me "[Y]our hair is your glory, so that just makes you. You can have on the raggediest outfit but your hair is ok [so you look good]." Catherine's quote alluded to religious aspects connected to feminine hair and beauty. According to Catherine, if a woman's hair was her glory, then hair made a woman.

Catherine was not the only one to talk about the importance of hair for defining womanhood. For instance, LaToya (53 and a 7 year survivor at the time of the interview) said "it [hair] gives women their features," which is why "losing the hair was a big thing for me." LaToya's claim that hair gives women features underscored how important hair is to the appearance of femininity. To her, hair helped to enhance her facial features as well as signaling to the world that she was feminine.

In my very first interview with Ramona—age 45 and now 15 years out from her diagnosis—she said this about her hair loss, "It was just like hair everywhere. I was like, oh my god, and I just started crying, crying, crying. I said…my hair's coming out. So, it was like, coming out to the touch. […] I mean, losing your breast is awful, but I don't know, something about *our* hair…." With Ramona's "our" she could be talking about black women in particular or it could be a nod to collective femininity. When a woman's hair looks nice, she is considered attractive and beautiful, and women enjoy many social benefits in addition to attracting male attention when they are considered attractive (Weitz 2001). Thus, when hairstyling is *done right*, hair embodies women with a certain sense of power, because women with attractive hair can be considered beautiful (Weitz 2001, 2010; Zimmerman and West 1987; Brumberg 1983,1993). This sense of power and the gender implications of hair partially explains why hair loss can be so traumatic for women.

Hair's loss is devastating because it disrupts how women perceive themselves as attractive. Farrah, 71 and roughly 3 years out from diagnosis, illuminated the distress from loss in the relationship between attractiveness and hair:

> It was -- you know, we always hate losing our hair. I knew it was going to happen because I experienced that with my mom so I knew to expect it to happen. And so it affected me more than it did her. And she said I can grow some more hair. I just want to get healed. And so I echoed the same thing with me. I know when it's going to happen. I can grow some more hair. I'll wear some wigs. I'll do whatever I need to do. I just want to heal. So that was, you know, I hated looking in the mirror. But you know, because of what it represents, and cancer is an ugly disease that robs women more especially, breast cancer, and the cancer itself, of beauty, of just so many things.

Farrah described a feeling that she likened to being robbed; cancer had essentially stolen pieces of her femininity, robbed her of beauty.

Interestingly the tie between femininity and hair was the reason that some women were moved to reject the feeling of distress of hair loss. Not all women I interviewed felt the experience of hair loss was traumatic, which in turn gave these women a sense of power. Brielle, diagnosed in her 30s, said she and her husband joked about her bald head. They began referring to her as "GI Jane, because of the bald head." She was determined to not let hair loss overpower her because she was different than other women. She continued, "And it wasn't something that I wanted to hide from people, like I didn't wear a wig. I may have worn a scarf if it was really cold outside, but otherwise than that, I just walked around with a bald head. I didn't hide it, because I didn't want people to think cancer was something for them, you know, that was a sign of sickness or to be shameful of, so I just wore my bald head. I just made sure I put on cute earrings and just took it as a part of this is life, one thing I have to get through." For Brielle, losing hair was one step along the way of being healed from cancer. Moreover, she expressed resistance to accepting the stigma she felt was attached to cancer and/or hair loss. She could make herself look pretty and feminine in other ways by using adornments like earrings and hair accessories (like headbands and scarves).

Other women also were empowered to embrace their baldness and redefine notions of femininity. Unlike Gretchen (see above), some women experienced easier transitions incorporating baldness into their gender identities. April, 61 and around 2 years out from her treatments decided to adopt a shaved head as her new hairstyle. So did Sue, also in her 60s, who learned that she liked the shape of her head and face with no more than a little "fuzz." She tells me that after her husband initially shaved her head during the treatment: "And I cut it today. I still cut my hair once a week." Both women came to realize they had "cute" heads, and where still pretty—if not prettier—with buzzed hairstyles. Thus, hair loss represented a pivotal moment in which illness is visible, and in order to cope, some[29] women incorporate baldness into their identities. For April and Sue, baldness became permanently incorporated into their identities.

Some women felt losing the power of hair paled in comparison to the potential deadliness of an unchecked cancer growth. Keisha, 52 and a 9 year survivor, passed concern for hair off as vanity. After I asked her if it bothered her to lose her hair, she told me "No, I'm not really vain like that. I felt like if I want some hair, I can go buy some." Similarly, a handful of women expressed that they had previously (before diagnosis) used wigs and weaves—usually because of

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[29] But definitely not the majority of my participants.

naturally thin hair—so being bald and wearing a wig was not necessarily out of their normal experience. Eden, age 60, who actually didn’t lose her hair, said this side effect never worried her, because “because I wore weaves and wigs anyway, so it didn't bother me if I had to.”

Brandy, diagnosed at age 40 (now 49), told that her hair loss was not especially distressing, “[b]ecause you know, I wear a lot of wigs, a lot of – I do a lot of different things with my hair, so it wasn’t traumatic for me in that aspect to lose my hair.” She continued by extending the concept of feminine beauty to include women with bald heads.

> So I just tell everybody, oh, I was just the cutest little bald-head person you’d want to see. But, of course, I wore scarves and, you know, different things, too. Hats and – you know. Because I always tried to make sure when I went to my treatment – and I think that’s important – that you try to look good when you go to your appointment because if you feel good – if you look good, it tends to make you feel just a little bit better. And so, I always tried to really be sassy that day. So that’s just what I did.”

While Brandy expressed that baldness was not distressing, she did talk about the alternate ways she could display gender similar to Brielle. Brandy wore hats and scarves to cover her head in order to look “sassy” especially at her doctor’s visits. Her words echo PRC rhetoric. When her hair was no longer present, she used head coverings to substitute for hair and thereby to pull off appropriate displays of femininity. however, Using other coverings to appear still feminine spoke to the salience of feminine hair for women.

How deeply the expectation for feminine hair is held in our culture can be seen in women’s interactions with young children after experiencing hair loss from chemotherapy. The importance of feminine hair is product of a socialization process that begins in childhood, as children learn early that hair serves an important function in displaying differences between men and women[30]. Moreover, girls come to realize that feminine hair possesses power; power to make women acceptable and attractive. At later stages in life, hair has sexual power as an aesthetic quality important for forming and maintaining romantic, heterosexual relationships (Weitz 2010). My participants predominantly identify as heterosexual, so this tie to heterosexuality is important in this chapter.

In this sense, hair loss can be perceived as a stressor in social relationships, especially interactions with young children. Shaunte, who was diagnosed at 33 (five years prior to our interview) told me of an interaction with pre-school aged relatives:

> I remember one time, I took off my wig and my nieces was there – they were young, like, three and four, and they was like, no, auntie, put your hair back on, put your hair back on – because they were so used to me always having long hair, that it was different, them seeing me without hair, it was kind of scary for them.

Seeing the loss of Shaunte's hair incited fear in her pre-school age nieces. It seemed almost natural to Shaunte for these young children to be afraid of a woman with no hair. Women without hair posed as enigma to younger and older children. Shaunte was not the only woman to voice similar experiences with younger loved ones. For instance, Andelle talked about her young teen nephew's reaction:

> And what really bothered me, one of my nephews came over one day, saw I had this black cap on, and he went back and asked his mom – he said, Mama, Auntie's hair done came out, and she was like, yeah, it's going to do that, the chemo going to take it out. And when she mentioned that to me, that really bothered me. You know, not that he was saying it to be mean, but it bothered him, too, you know, and – but I'm like, that's just one of those things that happened, you know?

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[30] Parents choose hairstyles according to their children's gender, and young girls often incorporate hair and hairstyling into their play.

Some women felt shame after traumatizing a child with the sight of their bald heads. For example, Ramona told me:

> […] my cousin, she had a little boy – I think he was about five then– he was little. Anyways, she picked me up from work and she took me home, and not thinking about it – because the first thing I do when I get home, I would just rip that wig off, and she hadn't seen me, either, without it, and I ripped it off and he just started crying, [Later] I called her, I said, I am so sorry, I didn't even think about it, because that's the first thing I do. And she said, you know, he just wasn't used to seeing you like that, and I wasn't either, so it kind of just threw us off and I apologize, but it was just – it was just like a habit, because I had it on all day and it's like, okay, let me take this off. You know, so – but like I said, once it came out, I was okay. I was like, it's fine. It's just – you have to have your moment when things like that happen, especially losing your hair.

Ramona only felt free to remove her wig in the privacy of her own home **and** alone. In addition to describing her young cousin's distress, Ramona implied that women should expect these reactions. She was even apologetic for scaring the boy, implying that it is a woman's emotionally manage other's adverse reactions to hair loss. Such interactions with children especially added to the distress some women felt while adjusting to hair loss.

Broadly, scholars are beginning to recognize the significant distress hair loss causes in women (Weitz 2010; Paus et al 2013). Based on my initial interviews and the small body of relevant research (e.g. Weitz 2010 chapter on hair loss), there is even reason to believe that hair loss is more traumatic than breast disfigurement for a significant proportion of women experiencing breast cancer treatments. Yet, the little that is known on this subject is based largely on white women's experiences. So what implications might (heteronormative) gender, race, and class have for hair loss resulting from chemotherapy treatments? This important question is understudied within the field of cancer research, just as the social contexts in which black women experience breast cancer are understudied (new Williams piece +). While hair loss from chemotherapy is an experience shared across races and ethnicities, I argue that many black women face unique processes related to hair loss and regrowth.

Doing hair work. While all women feel pressure to conform to beauty standards to perform gender appropriately, black women face additional pressures that relate to race. Whereas white women enjoy hairstyling chiefly as a way to enhance their Eurocentric characteristics, black women often use it as means of becoming more socially acceptable within a condemning society. Different hairstyles also evoke meanings of class for black women, as they do for all women; however, for black women the tie between hair and status is especially salient in everyday life (Craig 2002; Banks 2000; Weitz 2010). Some scholars argue that mainstream society (especially whites) are more tolerant of darker skin tones than they are of undesirable—very tightly curled or "nappy"—hair (Banks 2000, Craig 2002). Thus, black women adopt certain *hair work*—a term I use to use to reference "doing gender" in relation to hair—to display appropriate hair in order to thwart being labeled as too masculine, too black, or too poor (or all of the above). Research indicates that black women spend more time and effort on hairstyling than white women do (Banks 2000; Craig 2002).

Hair work becomes incorporated into women's identity, and for some of my participants this attention or importance of hair was why hair loss was especially painful for them. When women make statements like "You know, hair is major with African-American women," they called upon the shared knowledge of the various meanings of hair for black women, and the time black women are expected to invest in its care.

For over a century, black women have used hair straightening techniques to achieve textures in accordance with good hair standards. The first type of technique was the straightening comb (invented by Madame CJ Walker in the late 19th century). This technique calls for a heated, usually metal, comb to straighten the hair with the aid of greases and pomades to preserve the straightened texture and/or to prevent the burning of skin. One shortcoming of this process is that water and humidity can quickly revert the hair back to its natural state. In addition, the straightening comb can only get coarser—or kinkier—hair but so straight without completely burning the hair shaft itself. Walker is also credited with developing a later advancement (early 1900s) in hair straightening for black women: the relaxer, or what is more commonly known as the *perm*. A perm uses strong chemicals—like lye—to straighten the hair, and the results last for a much longer period in comparison to the straightening comb technique. Because of this invention, black women with coarser—or kinkier—hair textures are now able to achieve more optimal hair textures than hot straightening techniques provided. The perm actually chemically alters the hair's texture such that water is not such an imminent threat to straightened hair. On the downside, perms or relaxers are generally harsh and can cause (painful) chemical burns when they come into contact with the skin of the scalp or face. They cannot be washed out and often require years of cutting and regrowth to restore natural textures.

Why would black women invest so much time—and subject their scalps, ears, and face to pain—for this type of hair work? Similar to the pattern of privilege associated with skin tone, hair texture (and style) is associated with privilege or prestige not only by outsiders, but within the black community as well (Craig 2002). Characteristics like straight hair and light skin cause others in the community to take notice, especially when a woman has both. I use my interview with Catherine to illustrate this type of community recognition. She described where her family is from: "[My mom] calls it Little Texas. And Little Texas is where you would see a lot of African-American people that look like me. They are very fair skinned with straight hair. When someone from old, old school says where do you live and then you say, well I grew up in Little Texas, ... then they automatically know." Later, I asked Catherine about her hair practices before chemo: "And you never straightened your hair before either?" She replied, "No. it was bouncing and behaving, girl. I could do the commercials." Historically, media outlets—both mainstream and black—tended to feature straight-haired (and typically, light skinned) women in advertisements for straightening techniques like perms and flat irons. Catherine demonstrates this knowledge and the implied prestige her straight hair afforded her.

Catherine also talked about her experiences when she arrived at college many years ago, away from her family for the first time. She implied that many people at her home state (which was not Texas) HBCU were familiar with her family's homestead because of the light skinned, straight hair features that her family tended to inherit. Similarly, Gretchen talked about how her father's side of the family had noticeable features: "my hair prior to this really truly was on my father's side of the family, my father's genes in Boston, they had natural reddish brown hair, they're fair skinned with green eyes, and so that's how my hair color was. So I was a very natural -- I had the big Angela Davis twist. My head was brown and blonde-ish, and I wore a lot of, you know, two strands and braids and things like that."

Similar to Catherine, Gretchen (a light skinned woman) described a fair-skinned side of the family with particular hair features that align with European attributes. She also told me that she wore her hair natural before chemotherapy because she had Angela Davis hair prior to cancer. While Angela Davis is a pivotal civil rights leader, she is a light-skinned brunette black woman, with a hair texture she could blow out into a long voluminous afro. Craig (2002) calls our attention to hair texture and the Afro. While it is a symbol of black pride, people most able to don this style have a certain texture of hair that is relatively loosely curled and long.

The tie to Texas that Catherine mentioned had implicit meanings for non-blackness inferred by racialized paradigms of beauty. This illusion could (and probably does) point to the large proportions of Mexican and other Latina populations in Texas, groups of people with lighter skin and typically straighter hair than African Americans. Catherine was not the only woman who linked the relationship between a “good” hair texture and non-black ancestry. For instance, LaToya—a dark-skinned woman—described her painful experience with hair loss: “I was like, Lord, please, if you will, don't let my hair fall out, because I had long – I'm part – I have Indian in my family, so I had this pretty, silky, long Indian hair, and it was so wavy and curly, and you know, I always got a lot of complements on my styles.” She told me she was frequently complemented because of her hair, indicating that others took notice. LaToya also said that she believed her hair texture resulted from Indian ancestry.

Making links to non-black ancestry in this way is symptomatic of historical practices where American racial ideologies frame African characteristics and features as inferior or undesirable. These practices set the stage for the “good hair” phenomenon, a premise based on racial ideologies that preference white or Eurocentric physical characteristics (in this case, hair) over ones deemed black or African. Interestingly, women like Catherine and LaToya did not talk about the influence of white ancestry, which is likely the explanation for the “pretty” texture of their hair.

The history of “g***ood” hair***. In this section, I situate black women’s experiences by explaining the socialization process where black women learn to categorize themselves based on the distinction of “good hair.”[31] For black women hair *texture* is often conceived of as an important marker of prestige and class; a concept that is problematic because one’s hair texture is

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[31] While black men are also subject to social norms for hair, in this chapter I only focus on black women’s experiences.

biological (Craig 2002; Banks 2000). Straighter hair conforms to the notion of black respectability, which aligns with black middle class preferences and notions of attractiveness and represents a preferred way of “doing gender” for black women. “Nappy” or unstraightened hair is often construed to be masculine as well as a marker of low status (Craig 2002; Johnson 2011). The “good hair” phenomenon is a standard for measuring attractiveness and social acceptability of black women based on the texture of their hair.

The concept of “good hair” is rooted in slavery, as those with softer, finer, and more loosely curled textures were given relative advantages by their white masters. These hair textures also implied that white masters had mated with—or raped—their slaves, producing children that had European as well as African physical characteristics. Advantages included being placed on house duties instead of field work, the gift of trinkets, and perhaps even better meals than field-hand workers in particular. This tradition of prestige associated with “good hair” continued beyond slavery, as black women with these hair textures continued to be seen as more attractive based on white racist ideologies that extended to shape preferences within the black community, including preferences expressed by black men. For example, black women with “good hair” have historically been perceived as more suitable mating partners by black men. In all, this attraction to (or prestige of) women with “good hair” is indicative of the appeal to Eurocentric notions of beauty that govern women’s lives, similar to that of the preference for lighter skin. It is a metric for measuring status that has little to do with one’s access to financial resources (Craig 2002; Davis 1980; Collins 2001; Banks 2000; Keith 2009; Thompson and Keith 2001).

The ideology of good hair extends beyond texture to women’s hair length. In America, there is a strong cultural preference for women’s hair to be long, or in particular longer than men’s hair (Weitz 2010). Long hair is one criterion for displaying feminine hair, Eurocentric feminine hair especially. Hair length is also a component of the “good hair” typology. Within the black community, long hair is considered to be at least shoulder length or longer, which may not be the same standards for length for whites (Banks 2000). At this length, the notorious *hair flip* is possible (Weitz 2010). Weitz (2010) describes the hair flip as an important tool within heterosexual romantic encounters as a woman flips her hair in order to attract the attention of a man. Attraction tactics such as the hair flip, which is partly associated with long hair, are unattainable to most black women without the use of chemicals, weaves, and wigs. Hair also has to be light and soft enough to flip. One black woman Weitz’s (2010) interviewed says “but I often look at women who can flip their hair with envy, wishfulness, perhaps regret?" (Weitz 2010, 96). Thus, those who have long enough hair to do the flip are privileged within the black community in romantic relationships and even within relationships among other (black) women[32].

As far as romantic relationships, I found evidence that the black men in relationships with my participants with long hair shared in some of the prestige afforded this characteristic. For instance, Cassandra (age 69 diagnosed 13 years ago) told me she mostly wore long, wavy styles before her treatments because her husband “was one of those black men that believes, you know, you should have hair down to your behind and all that kind of stuff.” My interviews and existent

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[32] . The hair flip also implies certain meanings for the desirable feel or texture of hair. For instance, in addition to Weitz’s concept of the hair flip, I would like to add the idea of a “blow in the wind” texture. Based primarily from my own interactions with men, within the black community, if a woman’s hair can *blow in the wind*, she is perceived as more attractive. This generally means that the hair texture is loosely curled or straight, and/or not weighted down by products in order to keep the hair in place and/or straight. This notion also aligns with attractiveness and hair that is soft to the touch and long. Black men are often trained not to touch a black woman’s hair (Weitz 2010; 2001), unless, I argue, the texture or styling of hair can blow in the wind.

research support the notion black men with long-haired partners may form attachments to their partner's hair, because they, themselves, feel privileged based on their partner's appearance (Banks 2000; Craig 2002; Weitz 2010). This speculation applies to my own family context given my father's desire for my mother's long hair.

Good hair in practice: affecting interactions between me and the interviewee. Black women were aware of the prestige their long hair afforded them in other contexts as well, among other women especially. I believe women demonstrated this in our interviews, because several women voluntarily offered information about their hair length that was unsolicited by me. I began to wonder if they were expecting me to afford them some prestige as well. For instance, this occurred between Keisha and me as I transitioned the interview to the subject of hair:

> Me: Okay. And then lots of women tend to mention their hair. Tell me a little bit about hair. Did you experience hair loss, and just how did you feel?
> Keisha: Mhm. I always had long hair…

Then she began to tell me her story about hair loss. Similarly, in another interaction, when I began with the same prompt, Shaunte told me: "Well, before this, I've always had long hair – long, thick hair, so my hair was – probably stopped probably right here." She pointed to an area on her arm below her shoulders. This information about Keisha and Shaunte's long hair was unsolicited; yet, both women began their stories by letting me know they had long hair.

I did not find any class variations in the reporting of long hair (or distress from hair loss in general). Poor and well-off women reported having long hair. For instance, Keisha and Shaunte come from different backgrounds. Angela, a woman comfortably within the middle class, also offered information about her (long) hair length. However, it is the case that I interviewed many middle class women, and that a good number of women in my sample described their hair prior to cancer using good hair rhetoric in reference to its length or texture. I wondered if this observation about how some women described their hair prior to cancer could be a symptom of broader associations between class and racialized attributes that are patterned similarly to variations by skin color. There were 15 women[33] in my sample who reported having long hair. Of these 15, 60% (9) were middle class, which is much higher than the national average of black middle class Americans. However, this estimate is on par with the demographics of my sample, for which about 60% of my participants were middle class. Therefore, I do not know if hair texture stratifies women akin to trends observed by skin color.

This complex system of hair and status categorization emerged during my interviews in other ways as well. Some women even compared their hair with my own—an occurrence that made me a bit uncomfortable. For example, when I asked Naomi to begin to describe her hair loss process she begins by saying, “I was okay with it. Well, I had – you know, my hair was probably like yours, it was long.[34]” In another interaction, a participant compared my hair texture to hers. April, a 64 year old and year and a half survivor, forced me to confront my own conceptions of hair texture and race when she alluded to why hair loss may not have been as detrimental for her as it was for other women. She said, “I'm shaving it all off and I'm going to go bald. I'm – I was okay with it. Yeah. I don't – yeah, I don't have that kind of – yeah. I mean, your hair is beautiful, but I just – you know, I didn't have that.” She didn’t value her hair as much because it was not *like mine*?

I mention these comments because I find it difficult to typologize and understand women’s thought processes when they made comparisons to my hair. Even when women did not directly compare our hair textures, this part of the interview at least elicited a glance at my

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[33] Two woman, I probed and asked. All others offered the information unsolicited during their recounts of their hair loss experience

[34] —which I did not feel was that long at the time because I had cut it into a shorter style

hair. In these contexts, it was difficult for me to maintain distance as a researcher when women used my hair in their own stories. My hair was being classified by some of my participants, which of course meant my hair (and good hair typologies) was something influencing the whole interview process.

While many women said hair loss was distressing, I began to speculate that notions of good hair may have even influenced the feelings women reported throughout the experience. It was easiest to examine my suspicions by looking at the quality of long hair. Some of the women who struggled to adjust to a bald appearance (like Gretchen, my mother, Shaunte, and Ramona[35]) were women who described their hair as long prior to cancer.

It was harder to decipher the number of women in this group who had "good hair" texture too. Women were not as forthcoming in describing their hair prior to chemo as desirable. This may be a product of living in a society in which we are trained—whether we have "good hair" or not—to point out our hair's inferior qualities.[36] Remember when Catherine and LaToya described their textures, they attributed its prettiness to other ethnicities. A woman can have long hair and not necessarily have hair texture that adheres to the good hair standard and vice versa. However, it is worth noting that many of the formerly long-haired women I interviewed said they had never permed, forgone perming, or infrequently permed their hair well before their diagnosis. For instance years before their diagnosis, if Naomi, Brielle or my mother—all women who reported having long hair—wanted straighter hairstyles they used flat irons and did not

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[35] Ramona didn't report her hair was long, however I've had several interactions with her. Her hair is longer than shoulder length. She was also my first interview, and I developed more probes for hair as time went on. At the time of our interviews, she had permed hair and sometimes she wore weave.

[36] My grandmother—and her sisters—literally had straight hair. Yet she religiously straightened it every two weeks and often referred to her hair as nappy! It is worth noting that my grandmother was one of the darker of her very light skinned family. This and her subsequent nappy hair was often pointed out by her mother—a woman several shades *darker* than my grandmother.

perm. Also one woman, Dominique said she only permed her very long, straight her about twice a year (beauticians usually recommend retouches every 6-8 weeks). In the next section, I discuss the variations that arose among these long-haired women.

Long hair: trauma turns to agency. Long hair for black women is an interesting attribute for exploring how mechanisms of race and gender influence status and health. For some women, this attribute moderated how women processed hair loss. For women like my mother, the attachment to this attribute and its glory may have contributed the trauma associated with hair loss. Recall Gretchen who cried during our interview when she thought about her hair loss experience. She described her hair as long prior to cancer, and she wore her hair in a natural Afro style which she "worked hard to get" before her diagnosis.[37] "It was probably at least eight inches, six to eight inches, so it was pretty you know, long," she said. She also told me that she "started getting the magnifying mirror to look and see (laughs) how much hair was coming in." She still eagerly anticipated the complete regrowth of her hair by the time of our interview.

LaToya said that she was very attached to her long hair, and the process of hair loss deeply affected her because of that. "I ain't know what [to do]– I ain't never had short hair in my life. I didn't know what – how to wear that – I was so ashamed. I ain't going to lie. I was embarrassed. I did not walk out the house without a scarf or a hat or something covering my head. … I wouldn't even let my husband see my head." LaToya repeatedly told me that she was embarrassed and ashamed after losing her long hair. Even when it began to grow back, she was apprehensive about letting her husband and others see her short regrowth. Importantly, the shame that she felt seemed to be intensified because she feared the reaction of her husband (which actually was positive when she let him see).

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[37] Years before, Gretchen decided to return to natural hairstyles, or in other words, not use straightening techniques, in routine hair work. I will discuss the process of transitioning to natural styles later.

Agency within romantic relationships. Interestingly, this set of (long-haired) women—whether they were distressed by hair loss or not—consistently discussed a renewed sense of power or agency within their marriages after chemotherapy treatments. After cancer, they felt they had more power in their romantic relationships to decide what to do with their hair. This renewed sense of self is similar to events that Weitz (2010) pinpoints as moments when a woman's own desires trump those of her partner's as she decides to change her hair. Cassandra, who kept long hair for her romantic relationship (recall how she described her husband as "one of those black men") described this reclaiming of power in her marriage:

> At that time [before diagnosis], it was wavy and long, and it was a little past my shoulder. […] he said, your hair's going to come back, your hair's going to come back, isn't it? I said, yes, once I have my final chemo, my hair will come back. […]And then when it came back, it came back beautifully, and it – I had a little more salt and pepper in it, but that's to be expected, and then it got curly, and he said, well, aren't you going to let that grow out – because I had made an appointment to get it cut and shaped. I said, not right now. And so we have had that fight for 16 years. He said, why are you still [cutting your hair] – your hair grows real fast. I said, yeah, it does, so every month I have to go get it cut. I'm just not letting it grow back. I said, this is one fight that you'll never win. I let my hair be the way you wanted it for over half of our marriage, now it's going to be the way I want.

Even my own mother transitioned from long to short hair despite social expectations of the beauty attached to black women with long hair. She liked her new short hairstyles she wore after her first treatment in 2012. The following conversation occurred in my interview with her:

> Me: Did you let it grow out as much as before?
>
> Her: No. I cut it. I had a beautician cut it. I liked it, the way she cut it. It was like above my, right above my, well, I guess right at my neck. I liked it because I had never really cut my hair with a style that was short, so I liked it.
>
> Me: Why do you think you always kept it long before?

> Her: I don’t know. Probably just maybe when I grew up my daddy always said, you know, you can’t cut your hair. I know my husband didn’t like short hair.

This new sense of power seemed to help some women cope with the loss of their hair. For instance, an 8 year survivor, Angela, age 56, told me that she was not troubled or especially distressed by hair loss. She talked about the transition from long to short hair in the context of her marital relationship.

> It was almost down to my waist. My husband liked long hair but after it started growing back and I was getting these short haircuts and stuff I just like it short and decided not to grow my hair back, not at this age anyway. That was eight years ago, but I just said, no I like my short hair again. (laughs) In my 30s I had done a couple of short haircuts but let it grow back when we got married and he said I’d really like you to grow your hair but after this [cancer and chemo] I just kept it short.

After cancer, Angela was not willing to keep her hair long for husband, although at previous times in their marriage she refrained from cutting her hair at his request.

Similarly, Naomi said she adjusted to hair loss for the renewed sense of power in her romantic relationship and with another group of close men. “I was okay with it. I was looking forward to it (laughs), because I said, this is my time. You know, I grew my – I let my hair grow long for my husband, they like long hair, my sons like long hair, and they're so excited it's growing back, and I'm like, I thought me and the Lord had a plan where this was kind of my little reward for going through this, because I could wear short hair.” She maintained long hair throughout most of her marriage as it was expected and preferred by her husband *and* sons. Hair loss was a “reward” because she it became possible to devise a plan to keep her hair short after it regrew.

For these women, breast cancer and its treatment represented a moment in which desires of others mattered less than what these women perceived as beautiful and acceptable.

Importantly, these women had features which could be categorized as good hair or a property/attribute of good hair. It is equally important to note that women's husbands were not the only men expecting long hair from these women. Sons and fathers held these expectations too. Women did not report pressure from female relatives to grow their hair back. In all, the change in hair that cancer forces also seems to activate agency in some women. This is not the only form of power women demonstrated, as many women decided to stop performing another type of routine hair work after chemotherapy.

No more perms: freedom from dangerous hair work. Experiencing breast cancer and its treatments represented a pivotal event that marked a change in the way many women decided to do their hair. Eighteen out of the 38 women who had chemo definitively went natural after chemotherapy based on what they told me[38]. Going "natural" or having a natural hairstyle simply means that women opt out of perming or chemically altering their hair.[39] For most of the 20th century, natural hair has been viewed either as expressing a particular, often adversary, political stance or as an indicator of a pariah or alternative femininity. Black women who donned afros and natural hairstyles were believed to be revolutionary or of low class prior in the 1960s. Women who wore braids and dreadlocks, particularly prior to the late 1990s, were also considered to be operating outside of the middle class status quo. Poor African immigrants were initially first to wear such styles and more likely to specialize in doing this type of hair work than other black beauticians, serving to further *otherize* these types of hairstyles on black (American-

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[38] This count is of women who reported perming (or implied perming) and told me they chose natural hairstyles after chemotherapy. Some women were already natural, yet they were still affected by the quality of hair which will be discussed throughout the next few sections. Some women I could not tell about their hair work—these were usually the women I interviewed early in the study when questions about hair were not completely developed. See table on cover page for further reference.

[39] Women with natural hair often use heating appliances on their hair for blown out or straight looks. Again, these looks are temporary and not water or humidity proof.

born) women. Moreover, these immigrant hair-braiders challenged the (black) middle class status quo, similar to the condemning of the Afro in the 1960s and 1970s by many in the black middle class community (Craig 2002; Banks 2000; Johnson 2011; Baca Zinn 1979).

The ebbs and flows of the political and cultural landscape coupled with racial tensions have reformed the meaning of natural hairstyles to be that beyond the figure of a revolutionary or poor woman. Celebrities (such as Tracee Ellis Ross and Solange), reporters, and other black public figures have increasingly sported large/full tresses of unstraightened, curly and kinky hair over the last decade(s). I argue that given the climate of greater acceptance today, natural hairstyles are in some ways an attempt to reclaim the—or one's natural—self and establish an authentic (chemical-free) racial identity. This perspective may be especially salient for understanding decisions black breast cancer survivors made in transitioning to natural hairstyles.

Unlike with hair length and shorter styles, women who went natural did not frame this change in the context of their romantic relationships. What women articulated to be most important in this decision was the desire to be free of foreign bodies or chemicals. For instance, Farrah said: "In retrospect, even though I think I would like to have [my hair] [chemically] straightened again, it made me think about the chemicals that have been put in our -- so many things have been given to African Americans that harm us and we don't know about it." One "thing" that Farrah was likely referring to was the perm and the relatively unknown systemic effects of this treatment type.

Other women spoke about how exposures to harmful chemicals used during personal or beautification routines, like the perm, influenced their decisions. Bebe told me that an apprehension of chemicals informed her decision to go natural after cancer treatments.

> I just knew for me, going through chemo and that's that I used to do like—with the discoloration of my nails on my hands and toes—I used to get acrylic nails, I used

> to perm my hair. And, you know, just doing my own research […] I will never perm my hair again, I will never do nail stuff again. I just don't want any of that stuff anymore, because I thought, in my mind, those chemicals are in my body. I've had enough chemicals in my body. I don't need any other chemicals in my body.

She condemned perms and acrylic nails for their potential to alter the composition of her body. In her view, these agents were foreign and could have made her susceptible to cancer. Importantly, these chemicals are used to enhance or help with women's performances of gender.

Bethanie told me that she decided to stop using perms because, she was "just a little nervous about putting chemicals in it [my body]." This apprehension—or perhaps even fear—of chemicals and their potential to harm health led women like Yolanda to claim "I decided that I would not use chemicals again. So now I have natural hairstyles only." Again, she shared the going natural change with 17 other women in my sample.

At first, I immediately celebrated the return to the natural many women I interviewed underwent after experiencing the pivotal event of hair loss from cancer treatments. But as interviews progressed, I began to wondering what were all the factors underlying this change. One of the most perplexing, intriguing, and unexpected themes that emerged in my interviews was the ways in which women used good hair language to describe hair changes after chemotherapy. Most often, this change was framed positively. I cannot ignore that even as these women voiced reclaiming agency by freeing themselves of perms and sometimes heating tools, a chemical agent often spawned or underlay this change.

What's important in stories like those of Bebe, Bethanie, and Yolanda (and others) is what came before many of these women's decisions to go natural. For instance, Bethanie's apprehension for chemicals was one part of her decision to go natural, but she also told me this about a hair texture change *after* chemotherapy (a chemical). "It was really soft and curly. Yes.

It's very different. So I don't have a perm, and I'm still letting it grow out, and it's very curly still and thick. So trying the natural things or braids." Bethanie abandoned the use of perms and incorporated natural styles into her routine as a way to avoid chemicals. Yet, the difference in hair texture produced by a strong (and harmful) chemical likely had something to do with her hair change as well.

Natural styles tend to be wavy, curly, or kinky, but most importantly wearing a natural hairstyle means chemically-free but not untouched hair (Craig 2002; Banks 2000). Germane to this difference are good hair typologies for the quality of natural hairstyles, as women with more loosely curled textured are perceived to have better "natural" hair. They also have to put in less work to present acceptable hair. Chemotherapy, for some women, facilitated the ease of displaying appropriate natural hair styles that could also be interpreted as good hair.

"It came back so pretty": the implications of the good hair phenomenon and regrowth.

Chemotherapy—used as a medicinal therapy—is a powerful set of chemical agents that have the power not only to heal and to cause harm (and pain) systemically to women, but also to change hair textures. However, chemotherapy is never framed in the same regards as perms and relaxers when it comes to black women and hair. My research reveals a striking connection between *medical* chemicals and the production of racialized and gendered identities. Many women used the standard of "good hair" to describe their experiences with chemotherapy drugs while treating breast cancer.   In following dialogue on "good hair," I extend current research on chemicals and black hair to include the power of chemotherapy medicines to change the hair texture of women's heads upon regrowth.

The value placed on “good hair” influenced reactions to hair regrowth for all women I interviewed albeit in different ways for some. The most common reaction was a positive response to chemo-changed hair. As a matter of fact, there is some reason to believe that the potential for new good hair acted as a consolation prize before some women even began their treatment journeys. For instance, Kerrie, a 48 year old, 18 month survivor, told me that prior to beginning her treatments, her girlfriends tried to offer her some comfort:

> Kerrie: Well, it's funny because everybody said, oh, you're going to have some good hair. Well, I didn't get the good hair. (laughs) I mean, it's not bad, but obviously I had a natural curl, but I was like, oh, okay, you know, but – yeah.
> ME: So would you say that you feel like your texture is worse than it was before?
> Kerrie: No, I think it's better. I really think it's better. Yeah, I think – but it's not the curly, like, I'm thinking it was really, really curly soft baby hair. No. Nuh-uh. But I think it's better than what it was before.

Interestingly, even though her expectations for her good hair were not completely fulfilled, Kerrie considered the post-chemo hair more favorably than she did the hair she had prior to her diagnosis.

Monique, only a year and half out from her diagnosis, described her new regrowth and hair change as more than a consolation when she told me: “Everybody loves my hair. Everyone’s like, you look really good. I’m like, okay. This is probably the most expensive hair change I ever had so—because that was one of the blessings of going through this process.” To Monique, the good hair associated with post-chemo was a *blessing*, which is indicative of how pervasive this sort of racialized categorization is in black women’s lives.

So what is good hair to these women? How do they interpret and verbalize these meaning of race and gender for hair? While a few women specifically used the term “good hair," many used proxy terms. For instance in Cassandra's conversation (see above) with her husband about regrowth she described that the regrowth grew back "beautifully." She also told him: "It will come back real baby fine at first, and then I don't know if it's going to be curly like it was before, or if it's going to be – I have to get it pressed, and stuff like that." Cassandra used such positive adjectives as beautiful and "baby fine" to describe her new growth of hair. Gina, a 68 year old __ year survivor also used the same language when describing the straightness of her new hair. She told me, "At first, it was like real straight like baby hair." This analogy refers to the tendency for (black) newborns to have soft, straight hair. Then the natural texture emerges as the baby gets older, which is usually a coarser, curlier, or kinkier texture than *baby-fine baby hair*.

It is important to note that prized hair does not necessarily have to be straight in texture. Many women characterize "good hair" as loosely curled hair or hair textures that are wavy, ones in which individuals can opt to wear hair naturally or easily blow dry or straighten it for a more lengthened look. Perhaps the loose curls and waves are exoticized, an issue I will delve into in a moment. Women also described this hair as having "soft curls." Andelle told me of her regrowth, "[My hair] started growing back, and when it started growing back, it was just so pretty and wavy, and I was excited (laughs) because I had some hair." She went on to say, "So I went from sad to joyous, and I would just brush it and just stay in the mirror, because it was really pretty." The regrowth of good hair after chemotherapy and cancer diagnoses brought joy in a distressing time for Andelle. Other women echo her sentiment of satisfaction related to soft, curly hair. After her traumatic hair loss two year prior, Terrin, age 35, told me that her regrowth "was definitely softer and just curly," which she felt was a "good" change.

In addition to their own expressed contentment, some women got affirmations from others within their social support networks about their new curly regrowth. According to Yolanda, age 59 and 3 years out from diagnosis:

> But the texture of the regrowth was so different from my original hair texture. It was softer, it had a soft curl pattern to it, and when I showed them [cancer survivors friends] how much growth I had one day, one of them told me that she should not let me put the wig back on, she should snatch it from me and throw it off into the woods, because she thought my hair was so pretty when it started to grow back.

The experiences of individuals like Kerrie—whose friends comforted her during her cancer journey with the promise of good hair—and Yolanda—whose friends celebrated the texture of her regrowth— suggest that there may be a (black) cultural expectation for hair change from chemotherapy to be better than original textures. Does the possibility of good hair act to console women during their cancer process? What implications might the possibility of a prized hair texture after chemotherapy have on health for women, in particular their mental health? This is especially important given the tie between non-blackness and good hair which emerged in the discussion of women's changed textures because of regrowth.

Ethnicity and good natural hair. Now I would like to revisit Gretchen and her discussion of hair regrowth and change. She said: "The texture is different, but it's thicker. It's not as coarse as it was, but it's thick, which I'm grateful." Then Gretchen's description of her hair after chemotherapy introduced an even more intriguing nod to ethnicity and texture. Gretchen continued with the following after describing her father's family:

> [A]nd my mother -- because *we're also Native American*, and so my mother's side of the family is the Native, and *they have the jet black hair*, and all the elder women, it goes completely white. *They have beautiful white Native hair*, you know? So this is *my mother's genes that I'm coming into now*, so yeah, it was totally different. I kind of like the color that I had. I mean, I don't want to color it, and I don't want

> to change what it is now. I'm okay with it, where it is now, and I kind of like the salt and pepper that I have now. It's not completely you know, salt and pepper, but it's mostly you know, spot, and I kind of -- I like it now, but I did like the hair color I had before. As far as the texture, I would take this texture that I have now, because *it's easier to manage*.

The illusions to "good hair" in Gretchen's response to regrowth were profound, and the implications of optimal textures as signs of non-blackness were troubling to me. She talked about how her new hair may also be a result of her mother's Native American heritage instead of the byproduct of chemical agents. She liked her old color, yet did not want to color her hair now, likely due to an apprehension of chemicals many women shared. When she talks about "Native" hair, she not only is alluding to the color change, but she is also invoking my knowledge that Native American hair tends to be thick and straight. Recall that LaToya did the same thing to describe her straight, black hair texture prior to cancer. However, what does it mean that Gretchen believes that dormant genes are responsible for change rather than chemotherapy? Is she denying that chemo has the power to elicit permanent change? Her comment may also demonstrate some internalized racism in which attractive features are not interpreted to have African origins.

Manageability and natural hair. In the last line of Gretchen's quote above, she explained that she favored her new hair texture because it was easier to manage—a concept I believe means it required less time and effort in hair work. Her natural hair had become easier to manage, and according to her, not because of the chemo but because of a dormant Native American hair gene. While Gretchen had natural styles before, this change toward greater manageability is consistent with the justification many women gave for liking their regrowth textures better than textures before cancer (whether they wore their hair natural or not). Several women talked favorably about their post-chemo hair based on notions of manageability and ease of hairstyling.

Interestingly, even women who condemned the use chemicals (cosmetic products), compared the manageability of their hair prior and after chemo treatments to justify why they favored post-chemo hair. These women did so without giving a nod to chemo's power to change hair in similar ways as the perm is designed to do. Remember my discussion of Bethanie's decision to go natural. She permed her hair before treatments, and became apprehensive of chemicals after her cancer experiences. Yet, she saw her new curly, thick hair as easy to manage without a perm and conducive to natural hair styling. Similarly, Bebe, who told me she had had enough chemicals in her body—thus no more perms—talked about manageability aspects of her new hair. The following interaction occurred between Bebe and me when I asked about her regrowth:

> Me: So you did notice a change in texture?
> Bebe: Oh yeah.
> Me: Did it stay this texture, or what happened?
> Bebe: Pretty much it's still the same texture, it just curls. You wash it and it just curls.
> Me: Mhm. And what did it do before?
> Bebe: My hair? Rolled up and knotted, to the point where – you know, knotty versus curly hair.

First, I want to point out that Bebe's answer signified that she did not really consider her hair texture to be the same as before cancer despite her first claim. Perhaps she was telling me that her hair was somewhat loosely curled or manageable before chemotherapy, yet she called her hair "knotty." Bebe called on my own (assumed) knowledge by using this term to express how chemotherapy made her hair more manageable. From our shared knowledge, I could decipher that the terms “knotty” and “rolled up and knotted” are stand-ins for “nappy”—a characteristic of hair that can make black women feel unfeminine and (under)classed. However, her comparison between knotty and curly hair also points to the nuances and subjective interpretations of acceptable curly hair. To be honest, I think I know what she means by the difference between knotty vs curly hair. I just wonder if there is also some implication that nappy/knotty hair meant unkempt.

Similar to the deliberately tousled (or bedhead) look for white women, natural hair for black women does necessarily mean hair that is not styled or untouched. One must put in effort for natural hair to be deemed acceptable. The effort one has to put into managing natural hair styles maps on to good hair ideologies, which is consistent with how women frame the manageability aspect as justification for liking new hair textures more. Chemo made hair work easier to manage and the finished product (the natural hairstyle) more beautiful.

According to Olivia, “After the chemo treatment, it started gradually growing back, and now it's a pretty – a nice length now. So it came back a different texture, though. Where I used to have to use a lot of chemicals, right now my hair is straight, and I don't have to use – I don't even have perm in it.” For Olivia, straightening chemicals were necessary routines prior to chemotherapy because for her straight hair meant acceptable hair. Before her change after chemo, straight hair was also synonymous with the use of perms and relaxers, the chemicals she alludes to. She was delighted that her hair was straight without the use of chemical hair straighteners; however, this hair texture did not emerge independent of chemical effects. Chemotherapy drugs changed the texture of her hair, thus chemical agents may be underlying her decision to go natural.

Olivia, Bebe, and Bethanie were not alone in discontinuing perms because of the new texture that emerged. The following interaction occurred between Simone (a 41 year old, 2 year cancer survivor) and me. She most explicitly credits her new hair to the reason she did not go back to perming her hair:

> Me: And did you notice anything when it started to grow back?
>
> Simone: Yeah. It changed textures. *It was more curly. (pause) And so I did not go back to permed hair, relaxed hair*.
>
> Me: When you said it was more curly, would you say -- *How would you say it was before then?*
>
> Simone: Before -- *Well, I don't know, because it was relaxed, so it was straight*, but the natural pattern of it was I didn't see a curl pattern here so *I guess it was coarse but no curl pattern to me*.
>
> Me: Well, how did the new hair make you feel? Did you like it? Did you --
>
> Simone: Yeah. I liked it. I just liked the fact that I had hair again. (laughs) And I mean, that's what made me happy. The texture of it was a plus. I felt like it was easier for me to manage and go into a natural hairstyle, but yeah, just the fact that I had hair growing back was enough for me. […] I still keep it, just you know, wash and go type thing. I have not had it cut though, so I just continuing to let it grow.

Side effects from chemotherapy drugs made the wash-n-go hairstyle attainable for Simone. Dominique—who previously described her hair as long and straight, perming twice a year—also described her new hair this way and said it was why she no longer used a perm. Notice that Simone also said she did not know what her old texture looked like because of her history of perming. Yet, she drew the conclusion that her original texture was coarse (and not as good) despite not really remembering what it looked like.

For some women, the discovery that perms were no longer needed represented a re-introduction to what they remembered as their old hair textures. This re-introduction demonstrates how the discipline of hair work shapes women's lives from childhood. They talked about how straightening routines precluded them from experiencing their natural hair for most of their lives. Namely, some women found out that they never *really needed* a perm. For instance, Brielle had nostalgic memories she associated with regrowth:

> Me: Now did you notice any differences when it started to grow back?
>
> Brielle: No, I really didn't. I mean, it came back the way it was that I remember when I was young before I started putting relaxers in my hair and stuff. Yeah. It didn't come back any thicker or it didn't come back thin or anything. It just grew back the way it was.
>
> Me: Anything else you want to tell me about hair?
>
> Brielle: No, I was just not -- I still wear it natural now. It's grown out a lot. In fact, down to my shoulders the way it was before cancer diagnosis. It's still thin the way it was before, but yeah, not really a big deal.

Perming was routine in her life since she was a child. Yet, after cancer, she came to realize that this routine was not done out of the necessity to have more socially acceptable hair. Her realization also makes me wonder the extent to which black women are guided by good hair standards. Young black girls are taught and experience straightening techniques early.[40] Could it also be plausible to believe that women who believe their hair is now more manageable are actually dealing with their natural textures that are free from perms and other straightening chemicals, including chemotherapy? For instance, Angela told me this about the reintroduction to her natural hair:

> But before, I mean, when I was in my 20s, my beautician used to tell me, Angela you really don’t need a perm. But, you know, you do what everybody else is doing not knowing. So I just said okay, let me see if she really was right. She was so I’ve been okay.

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[40] These techniques are taught to us early despite our hair textures, because these practices were necessary for social acceptance for our grandmothers’ and mothers’ generation. Again, my grandmother did not need to straighten her hair for it to be straight, yet she still did. She taught her straightening technique (the hot comb) to her 3 daughters. Honestly, I don’t know a black woman who didn’t straighten (with heat) or perm their hair at some point in their lives.

Angela affirmed that her beautician was right. Her hair did not need a perm to be presentable. This means that prior to chemo, Angela had hair that was good enough without the use of perms or straightening techniques; yet, chemotherapy still spawned the discovery that perms were no longer needed for women like Brielle and Angela.

Many women perform additional hair work routines aside from chemically straightening, such as twisting and setting her hair for spirally curls. These new routines were not always easily or readily embraced by all women. For instance, Farrah wanted to go back to straight hair but was very aware of her daughter's apprehension to her mother using chemicals to change her hair. She told me: "So now I don't have [a perm] -- she encouraged me not to -- not to put chemicals in my hair, but I *prefer* straight hair. I'm still trying to get used to this stuff, this kinky twist. I had it pressed a few times as it grew. But not permed." Farrah, 71, still preferred her straight hair styles, which she had worn her whole life. Moreover, a lot of women talked about the process of getting used to this "new" hair, which may have just been their natural hair without straightening products. The natural hair change—similar to embracing baldness—was a process that required women to adapt their conceptions of beauty.

Hair doesn't always stay good enough. Whether they described their new hair as easier to manage, soft and curly, or baby fine, chemotherapy spawned a change in the body to which many women were not accustomed prior to cancer treatments. Despite the greater acceptance of un-straightened hair, black women receive routine messages that link black femininity and prestige with hair texture. The media provides important mechanisms for disseminating this message/image/ideology. Black periodicals and magazines continue to display many advertisements for weaves, chemical straightening products, and heated techniques. Additionally, black public female figures and celebrities—like Michelle Obama and Oprah

Winfrey, Beyonce, Gabrielle Union, and Vanessa Williams—often straighten their hair and wear hair extensions (Craig 2002; Banks 2000). Additionally, research shows that family members, especially older ones,[41] compel women to practice hair straightening.

Some women who went natural after the chemo process did return to straightening their hair. For some women, the chemically-induced change was not necessarily permanent. For instance, after I asked Drita about hair change she responded:

> Drita: Oh yeah, my hair was nice and curly when it started out.
> I: Okay. And then what happened?
> Drita: Then it started to grow back curly, and it goes back to -- Well, mine went back to its natural state.

What did she mean by her natural state? From my interviews with these women, I inferred that this meant their hair was less soft with fewer loose curls. Drita said that she returned to perming her hair after chemotherapy treatments, namely this return of the natural texture. She stopped about one year later, not because of chemo, but because "when I used to always get perms it would burn my scalp and I said this is ridiculous. I'm not going through this anymore, so that was it." While I did not interview Drita in person, I did meet her in person prior to her interview. Drita was a dark-skinned woman with a twist-out that stopped between her neck and shoulders. I thought her hair was pretty. In addition to liking regrowth textures, a few women expressed some dissatisfaction when the new "good hair" went away, and their old textures re-emerged--which ironically occurred as they moved further from illness back into health. The indication that chemo-changed hair may not be permanent was also demonstrated by Gina, a 7 year survivor. She said that after donning natural hairstyles for a while, "I did eventually relax it,

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[41] These older family members likely experience higher levels of racial intolerance over their lifespans/lifetimes.

but it was quite a while after that." Drita and Gina are both several years out from their treatments (past that ominous 5 year mark[42]), and these women were the only ones who could really decipher whether hair change was permanent. For women who liked their regrowth, it seemed that two patterns emerged: either they began straightening their hair again or realized their original hair was good enough. Its texture had been masked by perms and chemicals prior to their cancer experience. There was another pattern I found among women far out from their diagnoses as well: some women did not like their hair regrowth. Among them was Catherine—the fair-skinned, straight-haired black lady whose hair already adhered to traditional good hair standards.

Things are forever different: reactions of unfavorable hair changes. Not all women in my sample who experienced hair change due to chemotherapy celebrated the new regrowth. Some women did not perceive this new hair as better than their pre-cancer hair. Even, in the two and a half years between her diagnoses, my mother often complained that her hair was not growing back as thick as it once was (despite what she said in her interview, she complained about her new hair). It still looked thick to me, but for her it was never the same. Catherine most directly iterated this sense of longing for her old hair because of its socially favored attributes. This is what she had to say after I asked if she was satisfied with her hair regrowth:

> Catherine: No, because mine was silky, smooth, soft. I mean, it's still, you know, straight but it was the silky, smooth texture. And I definitely wasn't satisfied with those curls but it was good because it was short, you know. But it definitely wasn't my look. But shoot, now compared to the thinness versus the curls I believe I might have to take the curls back.
>
> Me: So would you say that your hair got straighter as you moved further away from chemo?

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[42] Five year remission is a commonly measured marker of survivorship.

> Catherine: No. I think if anything it's gotten a little coarser. I mean, I never have to straighten my hair or anything but it just doesn't have that same texture and volume that it had.

Catherine's hair—once straight—was now curly (very, very loosely waved/curled I might add based on my observation of her) because of chemotherapy treatments. Her hair was not as thick and luxurious as she once described it to be. Ideologically, her hair became "less good," and her dissatisfaction with its growth aligned with evidence from white women's experiences with chemotherapy (Weitz 2010). According to Weitz interviews with a handful of cancer survivors, white women were dissatisfied with the new, often wispy, sometimes curly hair that regrew after chemotherapy.

Women who were dissatisfied with their hair tended to describe their hair using favorable—or good—hair qualities. For instance one woman in the long-haired group, Shonda, age 70 and 13 years out from her diagnosis, told me: "I miss my hair. I'm just so used to having a head full of hair and it was thick and long. I thought it was pretty. I didn't realize it until I didn't have it anymore." Shonda and Catherine's sentiment about memories and hair aligned with many of the women who reported having long, thick, favorably textured hair prior to cancer. Others in this group who were far out from diagnosis were part of the group that discovered their hair was good anyway (e.g. Angela—8 years out from her cancer experience). Also, Beatrice, 18 years out from her diagnosis—who did not report her hair was long—was a very fair skinned woman (similar to Catherine) also expressed dissatisfaction with her hair after regrowth which was "more coarse" and "thinner."

In addition to textures and length, some women's dissatisfaction with new hair drove me to consider a new component of the good hair phenomenon. Desirable hair is also thick.[43] Many women talked about their new hair relative to the memory of their thick hair prior to cancer. Interestingly, sometimes the desire for thickness negated other effects of the chemicals that made hair straighter. For instance, Mary Jill, told me she had very thick hair before that grew back thinner after treatments. She told me, "Well, I think I liked it better before because it was – it was more thicker, more coarser. I mean, I like – it's fine now. I actually can – I guess what you call – a lot of people say wash-and-go hair now. I can do that. Like this morning, I took I shower; I just shampooed it, and I used to go to the hair stylist." She still longed for her thick hair, despite experiencing a change that led to a "wash and go" texture. However, others praised her for this new look and Mary Jill's quote still spoke to the concept of manageability and chemically changed hair. Thus Mary Jill's grievance with her new regrowth hair was not as severely felt as that felt by people like Catherine who had thick and straight hair before chemotherapy.

Conclusion

Hair loss from chemotherapy serves as an event that threatens the physical body and gender identity; it also changes interactions women have within social relationships. Unlike the voluntary decisions women may make about hairstyle choices, hair loss after the treatment of cancer represents a body modification in appearance about which women had little choice. Bald heads within our society have gendered meanings that usually connote the un-feminine or the ill.

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[43] Some women (like Gretchen) said that thickening was a side effect of chemo, which points to the nuances and ambiguity surrounding the effects of this class of cancer treatments.

Women experiencing baldness from chemotherapy lack the choice to actively accommodate or resist cultural norms about feminine hair, yet they are faced with facing a new identity that can be perceived as masculine, sick, and unattractive. Therefore, it is important to understand how women process and cope with this change in feminine appearance given the degree to which agency is stripped from women as they navigate through the cancer experience.

Approaching this topic from a social interactionist perspective is especially important given the tenets of the Pink Ribbon Culture, which dictate that women undergo breast cancer treatment while maintaining hegemonic ideals of femininity. For instance, the image of the breast cancer survivor has hair, yet when women undergo chemo, feminine hair can often only be achieved by use of wigs and coverings—which have become integral parts of the treatment process under PRC (Sulik 2011). However, the emphasis on coverings does not account for the distress women feel from losing their own hair.

While some of the women I interviewed demonstrated some degree of resistance to gendered norms associated with the pink ribbon culture by not wearing wigs and coverings, these choices are predicated on the narrow options for displaying femininity that are available during cancer treatments. Similarly, women facing hair loss may cut or shave their heads in an attempt to prepare for its imminent loss but that seems more as an attempt to accommodate illness or sickness. Partaking in these “choices” are an attempt to ready the self for a significant loss of something that is considered an important feature of beauty and attractiveness. Thus, gender expectations and treatments from life threatening illness complicate the experiences of breast cancer for women.

Social interpretations of baldness for women are problematic, because the presence or absence of feminine hair is not necessarily physiological or biological signs of health. These interpretations could produce physiological responses. For instance, individuals with alopecia are not diseased, yet have no hair. As in the case of low stage breast cancer, hair does not begin to grow back until treatment is nearly done or already completed. Women may be free of cancer yet still bald. At the same time, women with advanced stage cancers may be done with chemo but not cancer free. Therefore, the baldness that lingers as a result of chemotherapy does not necessarily signify that a woman is diseased or feels sick.

Even when discussing hair loss associated with chemotherapy, black women's stories are influenced by values associated with racism and racialized ideologies. *Good, baby fine*, *soft and thick*, *loosely curled, straight*, *wavy*, and *beautiful* are just some of the words many women chose to describe their chemically altered hair. The pattern of liking regrowth—and for some disliking the re-emergence of the old texture—seemed especially problematic not only given the relationship between hair and health, but also given the long ties between chemicals and hair straightening in the black community. "Good hair" regrowth is a symptom of lingering effects chemotherapy within one's body and chemotherapy is a treatment for cancer—a life threatening illness. Essentially, the return of one's own texture signifies moving further out from treatment and aligns with a re-emergence of health after cancer. How nuanced the process of sickness and returning to normal like is, if women like a symptom of *being sick?*

Some women were undergoing radiation, additional chemotherapy treatments, and sometimes surgery when their hair started to grow back. These particular treatments were therapies to address disease that was *still* in the body. Moreover, the new good hair also served as a sign that chemicals continue to linger in the body even after completing all treatments. Again, women were adverse to the thought of foreign chemicals lingering in their body highlighting a potential paradox for medical therapies like chemotherapy. For instance, one woman Esther[44], age 54 and a 7 year survivor describes cancer treatments as "This foreign […] substance that stole my hair and everything, that's what it costs." Yet, so many women relish in the side effect caused by this same ominous chemical agent.

Ironically, this fondness for the hair texture after regrowth sits in direct opposition with some women's (such as Bebe and Bethanie) perspective about how chemically altered bodies made them more susceptible to illness (e.g. cancer diagnoses). Recall how some women blamed the use of other chemicals—industrial, medicinal, and cosmetic—prior to cancer diagnoses as being culprits in changes in body composition that made the body more susceptible to cancer growth. Yet, these same women modified routine hair practices and interpreted their hair's texture as nicer because of chemo-induced changes.

Up next, chapter 3: One important theme that emerged from women having difficulty processing hair loss was the saliency of social support, in particular support from romantic partners. The ability of these women to cope with a huge stressor like hair loss highlights the importance of social support throughout the experience of breast cancer. Women told stories primarily of emotional support as important to the psychological process of dealing with a sick and unfeminine appearance. Emotional support ranged from encouragement to the active participation of loved ones in shaving ceremonies. This importance of this support carried across social locations and the variable relationships with hair women had before cancer diagnosis.

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[44] Interestingly, Esther actually didn't have chemo and did not experience hair loss like the other women. However, she believed that radiation thinned her hair, a belief that was shared with other women who did not have chemo (that I interviewed and came across during this experience).

Table 2: Hair characteristics for women experiencing chemo

	HAIR LOSS, level of distress (1-5)	REACTION TO REGROWTH (liked=yes, good hair qualities)	HAIR WORK BEFORE	HAIR WORK AFTER
ANDELLE*	Yes, 5	Yes	Not sure, probably perms	Natural
ANGELA*	Yes, 2	no rxn, no change	Perm	Natural
APRIL	Yes, 2-3	Not sure	Natural	Shaved Head
BEATRICE*	No, thinned	No	Not sure	Not sure
BEBE	Yes, 2-1	Yes	Perms	Natural
BETHANIE	Yes, 5	Yes	Perms	Natural
BRANDY	Yes, 1-2	Yes	Perms	Natural
BRIELLE*	Yes, 1	Yes	Perms	Natural
CASSANDRA*	Yes, 5	Yes	Not sure, probably natural	Natural
CATHERINE*	Yes, 5	No	Natural	Natural
CORA*	Yes, 5	No	Perms, Natural	Natural
DOMINIQUE*	Yes, 1-2	Can’t tell, change to curly	Perms (infrequently)	Natural
DOREEN	Yes, 3	Can’t tell	Not sure, probably perms	Natural
DRITA	Yes, 5	Yes	Perms	Perms→Natural
FARRAH	Yes, 4-5	Yes (and No)	Perms	Natural
GINA*	Yes, 5	Yes	Perms	Natural→Perms
GRETCHEN*	Yes, 5	Yes	Natural	Natural
JESSE	Yes, 4	Not sure	Not Sure	Not sure, would guess natural
JORIE				
KEISHA*	Yes, 1	Not sure	Not sure	Not sure
KERRIE*	Yes, 5	Yes	Not sure	Natural

LATOYA*	Yes, 5	Yes	Not sure, probably natural (+wigs)	Not sure, probably natural (+wigs)
LENA				
LENORE*	Yes, 5	Yes (and No)	Natural	Natural
MARIE	Yes, 3	Not sure	Not sure	Not sure
MARY JILL	No, but thinned	Yes (and No)	Perms	Natural
MONIQUE	Yes, 2-3	Yes	Perms	Natural
NAOMI*	Yes, 2	No rxn, no change a little coarser	Natural	Natural
OLIVIA	Yes, 5	Not sure	Not sure, wore weaves	Not Sure
RAMONA	Yes, 5	Yes	Not sure, probably perms	Not sure, probably perms (+weaves)
SHAUNTE*	Yes, 4-5	Yes	Perms	Natural
SHELITA	No	NA	NA	NA
SHONDA*	Yes, 3	Yes and No	Not sure	Not sure
SIMONE	Yes, 4	Yes	Perms	Natural
SUE	Yes, 3	Not sure because of new style	Not sure	Shaved Head
TERRIN	Yes, 4	Yes	Perms	Natural
THOMASINA	Yes, 2 or 3	Not sure	Not sure	Not sure, probably perms
YOLANDA	Yes, 5	Yes	Perms	Natural

***Women who have natural hair may use flat irons and hot combs to straighten for a change in hairstyles. Natural implies the use of no chemicals.**
Not sure=didn't ask; or woman did not specifically state her hairstyling methods

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CHAPTER VI

SOCIAL SUPPORT FROM SPOUSES, FAMILY, AND FRIENDS

In this chapter, I use my interview data to understand the role of social support in the lives of black breast cancer survivors. Breast cancer can be an isolating and traumatic experience. The type and amount of social support a woman receives can help alleviate some of the distress from a breast cancer diagnosis. Many of the medical treatments women receive for cancer cause injury, disfigurement, and/or impairment of the body; these can be traumatic and contribute to the distress from isolation that women feel (Regher 2012; Lee et al 2012; Glanz 1992). For example, many women in my sample demonstrated the devastation they felt when they lost their breasts or hair. It became necessary for them to activate social support to reduce this isolation and cope with the uncertainty of a cancer diagnosis.

Studies show that social support buffers against distress from breast cancer primarily by reducing feelings of isolation by providing women with both tangible and emotional forms of help (Bloom 2001; Glanz and Lerman 1992; Nelles et al 1991; Eli 1992; Lim et al 2010; Burke et al 2012). Within this subset of studies on breast cancer survivorship and social support, samples are predominantly white. Only a handful of studies focus on black women and social support during and after breast cancer, and these studies overwhelmingly focus on community level supports—such as churches and black media outlets—and their influence on screening and awareness (Walsh-Childers et al 2012; Salant and Gehlert 2008; Lincoln and Chatters 2005).

Social scientists define social support as the perception that one is loved, esteemed, and cared for within a community (Turner 1981). It encompasses a variety of human interactions including emotional aid, tangible assistance, and informational avenues (Thoits 1995, 2011).

Three types of social support are commonly explored within the literature: emotional, instrumental, and informational. Emotional support demonstrates the concern of others for a person, for instance, through displays of love and esteem. Instrumental support is the transfer of aid and material resources. Financial assistance is the most commonly researched form of instrumental support, but it can also include gifts like food or clothing. Finally, informational support describes the knowledge that is transferred among people in each other's support networks. In the case of breast cancer, it can represent information about support groups and natural treatments (Thoits 1995, 2011; Woodell and Hess 1998; +). Scholars find that all three types of social support from various sources can be beneficial for wellbeing after cancer diagnoses (Ashida et al 2009; Bloom 2001; Nelles et al 1992; Eli 1992; Glanz and Lerman 1992; Salant and Gehlert 2008; Lim et al 2010; Lim et al 2009; Burke et al 2012). In this chapter, I focus specifically on emotional and instrumental support.

The source of social support is another important dimension affecting this resource's relationship to health and wellbeing. In other words, who social support comes from can moderate the effects it has on health outcomes. Thoits (2008) distinguishes between two categories of sources: significant others (colloquially, loved ones), and secondary others--individuals who are similar in experience and/or status. Significant others include romantic partners, family members, and friends—which are the groups of people I will focus on in this chapter. Secondary others can be co-workers, medical and other professionals, neighbors, and other acquaintances. In general, support from loved ones (aka, significant others) demonstrates the most dramatic effects on health. A number of studies show the importance of social support from marriages, friendships, and family for wellbeing after cancer (Bloom 2001; Regehr 2012; Glanz and Lerman 1992; Nelles et al 1992; Eli 1992). The most researched of these sources is the support that comes from spouses (Boeding et al.) For the most part, spousal support, especially emotional support, is positively associated with physical and mental health outcomes for women with cancer (Kroenke et al 2013 a, b). Yet, there is little research focusing on married black women and the role of spousal support in their lives after breast cancer diagnoses.

Type and source can interact with each other to produce variations in how social support is experienced. For example, researchers find that emotional and instrumental support may be more salient for health when they come from significant others, while forms of informational support prove more beneficial when they come from individuals in more peripheral or experiential relationships, like health professionals (Thoits 1995, 2011).

Social support is an important psychosocial resource for health and has been shown to buffer the effects of stress on health and mortality, thus it is important to any discussion on cancer survivorship (Rosenthal and Wilson; Bell, Thorpe and LaVeist 2010; Berkman; Seeman and Berkman). However, different social groups experience social support and its consequences differently. Research on social support and socioeconomic status are most abundant and most consistent in terms of findings. In general, middle class individuals receive greater benefits from social support for health than do individuals of lower status. Middle class social networks are larger and different structurally (Turner 2009, 2013; Turner and Lloyd 1999; Brayboy Jackson and Stewart 2003). Social support networks—especially the ones with significant others—are fairly homophilous or similar in status and characteristics. This means that people tend to be of similar educational and income statuses as the members of their social groups. The homophily within social groups therefore stratifies the consequences of social support, and can affect the health resources a woman has available when facing breast cancer.

Race and gender are two additional important statuses that affect the ways social support works as a buffer against health threats in stressful situations (Williams and Sternthal 2010; Bird and Rieker 2008). Health literature on gender and social support yields consistent findings, whereas drawing conclusions about the relationship between race and social support is more difficult (Sarkisian and Gerstel 2004). Additionally, one important critique of the research on social support and race is that scholars often fail to consider the simultaneous influence of gender. This oversight may mask important meanings of social interactions for black women in particular (Sarkisian and Gerstel 2004; Harnois and Ifantunji 2013). Therefore, I will consider how race and gender intersect with each other and with social class to stratify the buffering effects of social support on health after cancer diagnoses.

Gender and social support. Women are more socially integrated than men are. Women tend to be members of larger social networks, and they maintain more intimate and extensive ties to family. They have larger numbers of friends within their social support system (Sarkisian and Gerstel 2004; Walsh-Childers et al 2012; Salant and Gehlert 2008; Lincoln, Chatters and Taylor 2003, 2005; Simon 2002). Women are also more likely to be members of community institutions like churches and report greater levels of support from religious affiliations (Walsh-Childers et al 2012; Salant and Gehlert 2008; Lincoln, Chatters, and Taylor 2005; Chatters et al 2008; Chatters, Taylor and Lincoln 1999). Additionally, women are more likely than men are to seek out counseling and support from health and other professionals. The larger networks of women translate into higher levels of social support (Turner and Marino 1994; Simon 2002; Turner 1994).

Interestingly, the reciprocal nature of social support may have adverse effects on health for women. Women's greater number of social relationships creates more opportunities for conflict and role strain associated with gender expectations (Snoek 1966; Simon 2002; Lincoln, Chatters and Taylor 2005; Turner 1994; Woods-Giscombé 2010). Additionally, women are more likely than men to internalize the stress experienced by their significant others, which in turn has negative consequences for personal health (Simon 2002; Agneessens et al 2006; Turner and Noh 1983; Woods-Giscombé 2010). One study on women being treated for breast cancer showed that women were likely to worry about the strain their own cancer diagnoses might place on relationships with partners, children, family and friends (Kroeneke et al 2013 a, b; Ashida et al 2009). I observed this pattern in my sample too. My interview with Brielle sticks in my mind because she voiced several times that she worried about her husband's reaction to her cancer. She told me: "I'm actually going through the cancer, but he's actually going through the emotional part of me going through the cancer. I almost just felt bad because he didn't really have anyone to go talk to about what he was feeling." Similar to the existent literature, Brielle was very concerned about how her husband (and children too) was processing her cancer.

One source of strain may come from the emotion work (or management) women invest to maintain their roles in relationships with significant others. Emotion work describes the disciplines and routines women daily engage in to maintain relationships. Emotion work for women entails a great deal of emotional management of the self and of others (Hochschild 2003; Sulik 2011). Women are expected to display a certain set of emotions which entail being pleasant, agreeable, and stifling feelings such as anger or frustration, especially to avoid conflict. Women are expected to avoid conflict especially when interacting with men; if women are heterosexual—as the majority of my women reported—these expectations affect life routinely by way of marriages and romantic relationships. These emotions norms also dictate or facilitate women taking on a nurturing role to console others. From chapter 2, recall how Cassandra had to console her husband that her own hair would grow back after chemotherapy because he loved her long hair. The gendered dynamic of social support can be especially problematic for diagnosed women who are expected to cope with the emotional distress of breast cancer diagnoses in gendered ways.

Black women and social support. Black women may be more susceptible to the strains that can arise within social relationships, as they have historically occupied more social roles than white women have. For instance, black women are more likely to take on bread winner roles in single and dual earner homes, a pattern that is a consequence of the long history of inequality in America, which stratifies economic resources along racial lines. Moreover, stereotypes of masculine black women and images of aggressive black women may lead to greater pressure for black women to heavily invest in emotional management (Katz and Piotrkowski 1983; Lincoln, Chatters and Taylor 2003; Chatters et al 2008; Cose 1993).

Race and social support. Research findings demonstrate that blacks have lower levels of social support than whites do (Lincoln, Taylor, and Chatters 2003, 2005). This is largely because on average blacks have fewer individuals from whom they can pull social support and because blacks' social support networks tend to be less diverse (Williams and Dilworth-Anderson 2002; Collins et al 2003). For blacks, family members and kin make up a much larger proportion of their social support systems than they do for whites. These types of networks can also increase the strain and negative interactions that one experiences from social support networks.

Social support is beneficial to health for both blacks and whites (Lincoln and Chae 2012; Bell, Thorpe and LaVeist 2010), however whites tend to enjoy stronger and longer lasting effects from this resource than blacks do (Christie-Mizell, Pryor, and Gorman 2008; Bloor et al 2006).

For instance, social support is far more protective for whites against depressive symptoms than it is for blacks. This dissimilarity is exacerbated at lower status levels, so much so that studies find no effect of social support for buffering the effects of stress on depression or physical health for blacks of low SES (Lincoln et al 2005; Katz and Piotrkowski 1983; Bloor et al 2006).

A lot of the literature on race and social support addresses race's intersections with class. This intersection is important in the case of breast cancer because black women are more vulnerable to the consequences of lower SES than black men (Collins 2001; Lincoln, Chatters and Taylor; Lincoln and Chatters). Social structures come into play for explaining both the lower levels and reduced effects of social support for black Americans. The greater likelihood that blacks themselves will be of low status exposes them to different social relationships when compared to whites. Moreover, blacks tend to have a greater proportion of lower status individuals within their networks, and are more likely than whites to have family members in precarious financial situations (Lincoln and Chatters 2005; Lincoln, Chatters and Taylor 2003; Bell, Thorpe and LaVeist 2010). Financial obligations some people feel towards family may contribute to higher levels of negative interactions.

On the other hand, some research indicates that family protects middle class blacks from psychological distress and that support from families is useful for coping with discrimination that arises within the racially integrated spaces they frequently encounter. Scholars theorize that the loss of such support from family ties—often a result of upward mobility for blacks—is associated with elevated levels of distress for black middle class individuals (Bonilla Silva 2003, 2004; Feagin and Sikes 1994; Braboy Jackson and Stewart 2003). Since my sample is majority middle class, I can explore these family dynamics for giving instrumental and emotional support.

In addition to finding racial differences in the proportion of family members within reciprocal support networks, studies indicate racial variation in other sources of social support between black and white women (Sarkisian and Gerstel 2004; Lincoln, Chatters and Taylor 2003). Black women are more likely to be reliant on community resources and interdependent on other women (often extended kin), especially when women have a lot of financial and household responsibilities (Lincoln, Chatters and Taylor 2005; Barnes 2009).

In general, black women report high levels of support from religious organizations (Taylor 2014; Sarkisian and Gerstel 2004). However, black women are less likely than white women to seek support from professional sources, like medical professionals and support groups (new 9.5 lit). These types of professional relationships provide social support that is beneficial to both physical and mental wellbeing. Given the psychological toll associated with a cancer diagnosis, underutilization of professional support services may result in crucial variations that contribute to differences in survivorship between black and white women.

Very little academic research talks about the context of marriage for black women. The most common finding is that black women have lower marriage rates than white women do. However, the majority of women in my sample--70%--were married when I interviewed them or at the time of their treatment. Therefore, my sample—though not representative of black women in general, only 30% of whom are currently married (48% never married)—may provide new insight into a group that is not commonly researched.

I concentrate the bulk of my analysis on variations in instrumental and emotional support women reported receiving from husbands.[45] I did not use a survey instrument to ask detailed questions about different types of support, so I combed through my interviews to look for certain patterns in the social support my participants received from spouses. I start with variations in instrumental support and how women described the tangible assistance they received or expected to receive from their husbands. I will begin by discussing the most common form of tangible assistance women reported receiving from their husbands: transportation.

The Knight in the Shiny Car: The Roles of Instrumental Support from Spouses in Reducing Isolation

One recurring theme among women I interviewed was the importance of husbands for transporting women to appointments and treatments. Most (married) women said that their husbands were often a source of transportation during their cancer process.[46] Sixteen of the thirty-two women in heterosexual marriages[47] at the time said they received most (or adequate) transportation from their husband. I add "or adequate" because one woman (Shelita) requested that her husband stop coming, because she grew irritated with people from her support networks

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[45] I will treat two (unmarried) women as married due to the nature, duration, and living arrangements of their relationships when diagnosed. I will acknowledge two of the cohabiting women as similar to the status of "married," because of the seriousness of their relationship situations, Terrin and Monica. Terrin married her then fiancé (partner of 5 years and father of her child) a few months before our interview, and Monica had been with her boyfriend for about twenty years. Of these two women, Terrin reported that her fiancé provided most of the transportation while Monica reported receiving no help from her partner in this respect for either one of her treatments (recall, she experienced a reoccurrence). Terrin's fiancé was unemployed at the time, which she called a "blessing" due to her need for his attention during her treatments.

[46] Except to radiation treatments, many women drove themselves. Radiation treatments were daily (can last over a month) an d are generally very short in duration (You have set times, and can be in and out in 30 mins or less). Also, radiation treatments typically happened on the tail end of treatment for most of my interviewees, and some had already returned to a regular work schedule.

[47] April was also married during (part of) her treatment, but she was the only woman with a woman partner in my sample. I left her out of this analysis because I cannot draw conclusions/generalizations with an N of 1.

accompanying her to chemo. Additionally, one woman, Naomi, chose to do her treatment in another state at the Cancer Treatment Centers of America. Her husband attended first consultations, and then could not attend her chemo sessions because he had to remain home, work, and care for their oldest child. Five other women said that their husbands provided transportation some of the time, which usually included the first consultations or appointments where major decisions were made.

In all, 21 (married) women[48] reported receiving this sort of instrumental support from their husbands. Their husbands provided transportation more than one time during treatments. The other 11 married women reported receiving no help with transportation (or no more than once), or they reported that the lack of this type of support was problematic.

Husbands assisted with transportation whether or not they worked. Angela, who reported that her husband went to some of the appointments, explained:

> He went to the appointments of diagnosis with me and the surgery with me. Matter of fact, him and my ex-husband (laughs) came and set together along with my pastor for the surgery. But after that, friends and family just stepped in and everybody just took turns so that nobody would have to miss work. And he worked days. And we had found, oh, I'm off this day, I'm off that day. No don't take off Fred, you're doing enough at the house. So we had enough friends and family that he really didn't have to go after we got through the diagnosis and surgery, taking off work for those appointments.

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[48] Keisha, Yolanda, Marie, Bethanie, Brielle, Simone, Catherine, Brandy, Miriam, Vivien, Farrah, Lenore, Jorie, Gina (husbands provided transportation to all or most); Shelita is an exception that told her husband to stop coming; Naomi is also a special case because she chose to do her treatment in another state
Angela, Cora, Pearl, Lena, Esther (husbands provided transportation some or more than one time). For Pearl, I have limited information other than he came to more than one appointment and he was "supportive." In the years between her treatment and our interview, they had divorced. When I began and asked her about how she met her husband (one of the opening questions), she responded "That will be a limited conversation." I probed about his involvement a little later, but not much as I did not want to derail the interview.

Angela told me that she did not want her husband to continually miss work for chemo treatments. (She did not have radiation.) She described her chemotherapy as “I went for three months once a week for chemo but at the very same time I also joined the clinical trial for Herceptin, which was also an infusion, so they were giving that to me at the same time as the three months of chemo. And the Herceptin continued out for a total of a year that I ended up still going back for infusions.” Therefore, taking off once a week for three months would demand a lot of time off from her husband’s job.

Likewise, Keisha, whose husband provided most of her transportation, said:

> But most of the time, 99 percent of the time, my husband came to treatment. We had our little – we had our little thing that we'd do. I would eat and go. We had our process, that's what I would do. But most of the time my husband. I don't think he wanted anybody else to take me but him. […] Some of the time, he was – he took off work, but he did it in between, and I would try to arrange it – get treatment like, for his schedule, so I could have it in the morning and come home and rest, and then he could rest, too, and then go to work, because he worked at night.

Keisha discussed working around her husband’s schedule so that he could transport and accompany her to appointments. She was also concerned that he got rest as well.

Some women had greater difficulty coordinating transportation support with their husbands’ work schedules. Cora—who told me her husband was not able to go to her first consultations because of work—said she made efforts to coordinate with his schedule so that he could drive her to radiation treatments. (Most women drove themselves to radiation because of the frequency and short durations of this type of treatment.) Cora told me: “I had like 26 treatments of radiation, and I would go every day and then I would go to work. I would – my husband would take me to the radiation because I’d always make it as early as possible.” Her husband's job hours were during the day and he was not allowed to take time off. The consultation appointments occurred at times of day where he could not be available, but they scheduled radiation appointments so that he could. She also explained that he had access to a car and she did not.

> So I would go and get my radiation and then I would go to work. And then at that time, I had joined a van pool, so he would take me to work [after radiation sessions] and then in evenings, I would come back on the van. But it was just – it was a lot to go through.

Lena also talked about work schedule and transportation issues, except that her husband did not have access to a car either. So when her husband was able to get off work and take her to appointments, they did so via cabs and public transportation (mainly the MARTA, Atlanta's mass transit train). Needless to say, social class shaped these two women's stories as well.

Other employed men were able to work around the time demands of their jobs to accompany their wives to both chemo and first consultations. Job environments for these men facilitated their ability to transport and attend these appointments with their wives. For instance, Brandy said:

> My husband, his job was just tremendous in allowing him to be the person to take me to every single appointment, and I know that that's – that's teamwork, you know, working with great people, you know, because who gets that, you know, without grumbling, you know? So if I got sick or wasn't feeling good – I mean, he works relatively close to the home, so it would be nothing for him to just come home and go back or – you know, just depending on what was going on. But everybody may not have been as fortunate to have.

Brandy recognized that the team atmosphere at her husband's job allowed him to come to these appointments. Moreover, she also recognized that some women may not be as fortunate as she was in that regard. Demands from work was the most commonly reported reason as to why men accompanied women to either some or no appointments, a pattern I will discuss further in later sections on inadequate support.

Long term boyfriends also served in the roles of transporter and appointment companion. At the time of her diagnosis, Bebe was in a long term relationship with her partner, although they never lived together. (Sadly, a few years later, her boyfriend died in a tragic accident.) She talked about how instrumental he was, especially in terms of transportation and attending appointments.

> [I] had a lot of doctors' appointments. [He] was right there for all of my doctor's appointments. [He was] very just gentle and just really took care of me like I was his child, so to speak. And when I say he was at every doctor's appointment, he was talking to the doctors like he was the husband or the father, and you know, he just kind of took things upon himself and just did it. Was always there at my house, you know, even when family and friends were there, taking care of me and getting them what they needed, and was always at my bedside.

Bebe told me that her boyfriend was very influential in decision-making about treatments which often occurred in the appointments to which drove her. Note that she said he "was the husband or the father" and essentially took care of things. I will talk about fathers' roles later in this chapter. Here I will examine variations among the husbands, to see if Bebe's claim about what husbands are expected to do was in line with the support married women reported receiving.

Seven of the 14 women who said their husbands transported them most, if not all the time, also said their husbands were retired.[49] Another (of the 14) was an entrepreneur, one was a physician, and three had managerial positions. For the two women whose husbands did not have managerial jobs, their jobs facilitated their presence at the appointments because of night schedules (Keisha) or an accommodating workplace (Brandy). Job structure will also be an important factor when I discuss variations in instrumental social support. In the next section, I analyze accounts of participation styles from the 21 women who said their husbands transported them at least some of the time to appointments.

Presence vs. active participation. First and foremost, the presence of husbands was important to participants I interviewed. As Keisha talked, she fondly recalled her chemotherapy sessions. She described her husband's support: "But my husband was always – he was always there. I think even when he didn't know what to do, he just still was there. He was there. And that makes a difference, because sometimes people don't know what to do and they just run away. But no, he was there." Keisha perceived a high level of social support from her husband because of his physical presence at chemotherapy appointments. Chemotherapy appointments can be hours long and lonely (according to women who had no support at these sessions). All (transporter) men were present, but not all of them were necessarily active participants in discussions or decision-making at appointments.

As women told me about interactions in appointments, I began to distinguish between two types of participation: presence versus active involvement. Simone best demonstrated this

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[49] Some retired men and couples took on entrepreneurial ventures.

difference between presence and participation when she told me this about the involvement of her husband, who was present at all appointments with oncologists and chemo sessions:

> So he was more of a doer, and he would go to my doctors' appointments, but initially he was not engaged in it. He would go, but–And you know, I needed a second person to be able to hear what was being said, and he was not that initially until we talked about it and how I felt about it, and then he was more engaged in the doctor's appointments, but there was an issue there.

What made some men assets at appointments and others just present? Men who were present listened to physicians and gave relevant advice or assistance to women who were deciding between treatments. After Simone told me about the lack of support at appointments, she said:

> It didn't necessarily have to do with me. He went through this with his mother, and his mother passed. So it was something that he told me that, and you know, he had not dealt with his mother's passing in regards to this, so it was just bringing things back up, so he was trying to be there, but disconnect himself at the same time from it.

She did not fault him for his inability to be there because his mother died of cancer.

Similar to Simone, Farrah and other women whose interviews revealed husbands who were not necessarily engaged in appointments (or treatments) excused their husbands' lack of attentiveness because of the feelings he might be having because of her cancer. Farrah said, "I think he was probably afraid like me." However, that a husband's mother died of cancer did not map on to less active participation for all husbands. For instance, Bethanie's husband's mother also died of cancer, yet she never described her treatment process (or decisions) without using the pronoun "we." Here's an interaction between her and me:

> Bethanie: And then of course we did research on the oncologist, and then we talked to a radiologist as well to make sure that they were good.
>
> Me: And when you say we, who do you mean?
>
> Bethanie: Me and my husband.
>
> [Bethanie decided to have a lumpectomy and I asked her to walk me through arriving at this option. She was given the option of having a mastectomy—a lumpectomy was advised by the doctor]
>
> Me: And how did you arrive at that choice?
>
> Bethanie: Well, we did some research, [and because of] the size of the tumor, yeah.

Bethanie's husband was an active participant in her treatment. Also, I have talked with him in the past, and I believe that his mother's death was the reason he chose to be very hands on (and protective) in his wife's experience with the disease.

Those manly men. I noticed patterns by personality/masculinity type in the way men participated in appointments. One important pattern emerged to describe men that were not likely to be active or helpful in appointments. Some women (mostly women over 50 at the time of our interview) were married to "manly men," which I consider to be men with aggressive, sometimes controlling personalities. Often these men were in or once held hypermasculine occupations at one point in their lives (e.g. soldiers, athletes, and police) and they had a lot of authority at jobs (which includes some pastors). Sometimes these men created negative atmospheres within the appointments they attended. Take Catherine's husband, a former athlete who owned an antique care restoration company at the time of her diagnosis. After she told me that he accompanied her to basically audition (and intimidate) the physicians, she talked about a disagreement her husband had with her surgeon:

> One thing I like about [my research center cancer center]. Some people in my [support] group, you know, we compare stories sometimes and no story's alike. But they go to the community surgeons and those community surgeons give them a

> choice. Girl, who knows what you need? Well, of course I’m a believer. But who knows what you need more than a surgeon, okay? That surgeon told me [to have chemo first]. [But] my husband had no medical experience, and he’s the type that wants to get [stuff] over with. He told me to go ahead with the surgery. Don’t do the chemo to shrink. If I had gone ahead with that surgery and not gone ahead with that chemo to shrink it, it’s a good possibility they may not have been able to get it all, okay, because it was big. And so I told him [my husband] that.

In this quote, Catherine told me that her husband did not agree with the surgeon despite her husband’s lack of medical knowledge. Her husband felt she should ignore the oncologists’ recommendations and follow his. She decided not to, and instead followed her physician’s recommendation. Catherine also told me that she relied heavily on friends’ advice when making decisions about treatment.

Catherine was not the only one to tell me about a negative interaction that happened during appointments when her husband was present. Here’s what Gina told me:

> I was supposed to get chemo and she was having a hard time finding the vein. And we really had to take a moment and catch a breath. Because I told her, I didn't want her to -- I wasn't going to get the treatment that day. That's how much it hurt trying to find the vein. So she asked my husband to leave the room for a minute and she sat down and she calmed me down. She said I'm going to give you a few more minutes and then we'll try again. And she was able to do it then.
>
> Me: Why did she ask your husband to leave?
>
> Gina: Because she thought that by him, his presence in the room, I was tensed.

I consider Gina’s husband to be a potential controlling husband not just because of this incident. When I asked about her employment status, she said she was soon retiring to follow her husband’s entrepreneurial vision. She also recently finished her degree in “Bible classes” because her husband did the same thing at the same time. He was a minister.

Yolanda—who expressed many grievances with her husband's support aside[50] from transportation (which I will discuss in the emotional support sections)—said her ex-military husband accompanied her to appointments. However, because of his personality, she wanted other people at her appointments and procedures as well. Specifically for her surgery, she asked a family friend to come because: "I wanted to see a woman, because I knew what his reaction would be."[51] Here's what happened instead:

> I asked a friend who is a survivor of double mastectomies to be there when I woke up from my initial surgery, and he didn't – did not let that happen. She is the wife of a veteran, and he is very active in the Disabled American Veterans – the DAV – and we had become friends. In fact, when I was diagnosed, my husband told her husband, and I happened to see her husband one day shortly after I was diagnosed, before I had my surgery, and he made sure that I connected with his wife. I mean, he got her on the phone right that minute, and I talked with her, and I told her I wanted her to be there. Well, my husband ended up telling her husband that she didn't have to come.

Unbeknownst to Yolanda, when she came out of surgery she found her friend was not there. Yolanda's husband contacted the friend's husband to tell the cancer survivor not to show up for his wife, although Yolanda requested her presence. Yolanda's husband was present, but blocked her from getting the support she wanted.

These type of men were also likely to give inadequate support, more broadly, including not providing transportation at all. For instance when I asked Jesse if anyone had been less supportive than she expected, she responded:

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[50] He was her usual transportation.

[51] This "reaction" I will discuss in the emotional support section

> You know what, actually, my husband. I mean, as sweet as he is, you know – and maybe there was just – I don't know. But I kept thinking, why didn't he take off work and, you know, come go with me? But he – he's not a hospital person, and he's – I mean, he was supportive as he could be in every other way. But he – he didn't really go to the doctor with me, or want to hear about the details, which you know, I guess is okay, because I don't want to know them either, really. But I – I don't know. I guess I kind of got a little ticked off at him because he wouldn't take off work, and wouldn't – my sister always went with me, and she would tell me he didn't have to go, because she was going to be with me.

Also, she said that he did not want to discuss details with her, which indicates that she did not receive the emotional support she needed—an issue I will unpack a little later—to process the treatment of breast cancer. Jesse's husband was a retired police officer who took up personal training and body building after retiring. Similarly, Cassandra said her husband did not accompany her to appointments either. Recall from chapters 1 and 2 the somewhat controlling and cold nature of her husband. He was a police officer and a retired soldier.

Too busy to drive. Ten married women[52] reported that their husbands provided little or no transportation during their treatment process. Two women, Shonda and Florence, are special cases in this category. Shonda's husband was a double amputee with many health problems. She was his caregiver before cancer, so it comes as no surprise that he was not there in this capacity. As a matter of fact, his ailments were so severe[53] that he had to be moved to a nursing home while she was undergoing cancer treatments. She relied on church members and friends throughout her entire treatment process. Florence's husband had just broken his foot, and could not safely assist his wife with driving. Thus she relied on her teenage son. The other seven

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[52] Florence, Shonda, Monique, Sue, Drita, Mary Jill. Jesse, LaToya, Monica

[53] He died in the time between our interview and her treatment.

women, however, did not give the justification that their husbands were incapacitated as a reason for the lack of transportation support.

The most commonly given reason for lack of transportation support from husbands was work conflict. For instance Monique told me her husband was not available. “[My husband] because of his hours, he was not able to be as involved as he would like. So he, at that time, he was working more of like, a 10:00 to 7:00, 11:00 to 8:00 type of shift.” Similarly Sue said that her husband “continued his work schedule,” the whole time she went through her treatment. Interestingly, however, LaToya’s husband was unemployed, but he did not accompany her to any of the appointments. She would not really tell me why he was not present, but she did say, “Well, he didn’t know what to do, really. […] –but down the road, he got a lot better, and he was supportive. But you know, he did the best he could when he could.” Many women shared sentiments like this when they perceived (or thought I perceived) inadequate support from their husbands (recall Simone from above).

So how did these women get to their appointments? LaToya and Mary Jill said they went by themselves, and usually had to use public transportation. Most of the other women relied on their family. Two women, Cassandra and Sue, relied on their children:. Cassandra relied on her son for transportation only, whereas Sue relied on her daughter to be her full support system. Usually women who reported insufficient support with transportation from husbands tended to rely heavily on family for all forms of support. Immediate family also stepped in to these roles as well. Drita relied on her parents and brother for transportation, Monique on her father, and Jesse on her sister. Monique told me about how her heavy reliance on her father during her treatment contributed to a change in their relationship.

> My dad did. He went to – he was at everything. He was – he and I became like [so close] (laughs). There's no way to say it. But he – yeah, he would take me to my treatments. So I would basically go there and meet him at their house, and so he would drive me to treatment, sit with me through treatments, then we would come back here, and then usually I would go back to my house or go pick my daughter up, and sometimes I would drive back to their house so I could stay with them for the weekend.

When husbands did not provide transportation support, this inadequate support usually translated over into other forms of tangible aid. Monique continued and explained why she stayed at her parents' house some weekends.

> Because a lot of times – particularly with the chemo – it's kind of hard to have to deal with a toddler when you're getting through like, the first couple of days of chemo, because you just have no energy and, if you eat anything, it may stay down, it may not, and so it's a bit much to have to deal with a toddler by yourself when you are going through that. So I would usually stay at my parents' the weekends after I had my chemo treatment and they would kind of help watch my daughter for me.

Monique's expressed difficulties caring for a child after chemo leads me to my next discussion of an important type of instrumental support that came from husbands: help with daily routines.

Young mothers and the division of labor. In addition to their spouses' presence at (and involvement in) appointments, many women needed additional support outside the treatment space to keep routines running smoothly. Why? Monique explained:

> At the time, my daughter was three when all this happened. Yes, three. So I still would have to be responsible for getting her dressed, coming home, grocery shopping, cooking dinner, doing whatever. So I mean, if he were to get home and, you know, she wasn't taken care of, he would, you know, definitely help out and

> make sure she got into bed. But for the most part, the majority of the day to day still would fall on me.

Monique talked about the difficulties of caring for a toddler—incapable of understanding her mother's sickness—when going through treatment. Monique also told me that it was painful holding a rambunctious toddler especially right after breast surgeries.

That said, husbands who did not provide support when a young child was present in the home were rare. Yet these young mothers typically had more daily routines prior to cancer diagnoses than other married women. The need to redistribute (traditional) distributions of labor within the home was a theme among this group of women, largely because they had young children (<18 y/o) in the home. Moreover, these women were also more likely to be members of dual earner households—as neither they nor their husbands were of retirement age. Marie described her husband's help with daily routines, including caring for their teen child, and his work ethic during her treatments:

> My husband was just my rock. I mean, we never lacked anything. He worked overtime. I don't know how he did it. He worked overtime, still maintained meals for me, made sure I was taken care of. He was just – I can't praise him enough. He was the perfect man. He might not be perfect at other things, but [he was] perfect during my chemo (laughs) cancer treatment.

Marie's husband not only took over the tasks she used to perform, but he also worked extra hours to make up for her need to be off work during treatments.

For many, cancer disrupted motherhood because cancer treatment (mainly chemo) made women unable to perform many tasks due to side effects. The role of husbands was very salient in this process. Bethanie talked about the taxing toll of chemotherapy:

> I didn't cook. Either my mom cooked or other people cooked for us, or my husband

> went and got dinner. I didn't cook a lot. I didn't have a lot of energy. The chemo was really hard on me. So I don't remember what day I went for chemo, Tuesdays or Thursdays or something. Normally I would be in the bed anywhere from 7 to 14 days after my treatments, nauseated, diarrhea, no energy, really tired and fatigued.

Importantly, Bethanie was able to lay in the bed for a week or two after her chemo treatments because important people in her life came to her aid. Bethanie had two teen sons. One was in college and the other was a high school student living at home. She told me that the high school aged son or her husband would do chores around the house when she was recovering from chemo. Moreover, Bethanie told me that her husband, as part of overseeing her care, coordinated help from friends and family who wanted to provide it.

Having men adopt chores and food preparation tasks was especially important for women who were diagnosed young. Brielle (whose children were about 10 and 16 years old at the time) described her husband's support:

> Yeah, so he would you know, take me to my appointments or get dinner prepared if I wasn't able to do that. He would help out with that. Washing the clothes, cleaning the house, taking care of that, and maybe if the kids needed to go to practice or [anything else they] needed to go to and I wasn't feeling well he would take them there. But pretty much everything that I used to do, he just took over doing if I needed him to.

According to Brielle, her husband adopted the roles she traditionally performed when she was sick. He did everything that she "used to do," which also implied that before cancer, their roles as parents were traditionally distributed, insofar as women traditionally perform more household chores than men and assume most of the childrearing duties. Cancer marked an important pivot (even if temporary) in the distribution of labor for some women. Men showed their support by doing household chores.

Terrin was 35 when I interviewed her. I remembered seeing her at a meeting when she was finishing up her treatment about 1 ½-2 years prior to our interview. While she wasn't married, she was cohabiting with the father of her son, who was about 4 years old at the time of her diagnosis.[54] She said this about the roles her then-fiancé (now husband) played at appointments and at home:

> Actually, he was the primary caregiver, so he was the one who was going in chemotherapy with me, because he was unemployed at the time, which is just -- We talk about that, and we know that it was nobody but God for him, because he was working prior to that and then he was unemployed and he got a job right after I finished chemotherapy, and so (laughs) like it was just like, yeah, he needed -- I needed him to be there and God knew that, so he went with me to chemotherapy, and he cooked, and he did everything, cleaned, like he was the rock when I was going through it.

Terrin described her fiance's unemployment as a blessing because he could take care of her and their son by performing household duties.

Angela talked about how her husband showed his support by cleaning their home frequently (a task she used to perform). However, his cleaning may have also served another purpose. Her husband's mother died of breast cancer.

> Well, nobody had to come clean the house. I think that was Ethan's outlet. He just cleaned all the time. His mother died of breast cancer and that was back in the day where you were dying if you know what I'm saying because if his mother was alive she would be probably in her mid-80s if she was alive. So he had flashbacks to that and so I know that was not easy for him and so he was one of those that just started

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[54] I learned that Terrin's son died from an unexpected bacterial infection about a month after she finished her treatments. She did not reveal that she had a child until the very end of the interview. After the timing of this reveal, I sensed that she was still grieving for her young son. My next interview also was with a woman whose son had died.

> cleaning house two days before my chemo session so the house would be germ free when I came home. He did those sort of things.

One “thing” he did not do was cook. Angela also told me that friends would frequently bring over food for the family.

It was not uncommon that husbands did not cook for the family, but women attributed this lack of cooking to their husbands not being skilled at the task. Florence said this, jokingly:

> Both of us are really for all purposes out of work, not working, you know, or whatever. But he couldn't cook. He thought he could cook. He couldn't cook. So my – my mother would cook and brought them food over, so my poor kids wouldn't [have to eat terrible food].

Recall from the transportation discussion that Florence’s husband was injured during her breast cancer treatment. He did not work while healing from his injury. She was a housewife at the time, and notice how she said they were both “out of work.” Her mother supplemented meals for her family, which I presume was part of Florence's work prior her diagnosis. Also, Florence was treated over 30 years ago, so the disfigurement of her breast surgery left her permanently unable to perform her once routine chores (see introduction).

Even Dominque, who had divorced her husband a year prior to her diagnosis, talked about her ex-husband’s salient role in childcare during her treatment. Her daughter was 16 at the time, so she didn’t need the attention and care that Monique’s toddler daughter did. Although Dominique's ex lived in another city, he came into town to be with Dominique for some appointments and treatments:

> He came. Yeah. He came because I had to tell him, no, he don’t have to come all the time. But he came. At the time, [my daughter] was a cheerleader and she

> traveled, so my ex-husband a couple of times, I couldn't go because I had just had chemo and he flew to Florida to be with her at the cheerleading competition.

Additionally, some women who were grandmothers who gave care to grandchildren also said that their husbands were helpful in helping them fulfill grand-childrearing duties.

Initially, I thought education might be a factor in this sort of instrumental support. However, husbands' job structure or occupational type seemed to be the important factor. Terrin's husband was unemployed, thus job structure was not an issue. Neither Brielle nor her husband had bachelor's degrees, but he had a high-ranking managerial position. Angela's ex-husband did not have a college degree but held a managerial position as well. Bethanie's husband had an advanced degree and was the leader of a large church. On the other hand, Monique and her husband both had bachelor's degrees, however he was not in a managerial position at the time of her treatments.

Research indicates that job structure is usually closely related to class status, but not so much for my sample. Education did not necessarily correlate with job structure, and in my sample many times women had equivalent or higher status jobs. Moreover, concepts and measurements of occupational status tend to be based on white samples. For instance blacks tend to be in managerial jobs that are service oriented. Also the status of ministers is high in black communities whether they have a salary to match or not ().

Routine care without live-in children. Older women without children at home also expressed variations in the household help their husbands gave. However, clear patterns did not emerge by job characteristics as they did with younger men. Older men were most likely to assist their wives with nutrition and medication monitoring. In other words, these husbands provided food and made sure women took their medications. Men provided food in various ways. Some cooked, whether they were skilled or not. Women still showed appreciation of the effort. For instance, Lena described her husband's cooking as: "Tomato rice is his speciality." While she did not care for his special dish, she called him very supportive during this time.

Most often, men brought in food. I asked Farrah, "[W]ho cooked while you were weak and stuff like that? Your husband?" She responded: "Oh heck no. No. (Laughs) Just made sure that food was in the house and it was, you know, I wasn't an invalid. So I could eat some soup, open some soup or you know, make a sandwich or something. It was easy enough to do. Or he would pick up something. So that's the way we got through that." She acted as if it was a crazy question to ask if her husband cooked.

Just because men were willing to provide food did not mean that women always perceived this behavior as completely supportive. Yolanda said of her husband: "He did everything that I needed, and that's the kind of person he is. He provides what you need. Now, your wants are a different story." Yolanda told me her husband would never bring her food she requested.

> But I ate because I had my husband pushing me to eat to live, therefore, I ate too much of the wrong things, and since I couldn't taste it much, I mean, I was just eating. […] when I wanted waffles for breakfast, he was going to go to McDonald's, so what do you need at McDonald's (laughs), okay? So he provided breakfast, but you know, it wasn't my choice. (laughs)."

Recall that I described Yolanda's husband as having hypermasculine, controlling characteristics.

Interestingly, women with husbands I previously described as having controlling, hypermasculine traits (e.g. Jesse, Lenore, and Catherine) were also concerned with making sure their wives were physically active as well. These men encouraged women and engaged with women in working out during or right after their treatments. Catherine told me about her husband's insistence she work out during her treatment.

> And I can remember sitting in my den and saying, gosh, Sylvester, this is going to be a journey. This is going to be a long journey. He said girl, this year will be up before you know it because, you know, they said it's about a year for treatment and everything. And he made me so mad. I had gained all this weight from the medicine and stuff. And he was like we had to go to the gym every single day. I was like, really dude? I've got to go to the bathroom, change out, because I have one breast. Scared to be in the steam room because somebody might notice. I'm like really? But it was the best thing for me. You know, that darn treadmill. But it was the best thing.

While she first resented his insistence that she work out, she came to appreciate that exercise was part of her daily routine. Interestingly, these controlling men were also the only ones reported to dress their wives' wounds after breast surgeries.

Again, food provision was the most common way that these "older" men helped their wives around the house. A couple of women said that their husbands helped with other daily routines. For instance, Esther (whose husband was a transporter some of the time) told me this: "You're limited in how you can even wash your own body. So you had to have some help. You know, I'd be like, Henry Henry, you know, I need you to wash my back or whatever, things like that." Similarly, Lena said her husband would offer to comb her hair in addition to bathing her when she needed help.

Once more, most of these women did not mention help with daily grooming (and I did not always remember to ask either). Yolanda, however, voluntarily reported about a lack of willingness to help with these sort of routines:

> He told me when I was diagnosed, if I needed cleaning or bathing, that I would have to call my daughters to help me. When he was diagnosed with [many chronic health conditions] with the severity of his illness, he had extreme diarrhea, and I had to do a lot of bathing and cleaning for him. […]his initial response of not being able to bathe me if I needed to, or clean me, or whatever, it did hurt my feelings,

> but I know who he is, anyway. He's a germophobic because of his liver transplant. So initially, I accepted that as the reason for him feeling like he couldn't bother with cleaning or – or any deep care, because he's concerned – he was concerned about contamination to himself, health-wise. But for just personal feelings and interactions, it still seems unfair. .

Yolanda’s case was a bit extreme compared to other women in this respect. Her husband believed bathing her was an unsanitary task.

I found it harder to decipher between differences in help with daily routines provided by my older participants’ husbands. Maybe health status mattered (recall Shonda’s situation), but Yolanda’s husband was not necessarily physically incapable of taking care of her. Instead, he had an aversion to germs because of a previous medical procedure. Instead what I noticed was that men who offered a lot of instrumental support around the house were also more likely to be very emotionally supportive of their wives as well.

Types of support do not operate independently from each other. For instance, the lack of instrumental support from Yolanda’s husband translated over into the level of emotional support she felt from her partner. Yolanda told me that several months prior to her diagnosis a relative was diagnosed with breast cancer and she (Yolanda) posed the question to her husband: how would he feel if it was her? When it was her, she described his reaction and support in the following:

> He said that we would just deal with it. So when I was diagnosed, he was supportive. His personality is not a nurturing kind of person, but a providing kind of person. So he provided what I needed, but he was not nurturing at all.

[Before she revealed more, she asked what I was going to do with the data. She asked if there was any way she would be identified by what she was saying. When I assured her the answer was no, she continued.]

> Okay. The lack of nurturing for my husband [was hard] He did tell me [later] that he did appreciate my caring for him, and that he had learned a lot from me. Now that he is mostly recovered [from his surgery and chronic illness]– we're seven months out now from the initial surgery and five months out from the sedation – his actions don't show the gratitude that he spoke of.

The nurturing that Yolanda spoke about proxy emotional support, which, again, demonstrate sentiments of love and concern.

Show Me You Love Me: Variations in Emotional Support

Identifying important types of emotional support was more difficult, as this form of aid is more intangible than demonstrations of instrumental support. I noticed patterns and came up four with categories for how women described emotional support.

Niceties and encouragement. In Yolanda's quote above, she demonstrated that in addition to her husband's inadequate support, his behavior was also not very kind. Note she said how his unwillingness to bathe her initially hurt her feelings. Therefore, I begin my discussion with the first typology of emotional support, kindness. Esther, Marie, Naomi, Shelita, Brandy and Miriam mentioned receiving this type of support. These husbands were kind to their wives with the purpose of keeping their wives in positive spirits. For instance, Brandy said:

> My husband was just tremendous. I told him that is the nicest – he's been nice all along because, I mean, you know, we're still in love, high school sweetheart, and I'm still crazy about him, but at the same time, that was another side of him that he was seeing that we both were very vulnerable.

Brandy talked about how her already nice husband’s behavior during treatment was very salient during her treatments. His kindness strengthen her romantic feelings for him as well. She talked about how both of them were vulnerable, albeit probably her more than him, given the fear that often arises from cancer diagnoses (Williams). This vulnerability contributes to the psychological distress women felt while undergoing cancer .

Cancer can be a fatal disease and a cancer diagnosis brings about a lot of uncertainty. Esther also talked about her husband’s support buffered her against some of these psychological effects. “I depended on my husband a lot, his spiritual knowledge, his upbeat tempo was always – you know, he's always trying to keep it on a positive note, which was just a blessing – which was just a blessing.” Her husband’s positive spirits helped her deal with treatments and side effects from radiation.[55] She also said: “My husband was just very much encouraged – an encouragement to me.” Esther’s husband’s kindness was for the purpose of helping her maintain a positive outlook on life, despite being diagnosed with cancer.

Similar to words like *encouragement* and *nice*, *inspiring* was another way to describe this type of emotional support. For instance Jorie said, “He would – the days that I didn't feel good, you know, [my husband] would try to inspire me. He would tell me, I know it's not easy, but it's not as bad as it could be.” This quote also demonstrated that Jorie’s husband was attentive enough to notice her changes in mood during treatments.

Interestingly, the men that were overly kind to their wives were also the men very involved in helping with women’s daily routines. This kindness included going above and beyond to make sure their wives were comfortable in their daily routines. Take Brandy for instance who said: “My taste buds were gone. We spent so much money on food because I could

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[55] Esther did not lose her hair because chemo was not part of her cancer treatment.

not eat. And my husband was just constantly trying to find what was going to excite my (laughs) palate." Brandy's husband did not just want her to eat, but to also enjoy the food. He also helped her bathe herself regularly even when she had accidents.

Sometimes, husband were attentive and kind and brought their wives gifts. Jorie also told me "when my legs hurt or – you know, he would rub them for me, and you know, some days I would cry and he would give me hugs. And sometimes he brought me flowers. He did everything he thought." Hugs, flowers and leg rubs described Jorie's support, which are acts that are above and beyond providing daily care to their wives.

Sit and cry with me: husband's willingness to have emotional discussions. In addition to demonstrations of love when women were down, some of my participants also talked about the support they received by talking with their husbands. Whereas most women reported they mostly confided in other women, some women were very grateful for the conversations they could have with their husbands. When I asked Naomi if her husband provided emotional support she said:

> Yes, because we could talk about things, you know, just knowing what was on his mind. So when we met, the only thing that was, I'm not going to say the only thing, but the biggest thing is, you know, how is that going to affect intimacy. So those were the questions where he – that was a valid question and I hadn't thought about it, you know? (laughs) But then he would say, when we get the answer to – and then you can kind of figure out how to work through that. So yeah, I think he was helpful. He was very helpful.

Naomi chose to do her cancer treatment at the Cancer Treatment Centers of America, even though she got the same prognosis from the local (research university's) cancer center. However, she insisted on doing her treatment at this institution despite the distance and the greater difficulty getting insurance to pay for all the treatment. Her husband was not only a support in the provider role, but when they were able to be together, he constantly reassured her of her decision and the security of their marriage. In the above quote, she worried about intimacy because of the distance and disfigurement associated with her treatment. Her husband told her that they would work that all out once they knew she was well.

Naomi also demonstrated the benefits of couples talking because she could know what was on his mind. A lot of women—who also reported receiving inadequate support—tried to figure out what their husbands were thinking. Recall Simone, LaToya, and Farrah from above who excused lack of support because they felt their husbands might be afraid. However, emotional conversations with husbands were one pathway by which women did not have guess about their husband’s emotions. Take Shelita for instance as she described and interaction she had with her husband. “He was right there too. He was like crying. I'm so sorry. I wish I could take it away from you, I would take it, boo hoo hoo. You know, when I had to tell him I got cancer, he just sat there boohooing by the bed (laughs).” Now Shelita was a jokester during our interviews. She joked about every process of her treatment, even still, when mocking her husband crying, I could tell she appreciated seeing that emotion from him. Recall she also told him to stop coming to all her chemo sessions.

> Shelita: I made him stop. He didn't go to my more chemos, because I said I don't want [anyone] to go. It wasn't nothing for him to do. I had the port. You sit up there. They give you your stuff. You put on a blanket and go to sleep. Wake up and go shopping.

When she woke from chemos, who was there to take her shopping? Her husband, of course.

My best friend: togetherness and doting. Shelita shared something else with women who reported receiving encouragement from and engaging in conversations with their husbands. Open conversations often gave way to high degrees of togetherness among couples. For instance, at the onset of the interview, I asked Shelita to begin telling me about her husband, she said: “We love to travel.” Shelita’s husband had recently retired and she said, “He just retired last Friday, so he'll be sitting there looking at me all day.” She also told me that they frequently went out to eat and to the movies together.

Moreover, women who talked about how they could have conversations with their husbands, were also some of the women that got the most transportation support *and* a lot of help in daily routines. After all these couples were always together or at the very least thinking about each other. Additionally, when I asked a question about who provided the most support, these women were likely to say their husbands only or name the husband first and after hesitation mention others. A handful of women fit this category of receiving all three forms of emotional support that I described: Marie, Naomi, Shelita, Brandy, Jorie, and Keisha.[56] Recall how Keisha told me that her husband was always there and just his presence was so meaningful to her. She also told me they developed routines around chemo, so much so that he preferred to be the only one to take her to appointments (although he did not stop people if Keisha wanted them to come).

Jorie also talked about the importance of her husband’s presence when she was scared:

> Sometimes he would just – you know, I would get scared and he would just sit next to me. He wouldn't say anything, he would just sit there. But the fact that he was there, and his presence, it made it so much better.

Women who experienced high sense of togetherness were also very likely to dote on and praise their husbands. Both Brandy, Jorie and Marie—the three women who probably received the most—lauded their husbands for their care. Recall how Brandy said she was still crazy about her

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[56] I suspect that Bethanie fits into this category too, although she did not explicitly mention things about emotional support. She was not much of a talker either, and usually gave short, “matter of fact” answers.

husband, especially because how “nice” he was during her treatment. Similarly, Jorie said: “And I tell everybody, anytime, my husband is my best friend. He is my best friend. When it comes to people, he's my best friend. So he was – he was there with me through the whole thing.” Jorie described her husband as her best friend, a man that provided high levels of both instrumental and emotional support.

You’re still beautiful: Supportive of breast surgery decisions. Instrumental and informational support was important to the women I interviewed. However, as women experienced and adjusted to transformed bodies, they needed emotional care, which leads me to the last category of emotional support I detected in my interview data.   This type of emotional support was pretty prevalent, and only two partnered women (Cassandra and Monica) did not receive this type of support from their romantic partners. For two more women, I do not have the data to assess whether they received this support from their husbands. Pearl and Drita had since divorced, and did not want to talk at length about their ex-husbands.

What does this type of support look like? To explain, I begin my discussion of this type of emotional support by focusing on the set of married women opted out of reconstruction after breast surgeries or could not complete this procedure. Six women fit into this category and five were above the age of 50 at time of diagnosis. Four of the women opted out of reconstruction, while Marie and Monica could not complete this process for reasons I will discuss later.

When femininity was threatened and gender identity challenged, women often relied on emotional support from their spouses to help them cope. The four women who elected not to reconstruct felt like their decisions were validated based on their husbands’ comfort level with their bodies after mastectomies. For instance, Lenore (61 and 57 at the time of her treatment) chose a mastectomy and no reconstruction. She said this of her husband’s reaction, “He wasn’t excited about me doing any reconstruction or the breast implants because it was going to involve too much surgery. He said it didn't matter to him if I didn't have breasts. It didn't make a difference." Lenore decided not to have reconstructive surgery, because her husband told her it didn't matter if she had breasts. She also sensed that he was apprehensive about additional surgeries.

When I asked Jesse how she came to her decision about opting out of reconstruction, she said, "I asked my husband what he thought and he didn't care. I mean, he really—he didn't care. He was just grateful I was alive." When I asked her how she adjusted to hair loss after chemotherapy, she said something similar: "It was traumatic at first, you know, to see all the clumps of hair (laughs)—but get over it. And my husband was—I mean, he was just always very supportive—and he didn't care. He was just grateful I was alive." For Jesse's husband, her physical presence on Earth was more important than the presence of her feminine breasts or hair.[57] Jesse received emotional support to help adjust to her transformed body.

Similar to support for breast disfigurement, most husbands were supportive after hair loss. Of all my married (or partnered) participants, there was really only one husband (Cassandra's) that comes to mind whose only concern was for when his wife's hair would grow back. Positive support after hair loss support meant a lot for women distressed by this in particular. When I asked Angela her husband's reaction to her shaved head, she said:

> My husband came in, looked at me and said hey, how you doing? Acted like he didn't even see it. But they knew it was coming but I just said I wasn't going to call and be hysterical. It came out and I had to get it shaved. I'll just go home. He came in, said hey, gave me a kiss. How you doing? And kept moving. I was like, he didn't say anything. (laughs)

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[57] I will not discuss hair loss and social support because I plan to write about that topic in a separate article.

Angela’s husband showed his support by acting as if nothing was different or odd. Angela was self-conscious about showing her new bald head to her husband (and son, who did say something). Her husband reaction helped her adjust, because he still saw her as the same woman.

Many women said beauticians shaved their heads, but some men showed their support by shaving their wives’ heads. For instance, my father shaved my mother’s head (in what turned out to be a very emotional event). Men who were heavily involved transportation tended to be ones who shaved their wives heads (unless the woman loved going to the beautician beforehand—something that Bethanie told me she enjoyed before cancer). Marie tried to have her beautician shave her head and the following occurred: “She was crying worse than me. So my husband actually shaved my head.” After, she said:

> So, I mean, I looked at my head, and you know, I told my husband, you all lied to me (laughs), because they said, you look fine. I said, you're lying. I think at the time, I was too much dealing with what was at hand, making decisions, that I – my emotion was not playing the part as much as they would have, you know what I mean?

Marie still had trouble adjusting, even though her husband and family said she looked fine. Honestly, my mother never adjusted to her bald head although people kept telling her that she had the face to sport a bald head. Perhaps as LaToya said in chapter 2, hair does give a woman her features. Recall LaToya from chapter 2 and her devastation after hair loss. She was reluctant to show her husband her bald head:

> I would wear a hat, a scarf – I wouldn't even let my husband see my head. I would go to bed at night with a scarf on my head, I was so ashamed. But one day, I got the – the boldness—I went without the scarf, and sure enough, for the first time, I showed my – my daughter came over. I said, I'm going to show my husband. And

> I ain't know what he was going to say, and I was like, look, my hair growing back. He was like, oh, I like that."

LaToya's husband was comfortable with her sprouting new hair and said he liked it. She felt that maybe she shouldn't have hidden her head for that long. (Also, I do need to note that LaToya found her comfort in debuting her very, very short hair after her beautician told her she had a good "grade"[58] of hair and should not be wearing coverings when it started to grow back.)

Some men went further and shaved (or offered to shave) their own heads. These tended to be men who were very emotionally supportive in the other three areas I discussed above. Take Naomi for instance, who told me this: "He shaved his head first and then shaved mine. Like I said, he was really supportive, so yeah." Similarly, Brandy said her husband offered to shave his and their sons heads, but she insisted that they not.[59] Dissimilar to the breasts, her hair was going to grow back, and she did not interpret this type of support as helpful when coping with the consequences of breast cancer treatments.

Importance of emotional care. Why was this sort of support in terms of the body so important to women during treatments? Marie offered an explanation:

> I think another thing that was different for me was I don't have the shame. A lot of women feel ashamed. Some women won't – don't want anyone to know they have – have breast cancer. I felt there was no shame in what I had. It isn't like I went out and had a venereal disease of something, you know? This was something – I didn't bring this on myself. So I don't think I carried the shame. But even to this day, many of my sisters, they don't want anyone to know, so they suffer silently. Where I had a great support system, they don't. My husband was wonderful. Many women have

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[58] Colloquial for texture

[59] I understand Brandy's sentiment, because if I had shaved my head in support of my mother she would have been hurt, and probably furious. She told us (my siblings) that she did not want us to demonstrate our support in this way. With that said, my father was already bald (or keeps his head clean shaved because he started balding early). Catherine also said her husband was already bald.

> divorced during this. In fact, I read a stat that 75 percent of marriages end in divorce[60] when there's a chronic ill spouse. […] I have been through a lot. I mean, I have the battle scars to prove it. I've had seven surgeries, you know, I'm here, I'm sitting with one breast, no ovaries, no uterus. (laughs) That's a lot to deal with, you know? But I go back to my husband again, you know, when other men have walked away and said they hadn't bargained for that, my husband – you know, he doesn't treat me different. He doesn't – I don't feel like I'm not a whole woman or all this crazy stuff that people deal with.

Marie selected reconstruction (implant with tissue expanders), however she experienced complications after the plastic surgeon decided not to put drains at the site. She had to have her implant removed because of leaking, disfigurement, and pain; and she did not elect to go back. Marie did not feel ashamed of her transformed body because her husband was not uncomfortable with it. He did not treat her differently, even though she had lost important feminine characteristics. She went on to say:

> I could be okay with one breast because he was okay. I could be okay with no ovaries and no uterus because he's okay. And had he – I probably would have had a whole lot of issues had he had issues, if that makes sense.

It did make sense, as the women who did not have this type of support did report issues with adjusting to their new bodies. For instance, Monica was not eligible for breast reconstruction, which made her feel like "less of a woman" (see chapter 1). Her interactions with her long time cohabiting partner did not relieve these feelings of inadequacy. Monica was very emotional during this part of the interview. She also told me that during her second bout with cancer, her

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[60] Some women did divorce after their treatments, but when asked, none of the women said cancer was the reason for their divorce. They cited previous problems, one said she never should have married him (which she did shortly before her first treatment), and another refused to talk about her husband aside from his education. I did not push her to avoid derailing the interview. As a matter of fact, I didn't push any woman about the details of an ex-partner (whether they separated before or after treatment) when negative emotions were triggered. I learned quickly that exes were off the table for many women by their body language, facial expression, and the responses: "that will be a short discussion" or "now, that's all I'm going to say about him."

doctors suggested removing her undiseased breast as well as performing a hysterectomy. At the time of our interview (about 1 ½ years after her tumor surgery), she still had not heeded her physicians' advice. Her treatments led to a permanent shift in their romantic relationship. She told me about an interaction with her partner:

> Yeah, and the hardest part of the whole thing [I usually asked my sister and cousin to come help me change my dressings after my surgery.] So one day I decided I was going to take a shower and try to change it myself, [and I couldn't], I had to get him to come in the bathroom and help me get my dressing back on, and that was the hardest thing in the world, to have him look at me like that. I was all swollen out to here, and it was – I was so ugly. I think that was the hardest part of it this year. No woman wants a man to see her look like that. And then I felt like he was looking at me real funny. The rest of the day, he just, you know, seemed like he was looking at me funny […]. And even though he tries to pretend that everything is okay, I still think that mentally, it's done something to him, too. He just ain't never going to say it, you know? I can just tell that, you know, he has his days where he want to go out and hang out with his boys and stuff. He tries to make me think he loves me and everything. But I know, after seeing me when I really was all swollen up like that, I know it bothered him, because the breast was his thing. You know, he liked to touch the breast. So I don't have that anymore, so he's constantly watching TV and looking at shows with, you know, women who got – you know, they're showing their breasts and stuff, you know, these reality shows that come on TV, and he likes to watch that kind of stuff, and it kind of bothers me, because I know that my life is never going to be the same [without my breast].

Monica felt that the loss of her breast became an obstacle in her relationship. The breasts were "his thing," she told me. His need to touch, see, and feel both breasts impeded his ability to support her while she coped with her transformed body. Moreover, Monica's partner was also not instrumentally supportive but in a way that I did not observe among other women.

> Monica: Well, he – everything as far as the home is concerned is – he owns the home, but I do help with bills and stuff, and yeah, I did feel like I had to borrow money at times, because I didn't want to have to ask him to buy every little thing. Yeah. He doesn't understand the things – a lot of things – personal things I need. He just thinks, you know, that I've gone and spent a lot of money on nothing, but you know, it's a lot of things that women need that he just don't comprehend. So it's been – it's an issue with that from time to time.
>
> Me: Okay. When you say you had to borrow money, who did you usually borrow it from?
>
> Monica: You know, like those little places like, Advance Financial, that type of thing. It would always be a small amount. It wouldn't be a lot. You know, just enough to get me through the month, you know, if I was running short, to keep friction down at home.

Monica needed financial assistance from her partner, although she infrequently asked him for it, preferring to borrow money from places notorious for their predatory lending practices. He also could not provide her with adequate emotional support because of his love of women's breasts.

She felt that their relationship would never be the same. However, she never expressed any willingness to stop the relationship because of her partner's actions. Instead, she talked to other women who suggested she talk to mental health professionals. Monica refused. "One of the surgeons that I had seen, and some of my other friends was telling me that I probably need to talk to somebody, but I never did because I felt like if the person I was going to see had never walked in my shoes, she couldn't relate to nothing I had to say, and it would just be a waste of time for me," she said.

That therapist can't identify with me. All but three women in my sample shared this same aversion to mental health professionals with Monica and did not visit therapists. For instance when I asked Brielle if she was offered psychological counseling she said:

> Mhm. Yeah, they always brought it up, you know, and they always talk to you about it, but I never needed it or anything. I talked to my pastor at church, so yeah, I didn't -- that was fine. I didn't need counseling outside of church or whatever.

Interestingly, Brielle voiced concern for her husband’s emotional state of being. She said:

> There wasn't anything discussed about who he could talk to. It would be nice if he could maybe talk to other men that were going through the same things so he could get out what he was feeling instead of just going over everything with me. There was a lot of help for the people going through cancer, but not a lot of help for the caregivers that had concerns or questions as well, especially for the men. You know, men don't normally discuss things, so it would be nice if they could get around other guys and talk to them about certain things.

Notice that she said her husband needed to talk to other men, but not a psychologist or mental health professional. She felt that other laymen’s accounts would have been beneficial so he could process his experiences as a caregiver.

It is very likely that if a woman was not open to mental health treatment neither was her husband. For instance Brandy told me this:

> Now, they do give you, when you going through chemo – well, they did give me some anxiety medicine, and I took one of those pills and I was just – it was just like – I can't even describe it. It was just like I was out of my body. I was like, oh no. But even though I would be sick and you know, just because I was just so sick, I would be crying. I would just – I would just be a mess, just absolutely a mess. And so my husband would make this little joke, I guess, when I would just get to be too much. He would say, you want one of these anxiety –? No, I’m good (laughs). I’m good (laughs).

Brandy’s husband shared her aversion to mental health treatments, as he would joke about taking the pills to get her to cheer up when she was sad. Importantly, in this quote, Brandy demonstrated that cancer treatments are stressful and sometimes overwhelming, no matter how strong a woman’s support system. I presume an oncologist gave her an anti-anxiety medicine. I am not sure how to interpret the symptoms she described that occurred after taking this pill. However, she was clearly upset before she took the pill, so was the "out of body" experience a feeling of relief?

Other women would hint that they acknowledged the need for counseling, but were not willing to seeing a therapist or psychiatrist. Yolanda, who was also distressed by her husband's unwillingness to bathe her (among other actions), said that she had not addressed this issue with her husband despite him having an illness years later where she did bathe him. She said, "I have talked with other people, not professionals, but other people about what I have felt during his illness and my own."

This is not to say that married women were the only ones in my sample that showed need and also refused psychiatric care. As a matter of fact, two of the three women who did visit therapists at least once were married.[61] However, many of my married women expressed difficulties dealing with interactions between husbands. These difficulties arose because complexities in instrumental and emotional aid sent mixed messages about how supportive their husbands truly were.

Mixed messages. Recall Simone from above. She discussed how her husband was a doer and not an emotionally supportive person. When I asked her: "Were there certain people or sources of support that you found to be less supportive than you expected?" She replied.

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[61] One was April, the only lesbian in my sample. She was also the only woman open to other religious practices. She said practice Buddhism, while incorporating principles of Christianity—the reason why I can say that all women in my sample identified as Christian. The other married woman who sought counseling was my very reluctant mother. She only went because my sister and I insisted she see someone, however, if I had known about the provider's identity beforehand I would have prevented her from going. I am a firm believer that therapist should at the very least be gender matched. The third lady who was open to psychological counseling was divorced and described herself as a spiritual leader that followed Iyanla, her spiritual mother.

> No, I didn't get that. I didn't experience that. Well, I guess—initially with my husband—because I needed him emotionally and he couldn't provide that for me, but then you know, just understanding after, you know, why that was.

Simone articulated the specific types of support her husband could provide; she perceived her husband’s level of emotional support as inadequate. Her husband was more of an informational person. However, she also indicated that at first, he may not have been that much of an informational or instrumental support. She said he was initially not engaged in her appointments. Moreover, as far as household chores, she told me that they shared duties like cooking prior to her cancer. I’m not sure he took over her half of the duties, however, when she was going through treatment. During her cancer treatments, friends and family provided meals when she was unable to cook.

I often felt I had to read between the lines when some women described the support they received from their husbands. Women seemed to be undertaking emotional work with me during our interviews as evidenced by their reluctance to discuss and need to excuse what they perceived as shortcomings in their husbands’ support. Remember that Jesse told me that she could adjust to the loss of both hair and breasts because of the support from her husband. In short, Jesse gave me mixed messages. First, when I asked her who was influential in her treatment decisions, she told me she asked her husband and he did not care as long as she was alive. However, seconds later, she told me that she could not even remember if (and when) she told her husband about her treatment between the time of her diagnosis and first treatment. Later, in the interview, a similar question arose about people influential in her treatment, and she told me she relied on her (female) oncologist and a couple of family members. She said this of her husband: “And my husband, he didn't go a lot, but you know, I discussed it with him. *But not really*.”

I would like to unpack Jesse's story a little more as it relates to her social statuses. Jesse had a master's degree and her husband had a bachelor's degree. Jesse's education was higher than her husband, a pattern which tended to map onto women who said they made decisions about mastectomies and lumpectomies independently. While Jesse initially said she consulted with her husband, the rest of her interview contradicted that statement. She did not "really" discuss treatments with him, and he rarely came to appointments. Instead, Jesse talked about her sister's role in going to appointments and discussions about treatment. When Jesse's sister could not be there, Jesse's brother stepped in and provided transportation and support.[62]

Jesse was not the only woman who first spoke favorably of their husbands, yet later in the interview revealed less praiseworthy behavior. Take, for example, Esther, who spoke favorably about her husband's participation before she confessed some failings on his part:

> He came some [to appointments]. He came some, but I told him, the one time I really needed him to come he wasn't – not there. And he's a – he's been just a blessing. He was there to help me a lot. But you know how sometimes it's just like, one something you feel that you need, and – I don't know. He's said, well, I think you can go – go on your own. And I got silly sick at the stomach because they had me on some sort of medicine prior to the surgery, and I got off schedule taking it and I didn't think I was going to make it to the hospital that day. But he came some, not every time.

She never discussed this issue with him. She explained why: "But you know, after a while, you can see that these things are heavy on the heart of the people that you're the closest to, and it can become a strain on them. Caregivers, they really go through and do a lot. My son was – it was

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[62] It's probably important to note that Jesse had a young sister die of breast cancer when Jesse was in college. (Jesse is also the mother of another participant.)

not the easiest information for him to have to hear, being in high school, but like I told him, this is – this is where we're at right now, but this is not necessarily the end of the journey." Wives often offered rationalizations when I asked them about the emotional support they received from their husbands. Women were also more likely to do this with their sons than with their daughters (which I will discuss shortly).

Similar to Esther, Brielle—who praised her husband for his instrumental support, and relied on his advice in decision-making—talked about the burdens of caregiving and the toll a breast cancer diagnosis can take on the husband:

> He was supportive. He was, *but* -- He was supportive. It's just a lot of things is that for them, like he gives support to me, but like I talked about earlier, there was no support for him, you know, for him to go and speak to anyone about what he was going through, because you know, we're both going through a lot of things.

I am not sure what Brielle was going to say when she said "but" after telling me her husband was supportive. Throughout our interview, she talked about how hard her cancer diagnosis was on her husband and how she was saddened by his distress. She told me that she was more worried about his adjustment than her own. While she did not specifically name his shortcomings, her concern with his feelings demonstrates the emotional work (or management) women are often engaged in while they face treatment from cancer. She offered rationalizations as to why her husband could not be fully engaged.

Changes in romantic relationship dynamics. What women perceived as husbands' inability to provide emotional support often led to negative interactions, as sometimes this lack of support contributed to higher levels of stress, relationship conflict, and perhaps even morbidity (although I cannot directly measure that). Based on their accounts, some women's husbands/partners really did not react well to their wives' transformed bodies. These sorts of reactions may well have contributed to women's depression symptoms, given the meaning of breasts for a feminine identity. I also began to wonder if some of these women lost a little bit of respect for their husbands, due to their behavior. I asked Cassandra about her husband's reaction after she experienced an infection, which complicated her reconstruction process.

> This is something I've learned [from my support group]. Most men cannot handle breast cancer. They can handle you having any other cancer. […] but he never once saw me without – and I wasn't trying to hide it – without my bra – you know, without something on, a t-shirt or something, and he never asked to. When I'd get dressed, he'd go out the room." One time she got stuck on the couple's waterbed. "And so at that time I had a – I had a robe on, and I know he saw my breast because he – his mouth was just open. He said, where's your thing, where's your thing? I said, I don't wear that around the house, it's too big anyway, and it – you know, a prosthesis [is cumbersome]. And then I was always afraid it was going to show, so I never wore it. I guess he tried – he tried not to look or anything like that. I took him years – I mean, years to realize, you know.

She also told me that months after her diagnosis, she found out his family was unaware she had cancer. "It's nothing to hide," she told him. Her description of his reactions almost evoke the stigma and shame so commonly attached to this disease prior to the breast cancer advocacy movement beginning in the 1970s.

Marie, who had a supportive husband, believed that this stigma may still be a problem within some black communities. She had this to say to husbands less supportive than her own:

> I want it to be a message for spouses who – husbands whose wives are dealing with it and they see – no one got married expecting to have breast cancer, no one did anything, but it's happened, so how much that wife needs your support, how much they need the – a family. I had my husband – I could be okay and not have no self-esteem because he was okay.

According to Marie, no one chose to get breast cancer, therefore partners must be supportive of their distressed wives.

Lack of support within this context can lead to regret and to conflict and strain in one's relationship in the future. After all, Cassandra believed:

> I would have [handled] my husband – the husband situation a thousand times differently. You know, I would have made – because one girl told me – she said, I made my husband look, I made him touch it. You know, I'm still me, I'm in here. And 17 years ago – yeah, we were only married **30** years then, yeah, 31 years or something. There should have been more communication. […] But the last 16, 17 years he's been in church and doing – and he's a great father and grandfather, and he's a great husband. […] But you know, I told him, you know, too little too late. Sometimes I'll tell him that, but I really don't mean it. I said, I should stop being mean to him, because I've forgiven him. But forgive and forget are two different things."

Cassandra wanted to remind her husband that she is still the same person, presumably that her husband married 30 years prior to her diagnosis. She had to adjust to her transformed body, and it sounds like she wanted him to adjust to it, too. Neither member of the relationship had a say in her developing breast cancer. In our interview, she jokingly talked about how she addressed the subject with him. "Too little, too late," she said. Note that she also felt that confronting her husband about his lack of support (and aversion to her body) and harping on it for 16 years was *mean* on her part.

Like Cassandra, Yolanda was apprehensive about expressing her concerns about his support with her husband. However, unlike Cassandra, Yolanda (only 3 years out from diagnosis) still had not reconciled the issue with her husband. Recall that Yolanda had to care for her husband when he fell ill after her breast cancer treatments. When I asked her if she had talked about the issue with her husband, she had this to say:

> No, because I'm waiting for the timing to be exactly right. He still – his health is still up and down a little. Although I'm going back to work next month, he's still – I'm still concerned about him, so expecting another serious health situation for him keeps me, I guess, more concerned about him than being concerned about myself and my feelings. [She adds] But I think because of my spiritual life and conviction, first of all, I don't hold any malice against him.

Yolanda's interview was filled with accounts of how she and her husband reinforced and reproduced gender traditionalism within their relationship, especially in terms of emotional regulation. Moreover, in terms of health benefits, research shows that marriage is beneficial to men because wives are concerned with husbands' health, care for them when they are sick, and make them go to doctors. This sort of marriage benefit does not exist for (heterosexual) women's health (Bird and Rieker 2008; Clark 2011; Simon 2002). Notice that Yolanda said that her concern for a future, possible illness for her husband trumps her present feelings. This possible illness was the reason she avoided conflict. Even though her feelings were hurt, she remained passive about the situation and did not display emotions of anger and frustration towards her husband.

Explaining variations in emotional support. I searched for variations among women's partners to help explain patterns in emotional support. I found none. Highly educated men (with advanced degrees) and men with little education (high school at the most) were equally likely to be sensitive towards their partners. Occupational status did not matter either (I did not ask about income). Age—or generation—did not seem to matter either. For instance, Simone and her husband were in their 30s when she was diagnosed. He also had a STEM master's degree. Sue's husband had a PhD, and they were both in their 60s when she was treated. On the other hand, Monica’s partner did not have a high school diploma and he was probably in his 50s for both of her diagnoses and treatments. Marie’s husband did not complete high school and her stories demonstrate that he was one of the most supportive husbands in my sample.

Nor was the level of support determined by a husband’s past experience with cancer. Recall that Simone’s husband could not be there for her because of the memories of his mother. By contrast, Bethanie’s husband (whose mother also passed from breast cancer) was determined to offer every type of support possible because of his loss. My inability to find patterns in variations within these men is a little perplexing. I can say however, that the controlling hypermasculine men tended not to be husband that provided a lot of emotional support.

Gretchen offered an interesting explanation about black women and self-care that may explain not only these women's underutilization of mental health services, but also their acceptance of insufficient support from husbands. She says, “We suppress [self-care] or we put it off, and is that a part of the self-care that we were never taught, you know? We weren't taught to lay in bubble baths, you know (laughs) and have people pamper us or our husbands lay flowers at our feet all the time, you know? We were taught to be the strong Black women.” Ironically, black women stepped in to major supportive roles when other black women were diagnosed with cancer—a phenomenon I discuss in the next section.

“If It Wasn’t For Sisters, Moms, And Daughters, We’d All Be Dead”: The Crucial Role of Women Relatives and Friends

Spousal support was clearly important for women's survival. However, I began to wonder whether key women in my participants' lives played more salient roles in experiences than many husbands. For instance, 21 out of the married women (and nearly all the unmarried women) mentioned a woman when I asked the question "Who—out of all these people—did you depend on the most?" Some women included their husbands in the answer alongside the named woman and some did not. Most often these supportive women were sisters and daughters. Mothers were mentioned frequently, but some women in my sample had deceased mothers and some women were caregivers of their elderly mothers.[63] Close women friends frequently stepped into dominant caregiving roles as well. While I'll begin this section talking about married women's experience, I will also branch out to include unmarried women in this discussion as well.

Girlfriends: down for me whenever, wherever. Women who lauded their husbands' support, like Bethanie and Keisha, also recognized the role of close women. Keisha said: "I would say my husband was there, my son was 16 years old at the time, he was there, I had another son deployed, my dad, my best friend Joanie, my friend Deidre, my cousin Leona. My mother, she was there, but not like she could have been, but then, she was sickly, too. But anyway, the primary was my – my husband and my son and my dad and my friend, Joanie. *She supported me forever, wherever*." Bethanie too named an important best girlfriend along with her husband.

Female friends often stepped into instrumental roles in households where women had husbands and children. Take Simone, for instance. She said: "[My friend] organized my meals

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[63] And often, these ailing mothers still came to the aid of their diagnosed daughters. They often could not physically perform some of the tasks for their daughters.

for my family. She was there for me during chemotherapy." Simone also talked about the important role of other family and kin even though they did not live in the area. Girlfriends also provided lots of emotional support. For instance both Monique and Catherine said they relied on close friends for encouragement.

Single women tended to rely on larger circles of female friends. For instance, Essence told me that most of her family did not live in the same state as she did. When her family could not make it, she told me about the role of her girlfriends. "And then I have best friends, sorority sisters – yeah, so I had a very good support system. Very good support system." Essence also told me that she lost her job after being diagnosed while simultaneously finishing her master's degree. She talked about the role of friends again:

> I reached out to them, and without a shadow of a doubt, they came straight for it. Kim, what needs to be paid? What is your bank account number? What is your address? I mean, so I had people just pouring into my life.
>
> Me: Were they mostly friends or family?
>
> Essence: Friends. It was friends, you know, some family. So, you know, I had – I didn't want for anything.

Kerrie was also single at the time of her treatment and also talked about being surrounded by support from women: "One of my girlfriends – I didn't really depend on her, I think she kind of like, forced herself – so I said, well, let me – not that I took – well, I did take advantage of it, but I would say of all – my sister – probably my sister that's two years younger than me, and then my girlfriend – one of my girlfriends, Belinda, and my sister Tina. Yeah." Kerrie's close girlfriends also participated in parties Kerrie threw for herself to mark milestones.

Sisterly love. Kerrie also mentioned the role of another woman, her sister. Sisters were often involved in treatments whether women were married or not. The birth order did not matter either, as younger and older sisters came to the aid of my participants. When there was a family history of breast cancer, sisters were especially involved. Take Jesse for instance, whose older sister died of breast cancer thirty years ago, and her mother also had a breast cancer diagnosis as well. Remember how Jesse gave mixed messages about her husband's involvement. Her younger sister was the one that stepped in to provide the most help:

> My sister always went with me, and she would tell me [my husband] didn't have to go, because she was going to be with me. (laughs) My sister is real assertive. Yeah, I'm the older – I'm older, but she's – everybody thinks she's older, because she's very assertive. She's a takeover person. Yeah. I let her. I don't question her. Whatever she says, goes.

Jesse's sister not only provided support, but she also was assertive in the decision-making process about Jesse's treatments.

Sisters were also confidantes. Lenore, whose mother died 3 months before she was diagnosed the first time in 2012, told me this about her older sister:

> But Joy (crying) I don't know what I'd do without her. She calls me every day. She just calls every day and we just talk about stuff that sisters would talk about. She doesn't miss a day calling me. She came up here when I was doing chemo. She pretty much like, she's like my sister but she's my sister and like filling in what my mother would probably do.

Lenore's sister Joy stepped into the motherly role as both had lost their mother only a few months prior to Lenore's diagnosis.

Terrin had 2 supportive sisters. She said: "I have a sister in Miami and one in Mississippi. The one from Mississippi came here and shaved her head. Her hair was (laughs) down her back[64]. She shaved her head, and my sister in Miami shaved her head, and it's nothing [for them to grow it long again] the hair is right back. It's down her back. It's like—It just grew back, so—(laughs) Yeah. It was a blessing for them even to do that. I did not expect that at all, (laughs) but they did. Both of them shaved it so yeah." Terrin's sisters showed their love for their (younger) sister by shaving their heads as well. She told me later that even though they were not in town, being able to call her (Mississippi) sister and mother all the time for their support helped Terrin through her treatments.

My daughter, my cheerleader. Daughters were heavily relied upon by women in my sample as well, especially if the women's husbands were (in the woman's view) unsupportive. For instance, after I asked Sue whom she depended on the most, she replied: "My daughter was my caretaker. But other than that, if I wanted somebody – I basically went by myself. If I wanted somebody to go with me, I would get my daughter to travel with me." She firmly told me several times that her daughter was her caretaker. "So she did all the washing up, if any, measuring the liquid – I mean, in the [surgical] drain.[65] I mean, she took care of me. She was my caretaker." I must note that Sue was apprehensive—if not reluctant–-to interview with me. She made it seem as if her participation was obligatory and when we started the interview her answers were short and direct. She informed me that she tried not to remember her diagnosis and didn't know how helpful she would be during the interview. But, as our conversation continued, I realized some of her abrasiveness was a defensive mechanism or way of coping with

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[64] Remember the discussion of long hair and prestige from Chapter 2. Terrin's sisters had long hair, which she insinuated made their support mean even more. She also told me that her hair was not that long an d only shoulder-length. Of course, some research says in the black community, long hair is shoulder length. However, when you are used to being around women with longer hair, this standard changes. I do not consider shoulder-length to be long either, largely because of my experiences with my mother and her family's hair.

[65] After mastectomies, lumpectomies, and often reconstruction, a tube and a holder (the drain) is left at the site so that fluid

the trauma and grief associated with breast cancer. I suspect that the inattentiveness of her husband was hurtful, because she so firmly repeated how much she relied on her daughter. When I turned off the recorders, she continued to talk even though the interview was over. She talked about how she supported her husband for years as he pursued a doctorate, yet she was still apprehensive about showing her husband her body because she feared his reaction.

Cassandra said her oldest daughter was the person she depended on the most. She also told me that her youngest daughter—the one that found her without bandages which led to an infection (see chapter 1)—frequently traveled back and forth from out of state to help with her mother. She also told me: "I guess I should put my son, too, because he took me to every single chemo thing. He even carried me out of the last one. The last one, you know, you don't want to go to. You really don't. I mean, because you know how bad you feel – you want to get to the end, but then you say, gee, this is it, you know, how am I going to feel? I know how I'm going to feel – I mean, and you feel it the fastest the more you get in your system." She did not add her husband to the list (for obvious reasons).

There was also a pattern among women who said their husbands provided them with transportation, but were fairly inactive in the process, to rely heavily on women, especially daughters. Daughters frequently accompanied mothers to appointments whether husbands were present or not. Daughters were important, so much so that when I asked Farrah to talk more about her husband's support she replied: "Oh gosh. Just making sure that I had my meds. My daughter, I'll talk to you about her." Needless to say, we then transitioned to the discussion of her daughter, a woman Farrah praised because of her help both instrumentally and emotionally:

> My daughter took care of all of my appointments. She put them in her phone. She would be at the doctor's office and I didn't have to worry about when I needed to

> go to the doctor because she would tell me. She would say, you know, you have an appointment tomorrow. Or you have two this week. So she took care of all of my appointments. She did. So I didn't have to think about them and where I was going and what time I was supposed to go. So that was a big help to me. Anything that the doctors told me I had or they named something, the doctor and my oncologist would say and explain it, she would look it up and do the research on it. And then she would explain it to me. I just didn't feel like I wanted to do the research, so she was the researcher. […] And she was my biggest cheerleader. And I know, I'm sure she went away a lot of times when she saw me and going through the treatments and cried at night. But she encouraged me so tremendously.

Farrah’s daughter scheduled her mother’s appointments around her work schedule. Because she was an entrepreneur she had the flexibility to do so. If not, sometimes mother’s scheduled treatments around their daughter’s work schedules as well. For instance, even though I had a fairly flexible work schedule, my mother often set her appointments on days were I could be free to accompany her to chemo.

The roles of women like daughters, sisters, friends and mothers during my participants’ cancer treatment experiences demonstrate the ideology of the strong black woman and the explanation of how black women are trained that Gretchen offers. Within this strong black woman ideology lies the notion that strong black women take care of and confide in each other (Mullings 2005, Collins 2001). Apparently this happens whether women are married or not.

Children and gender differences. That is not to say that men (other than husbands) did not provide support to women during their cancer treatments. Sons were the most likely male relatives to help women, especially when there was no spouse or an unsupportive one. Most often, sons would provide transportation (e.g. Cassandra and Florence) and they would visit—occasionally—and call (e.g. LaToya). Yet, sons were nowhere near as likely to offer instrumental and emotional support as did daughters, nor were they expected to do so. I noticed that women framed the participation and personality characteristics quite differently when describing son and daughter involvement.

Many times sons were lauded for minimal participation, and daughters were held to (and critiqued by) very high standards. I will use LaToya to demonstrate this example because she had sons and daughters. In this next quote she is referencing her local daughter and her son who lives in state. When I asked about her children's participation, she said this:

> She said, mama, you always been a strong, healthy woman. Seeing you sick like that, it was almost unbearable, and she was like, I couldn't stand it. I couldn't – I can't – I need you, you know? I said, baby, let me tell you something, don't you never love somebody so much you can't let them go, because when it's their time, it's their time. I know you love me, show me love while I'm breathing, give me love while I'm living, you know what I'm saying? But she – she apologized and said she's sorry that she wasn't there like she wanted to be, but she just couldn't bear seeing me sick. So I was trying to prepare her, well, this going to happen, where the doctor said I'm going to lose my hair, the doctor said I'm going to have pain. But, you know, one day she came over and I had a little episode, and she fell all to pieces and she ran out the room. My husband was like, no, you got to be strong for her. […] But my son, that was – he's the strong one. He would check, mama, how you doing today, mama, what you – you know, I prayed for you. Like I said, he stayed in Wallace, North Carolina. He couldn't really get to me like he could all the time, because he had a lot of things going on, plus his car was down for a while. But he could always get on that phone and pray for mama.

Latoya's daughter who often visited and sometimes provided care apologized for not being there for her mother. Latoya also described her daughter as emotional and unable to handle things in another part of the interview. The interaction she described above happened when her daughter saw her bald head for the first time. Her son, LaToya described as "strong," yet he rarely visited and mostly showed his support through phone calls. This may indicate a double standard as her strong son was rarely in the presence of his sick mother.

Similarly, Jorie used an adjective to describe her daughter that demonstrates the different expectations of sons and daughters. She had three adult children (in their late 40s and 50s).

> But she's kind of squeamish, so she would go with me to appointments a lot of times. She and my husband, but she would do the most asking questions, a lot of times. And she came over a lot, and she talked to me every day, and you know – but like I said, she's kind of squeamish. Some days when I was not having such a good day, she wouldn't come around. She would just talk to me on the phone. And my sons, my oldest son, his family came when I had the surgery the first time, the mastectomy. And my younger son would call me up and I think he popped in a couple of times when I was going through the chemo or when I was going through the treatment.

Her daughter was *squeamish*, yet was engaged in appointments and per Jorie “came over a lot.” Her sons however, rarely visited. Notice the difference when she talked about how on really bad days her daughter wouldn’t come around, but “just” call her on the phone. Accordingly, calling was what her youngest son did mostly. She did not use adjectives to describe her sons or their support.

Some women held their daughters to such high standards that implied an expectation that their daughters were supposed to be the main caregivers. Take Gina for example, she said this about her two daughters’ involvement:

> I have two daughters. And my oldest daughter, she brought me to chemo once or twice. She washed the chicken for me once. That was pretty much the extent of what she did. My mother who is going to be 89, she and my grandson, they came and cleaned the house for us. My father was living with us at the time too. So my

> husband, he took care of me and my father. My grandson was staying with us at that time and he helped out also, you know, watching my father, running errands. So actually, except for my mother, husband, and my grandson, my church, the church really became my support. And my youngest daughter, she had just had a baby a couple of months before, so I let her off the hook. She had a baby that September. I mean August. And I was diagnosed in October. So I gave her a pass as far as the visiting and coming to, you know, help do stuff, because I know her hands were pretty much full.

Notice that Gina did not really acknowledge her daughter's help as supportive. By contrast, when son's visited once or twice they were framed as supportive. Gina also indicated later that she may be estranged from the youngest (if not both) of the daughters. She said her youngest has always maintained "physical distance" from the family since she's been an adult. Also, it's worth noting that Gina began this description by saying: "He [my husband] became my caregiver. As a matter of fact, he helped more than anybody in my family." Was that not expected? Or did she expect her daughters to give her the most support?

Mothers were also more likely to say that they kept some details of their illness from their sons. Perhaps not explaining details to sons could account for why sons were framed as strong (e.g. LaToya, who did not disclose many details to her son). How does one react to something he has not seen or does not fully understand? For instance, Deanna (who adopted her grandson and referred to him as her child) described her college son's involvement: "He's a male, and he's pretty much concerned. He and I text and talk fairly regularly. I guess I have more interaction with him than I do [my daughter, his mother], but I haven't told him the full story about everything. He just knows yeah, mom, you're sick, and you're going to the doctors, and blah, blah, but I didn't want to distract him." Not telling her son the full story is something that mothers were more likely to do when they had young children (like <10 years old) or if they had adult sons. She did share the full story with her (absent) daughter, and was displeased by the lack of involvement from her child.

Siblings. The patterns for describing sons' vs daughters' support appeared as women discussed siblings as well. Thomasina (divorced, with grown sons that minimally participated in her treatment), for instance, talked about gender dynamics among her many siblings—the dynamics that generally led to men offering less assistance. She said, "The boys - You know how that can be. (laughs) Men, they talk to each other, but they don't talk to us too much." She said that she received support from some of her sisters and her mother (Thomasina was one of fourteen children), yet she did not really fault her brothers for their lack of involvement.

Consistent with literature on caregiving, male relatives, similar to husbands, were less likely to offer emotional and tangible aid than women relatives (Horwitz 1993; Williams and Dilworth-Anderson 2002). However, when both sisters and brothers did not offer support, women were more likely to condemn sisters for their lack of participation. Take Keisha who said none of her siblings were involved. When I later asked if there were people less supportive than she expected, she said:

> I think my siblings – I felt like my sisters could have done more. I would have, for them. I had. But now that I think about it, in retrospect, my one sister – they just – I don't know if people sometimes just go on about their life. They're affected, but they still just do whatever they're doing.

Her brothers must have also kept doing "whatever they're doing," because they did not visit or provide support either.

Similarly, Esther expressed grievances with her sisters. When I posed the same question to her she said:

> I felt like my sisters could have done so much more, could have, you know, called

> maybe, just once a month or every two weeks, just wanted to check on you, just to see how you're feeling, blah, blah, blah – you know, no kind of outreach like that at all. But nevertheless, if you can depend on no one, just make sure you're connected with the Father, because he's going to be right there for you.

Esther's lack of support from her sisters really bothered her, as evidenced by her appeal to God as being someone dependable if no one else steps up (although her husband and son were supportive). Esther had 3 sisters…and 7 brothers! How did she describe their interactions with her during her treatments? She said: "And I didn't discuss really any of this with my brothers. So I haven't talked [about my breast cancer experience with them] not until years later, you know?" I wondered if she asked "you know?" because she expected me to understand why she did not involve her brothers (just as Thomasina did). Her feelings also imply that she let her brothers off the hook for not being supportive, but condemned her sisters. That is not to say that all brothers were uninvolved. For instance, Drita's brother was involved with her treatments as much as her parents.

Maybe the difference in standards between expectations for men and women relatives in my participant's lives can be attributed to notions like Cassandra's theory about what men can handle (see above). Cassandra even compared her brothers to her husband in the following quote.

> [M]y brothers – you know, they're like, you know, women stuff – they would call, but they wouldn't – they were more or less like my husband, you know? They didn't want to know. All they wanted to do was you to say I'm feeling fine, you know, I'm okay, and that's what I learned to say. Now, [my sister] would always want complete details.

Her mother was deceased and she said this about her father:

> He had to see me. He would be calling all the time. And so that summer [I went up to Philadelphia] We used to drive to Philadelphia like, three or four times a year

> when my mother was alive. After my mother died, you know, I told you I married my father, so (laughs) – I called him, but I wouldn't call him every day like I used to call my mother. But I knew this – he was really, really scared for me. So I had to go over there. And I wore the wig, and he said, you cut your hair all off – he's one of those hair [men] – it was – because my mother had beautiful hair. None of us had hair like hers, down to her shoulders, and she cut hers about a year or two before she died (laughs), when she finally got some sense, you know, about men. But I had to go there, physically go there, to let him see that I was okay. And the fact that I was skinnier didn't bother him. So he just, you know – chemo and that kind of stuff, it didn't phase him.

Cassandra demonstrated that she put in emotional work to interact with her father just like she did with her husband during her treatment. First, she made an uncomfortable trip during her cancer treatments to settle her father's distress about her cancer. Then while she was visiting her father, she felt the need to cover up the side effects of cancer treatments with a wig. She knew her father desired long haired women. He still noticed her hair was cut. Her father accepted the fact that she was skinnier and was relieved to have seen her because she put on a performance of wellness for him.

Fathers often showed concern for their daughters. Recall how Monique's father was very instrumental in her care. Similarly, Essence told me this about her father:

> My dad – my dad actually lives in Texas, you know, caring for my grandmother, but he was – even though he wasn't here all the time, he was always on the telephone. So he was involved, you know, not – he was involved via telephone and – you know, but when he made his way here to visit, you know, he was here. He was actually here when I started treatment. I think he was here when I started radiation, or I was going through radiation and my daddy – no, my daddy came right before I started radiation. I had started the Tamoxifen, but he was right before I started radiation, my daddy was here.

Notice how Essence also transitioned to use a more affectionate term for her father as she remembered his involvement in her treatment.

Single women. Often brothers, uncles, fathers and other male relatives provided the financial assistance, and this was especially important for women who were single. For instance, Olivia, a single mother at the time of her diagnosis told me: “My brother is involved on a financial level, but he doesn't like hospitals. He'll come and quickly leave.” She went on to say:

> I have a lot of like, half sisters and brothers, but they didn't do anything. My brother is – is like, my sole [only full] sibling, just like – like, we have the same mother, we grew up together, you know, – so he's like – he's like, there. But he's there in a different aspect. He's not very good at – when you're going through some stuff, he's kind of like, if you need me financially, I got your back, and that's how he is.

Olivia’s only full brother[66] was not there emotionally, but would provide whatever she needed financially.

Unmarried women in my sample were more likely to struggle financially than women who were married. A handful of my participants were terminated from jobs (or placed on unpaid leave) when they were diagnosed with cancer. When women were married, like Bethanie, their husbands’ income could keep them afloat. (Bethanie's husband also helped seek out legal counseling about her termination during her treatment.) However, when a woman did not have a partner, there was usually no additional income entering the home. When women were caregivers either to ailing family members or to children, financial situations were even more precarious.

Caregiving and family strains: reciprocity within social relationships. At the time of our interview, Gretchen had been both divorced and widowed. She was unmarried at the time of

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[66] Per my participants, half siblings tended to be less involved in women’s treatments.

her treatment and was a caregiver to her elderly mother. She also had somewhat dependent adult children. Sometimes, this added responsibility of caregiving during cancer treatments was especially taxing for women (see above). Gretchen worked in a contracting job at the time of her treatment. She qualified for and purchased an insurance plan through the Affordable Care Act. Right after her last radiation treatment, government officials notified Gretchen of a (small) accounting error, and for this reason they rescinded her coverage. At the time of our interview, Gretchen was unable to pay for her the rest of her chemotherapy treatment, including her prescription of Tamoxifen.[67]. She told me that she was currently rationing her insulin (she also had diabetes), as she would no longer be able to purchase that until she could file her taxes again for the next year. Her inability to satisfy her own medical needs (via paying for treatment) was compounded by her commitment and responsibility to care for her ailing mother who was in her 80s.

Some women in my sample talked about strains that arose from financially supporting adult children or grandchildren. For instance, when Deanna (67, single, working class) and I spoke, she had just had a lumpectomy and was going back for a consultation about another possible surgery. She told me this about one of her children:

> I have a daughter that's 39 and she lives here, and she has six kids, but she's only raising two, and then I have her oldest son, I adopted him when he was a baby, so he's in college now. He's 23. Finally got him up, and in fact he's graduating the end of this month, so we're looking to celebrate that. […] And then he has a little boy, so I'm a great-grand. He's a great-grand, my first, and I'll be picking him up the end of this month and keep him for a couple weeks, so I've got to get my energy up, (laughs) because it's going to be [a lot of work].

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[67] Used in the treatment and prevention of estrogen receptive breast cancers.

Deanna’s (“only blood child”) son passed away a few years prior to her diagnosis. She left her adopted son in the dark about the severity of her illness, and just told him she was sick and going to see doctors. Her daughter who lived in the same city was largely absent from Deanna’s life. When Deanna asked her daughter for help, she ignored the request despite repeatedly taking assistance from her mother over the years. Her family responsibilities created strains and she had little support from others during her treatments. After our interview, she planned to prepare herself to watch a young toddler for several weeks.

Similarly, Shonda talked about negative interactions with one of her older sons: “[My husband] was a double amputee and I couldn't do any lifting on the right side (after the mastectomy). At first, I had a care giver to come to help me at first. He did pretty good. And then my son and my daughter-in-law, they moved in, but they was no help at all. They were just like a hinder to me. Because I felt like I was taking care of them instead of taking care of myself and my husband. But they were like living downstairs. It was terrible.” She also told me that she ended up giving this son one of her houses to appease him.

If single women could, they relied on family members when they had financial and other struggles. For instance, Thomasina was a twice divorced, single mother at the time of her diagnosis 19 years ago. Thomasina was terminated from her job during her treatment. She had COBRA in order to maintain insurance coverage.

> Thomasina: And it cost me a fortune, and my income was very small at the time, had a lot of medical bills and I went to doctors and hospitals, advocacy groups, and they did take care of a lot of my medical until I got back to work and got the insurance again. (pause)
> Me: And then did you have to take out loans or anything?
> Thomasina: No, I was on the short term disability and during that time the company, you know how they terminate you and then I was left without insurance, so I had

> to get some type of insurance, and that's when I got the COBRA with the little SSI. That's all of my income, so family helped a lot.

Women relatives and friends were also very important to single women during their cancer treatment processes. Thomasina lauded her two best friends for their support during treatment. They accompanied her to appointments, brought food, stayed with her when she was sick, and were always available to talk. She also told me that two of her sisters would come stay when she needed them. She had two adult sons at the time, but did not mention their role much.

I did notice one trend by class: middle class women tended to have more supportive relatives, who were both women and men. Their relatives were more likely to call, provide emotional support, and offer assistance with daily routines and care after treatments.

Conclusion

In this chapter, I explored how social support influences the experiences of black women following a breast cancer diagnoses. I included a strong focus on support from spouses, given the small body of literature that considers marital contexts for black women. I began with exploring instrumental support from spouses. The most common way that men were involved in their wives' treatment was by providing means of transportation. Men often transported women to doctor's appointments and chemotherapy sessions. Many men accompanied women into appointments, especially when patients were provided with a lot of information and choices for treatment (namely mastectomy and lumpectomy choices). However, there was variation in how involved or active husbands were in these treatment spaces. Job structure mattered.

Instrumental support from spouses was also salient when women were incapacitated or weakened by treatments, chemotherapy in particular. When women had young children when diagnosed, this type of support was even more important. However, not all young women with children received sufficient instrumental support from their spouses. Women were likely to turn to family members to make up for deficiencies in social support from spouses. Men's job structure seemed to matter for variations in social support that young women reported receiving from spouses. When husbands did not have managerial positions, instrumental support was low. Education did not matter in this relationship, but instead, these types of positions tend to come with more autonomy over work schedules.

As for older women and instrumental support, there were fewer clear distinctions among men who gave too little instrumental support. Husband’s health status mattered for women, but in very different ways. Caregiving by my participants for other close family members also contributed to variations in the amount of help women received in performing daily routines.

Emotional support was important to women, especially as they adjusted to the transformed bodies that resulted from plastic surgery. This was the most common and a prevalent form of emotional support that women discussed. However, women frequently reported insufficient help in other aspects of emotional support from spouses. While most women did experience emotional support in terms of body change, a few women reported negative interactions in which their bodies were scrutinized by their partners. These particular interactions changed relationship dynamics, whether women addressed the underlying issues with their husbands or not.

Women relatives and friends played very important roles in the cancer treatment process for the women I interviewed. These women were salient in their lives irrelevant of the marital status of the woman with cancer. Sisters and daughters especially picked up the slack when women lacked certain types of instrumental support during their treatments. These women accompanied participants to appointments, were engaged in appointments, gave advice, and provided daily care to sisters and mothers while being treated. Some women reported that their sons transported them to appointments, but in general, sons were far less knowledgeable about treatments than women supporters like daughters. Moreover, my participants were less likely to disclose details of their illnesses to male relatives than they were to female relatives. Some women said they shared more information with female friends, mothers, daughters, and sisters than they did with their husbands. Thus, women tended to report they received higher levels of emotional and tangible support from women than men. My participants were also more likely to confide in women than men.

Single women also heavily relied on other women. Single women with financial difficulties tended to turn to family members (both male and female) during their time of treatment. Often, these family members were male. Female friends were important for women who were not geographically or emotionally close with family members.

I designed this chapter to primarily focus on the interactions between spouses, because little research exists that examines marital contexts for black women. However, as I sorted through the data, I could not ignore the interdependence and heavily reliance between women while my participants underwent treatment. Support from women was important regardless of women's martial or class status. The majority of these female supporters were black. These findings support research that demonstrates the existence of strong solidarity or sense of community between black women. This research tends to focus on the distribution of resources primarily among long income single mothers (Collins 2001; Barnes 2009;+). My findings extend this research by showing that interdependence exists outside of low SES contexts and even when women are married.

This chapter also reiterates the importance of family within the black community. Family members frequently provided emotional and tangible forms of support to women going through cancer treatments. Women could rely on family whether they were married or not, and only a handful of women said family members were unsupportive.

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CHAPTER VII

CONCLUSIONS

While race has been recognized and accepted as a largely socially constructed phenomenon, its consequences are real and persistent. De jure forms of racism became obsolete with certain social movements of the mid-20th century, yet racial inequalities still structure social institutions (Acker 1990, 2006; Martin 2004). In the case of breast cancer, these ideologies shape the knowledge that physicians and scientists have about the nature of these type of diseases.

In my dissertation, I have shown how the disease(s) of breast cancer is treated much as a gendered phenomenon. In America, breast cancer is a woman's disease. However, this gendered component—while it may be annoying to some and symptomatic of the importance of socially constructed gender—is not necessarily a bad thing in terms of mortality and survivorship. In the midst of the PRC, which focuses on aesthetic coping, breast cancer survivorship has increasingly improved. This survivorship takes on a stair-stepped pattern, based on stage. For white women, the survival rate for Stage I is 100%; and for Stage IV, white women have a little over 1 in 4 chances of surviving. The latter a stark improvement to the less than 10% survival rate during Halstead's time. Currently, for black women, Stage I survival is about 96%, and Stage IV survivorship is a little over 10%. Additionally, at every other stage, black women's survival is lower than white women. Moreover, some research shows that for white women survivorship is improving at a growing rate, which also means that disparity gaps in survivorship are widening just as quickly as black women do not reaped the same benefit from gains.

The National Dialogue on Cancer (NDC) is a federal prevention foundation established in 1999. The aims of the organization are to eliminate cancer as a major public health concern and threat. The third tenet of their mission reads as follows: "[There is a] moral obligation to reach all people, with special attention to those at greater risk, and in particular, ethnic minorities and the medically underserved who disproportionately carry the greatest burden of cancer" (Williams 2010, 336). This organization also calls cancer an illness that plagues affluent civilizations, in which current knowledge gaps lead to millions of lives being lost needlessly (Williams). Race facilitates the needless loss of life from several illnesses, including breast cancer. American culture's fixation with breast cancer makes it a gendered illness, in which most women have enjoyed improvements in survivorship over the last several decades. On the other hand, racism makes this disease incurable; a disease from which black women unnecessarily perish because of an unwillingness to acknowledge the systematic and persistent ways race continues to structure American institutions.

Perms and pesticides. Women's explanations of their causes of cancer point to important implications for interventions and further health research especially in the area of race and its institutional effects. Some women discussed how repeated chemical exposures, such as perms and cosmetic products, may have made their bodies susceptible for invasive tumors. More research on the effects of hair care products—part of the cosmetic industry that is totally unregulated by the FDA—is needed if society continues to encourage women to use these beautification techniques. For instance, what are the long-term systemic effects of harsh chemicals in perms and relaxers? So far the few studies on hair chemicals and cancer present mixed findings and are outdated. One study that began in the 1970s found that dyes and perms (to make the hair curly or wavy) do have harmful carcinogens. Moreover, hairdressers who worked around these chemicals had high levels of carcinogens in their bloodstreams. In this study, the sample was predominantly, if not an all, white (Doyle 2014). Given that black women spend more effort on hair care (and the chemicals to straighten are likely harsher) this type of research is well overdue.

Women also had concerns about larger environmental forces that predispose their bodies to cancer. Their concerns align with my goals for future research which addresses environmental toxins/injustice, migratory patterns and breast cancer incidence in black women in America. Given the history of black Americans in this country, an evaluation of long term environmental consequences is relevant. For instance, for centuries, most blacks were relegated to the same Southern areas of the country. Recall Mary Jill's story about pesticides was most egregious as she described the pesticides that the pilot would "intentionally" dump on their heads. This type of environmental justice likely describes the experience of a large proportion of blacks especially in the days of the early 20th century. But the implications of these sort of injustices could extend beyond the Southern United States due to the migration to the North and West by many Southern blacks over the 20th century. These environmental toxins can have generational systemic effects. Environmental toxins can cause genetic changes and mutations that may spawn cancer growths (Levine and Veneroso 2010). Did the atrocities of slavery and the century that followed—in which blacks were lawfully oppressed, segregated into dirty areas, and likely to be sharecroppers—trigger mutations that predispose generations of black women to different types of breast cancers?

Levine and Veneroso (2010) discuss how continuous environmental injustice towards blacks underlies both the differences in mortality and the nature of diseases that affect black women. Often cancers that affect black women are less likely to hormone responsive (progesterone or estrogen) and more likely to mutate at faster rates (Levine and Veneroso 2010; Ikpatt and Olopade 2010). These scholars along with other scholars, argue that current studies that consider race and breast cancer are inefficient because they do not take into account that black women tend to present more aggressive tumors often in premenopausal stages of life. Moreover, black women's cancers often have biological characteristics (i.e. genetic/chromosomal mutations) that are unclassified and understudied in biomedical and cancer research. This argument reflects systematic effects of racism that inform medical and scientific knowledge.

Intersectionality and Age

The dynamics and characteristics of my sample of black women speak to the need for intersectional scholarship along several dimensions when studying illnesses like breast cancer. Nuanced sampling and methodological approaches would strengthen the body of knowledge that describes disease characteristics that affect black women. Race and age is one intersection that needs further exploration. As Levine and Veneroso (2010) discuss, this relationship between race and age may mask the true nature of disparities that exists between black and white women with breast cancer diagnoses. Particularly, should health scholars approach cancer research similar to how Geronimus and her colleagues (2006, 2010) did when examining variations among women? In a series of studies, these scholars analyzed group differences between black and white women using biological markers such as allostatic load and telomere length. This research indicates that black women biologically age faster than white women due to processes and the effects of external stress. These findings help to explain the patterns in health in which black women develop chronic conditions at earlier stages than white women. Biological aging differences may underlie variations in breast cancer diagnosis for black and white women.

Additionally, exploring African diaspora patterns and trends may also be useful mechanisms for understanding breast cancer in black women. According to Ikpatt and Olopade (2010), breast cancer is fairly rare disease in Western African nations—the region where most black Americans can trace their African ancestry. However, when breast cancer does strike in these nations it affects younger women and present as very aggressive diseases. These characteristics of disease also exist in black American women. In the next two sections I review the age patterns I found in my sample.

After completing the descriptive tables and figures for my sample, I came to realize that my sample's treatment history may be more generalizable than I initially thought. In other words, the nature of severity of disease and the young ages of my participants may be representative of the breast cancer disease burden American black women face. In medical literature on breast cancer, the age range for young diagnosis is 30-49. When I discussed women in my sample, I used a more conservative cut-off and considered young to be 45 and below based on my sample's distribution of ages at diagnoses. If I apply the traditional cutoff, 59% of my sample meet were diagnosed young, as they received their first diagnosis before the age of 50. This is an alarmingly high proportion. Could it be that young women are more likely to seek out support groups? Based on my own experiences with the Sisters Network, I would say no as most active participants were older. Could the high proportion of young diagnosis reflect disease patterns of black (and African) women who are stricken with the disease?

Cancer characteristics of young diagnosed women. Four women who had young diagnoses identified their cancer as triple negative (the most aggressive and least understood type of cancer). These cancers are the hardest to treat, more likely to be unresponsive to treatments, progress faster, and have higher rates of reoccurrence within the first 5 years. Nine women in this group did not know their cancer type, which may be problematic, especially if have cancers that do not respond to hormones. With that said, less than a handful of these women likely could not recall their type because this type of biological testing was unavailable (e.g. Florence and Beatrice). The rest of these 29 women said that their cancer were responsive to hormones (either Estrogen and/or Progesterone or HER2+). These women also tended to present diseases that were Stage II or above.

Cancer characteristics of older diagnosed women. My participants who were diagnosed at later ages had a greater incidence of triple negative cancers than younger women. Six of these twenty individuals identified their cancers as triple negative. Of this group, another six women were unsure of the breast cancer type. The others identified their cancers as hormone receptive. This older group of women had more stage I and 0 (DCIS) diagnoses than did the younger women, which may be a symptom of the routine mammograms older women practice. However, if this group also has higher incidence of triple negative cancers is low stage as significant a predictor of survivorship? After all, my mother presented with the lowest stage, triple negative cancer, yet her cancer metastasized and she died about four and half years later. New empirical research supports the need for a new staging process when dealing with hormone negative, aggressive cancers. Again, these cancers are far more likely to affect minority women than white women (Levine and Veneroso 2010; Parkin 2010; Williams 2010).

More on treatments. The slight majority of my sample had mastectomies—a characteristic that is not typical of national patterns for treatment. This figure is even more irregular given that the majority of my sample is middle class. The time range for treatment in my sample was wide, however with the exception of Florence, women were treated after the 1970s, a decade that coincided with rise of lumpectomy and radiation treatments. Since 2000, the numbers of mastectomies performed has been on a downward trend. For, middle class diagnosed women, mastectomies make up about 20% of treatments. For the poorest of women, that figure is about 30% (Sweeting et al 2016). Both of these national figures are much lower than what I found in my sample. I have no reason to believe that my sampling techniques made me more likely to pick women with aggressive cancers. Most national studies do not disaggregate data by race, which may mask that black women are more likely to have mastectomies, because their diseases tend to be more aggressive.

Additionally, the overwhelming majority of my sample had adjuvant chemotherapy, another indicator of the severity of disease that existed within my sample. For thirty-nine women, chemotherapy was a part of their treatment. For future research, I will consider how many women had chemo before surgery, another indication of the aggressive nature of cancers that affected my women.

Intersectionality and Feminine Bodies

My analytical chapters concentrated on the social contexts surrounding body transformations and treatments associated with breast cancer. My findings support the need to use intersectional approaches to understand health and social contexts that affect black women. Moreover, in the case of breast loss and reconstruction, the findings from my intracategorical (intersectional) analysis of black women have broad implications that could apply to all American women who experience this illness. In America, women experiencing the disease of breast cancer are exposed to PRC norms that encourage aesthetic ways of coping. Often women are exposed to these norms within physician’s office. I did not find literature that specifically addressed interactions that women had with plastic surgeons and oncologist about breast consultations for reconstruction. Thus, my findings from Chapter 1 on breasts loss and reconstruction may have broad implications for how all American women experience breast cancer as an illness.

Selling breast reconstruction: PRC norms and breast reconstruction. My research indicates that early contact with plastic surgeons may overwhelm some women. Women were faced with decisions about fixing their bodies before having (life-saving) breast surgeries that would lead to future disfigurement. Making these decisions about life-saving treatments was sometimes overwhelming for my participants, thus maybe there should be less of a push for immediate reconstruction. Some felt rushed in these decisions, and few women came to regret the choices they made. Perhaps reconstruction should be delayed a year or two after women have had the time to adjust to the transformation and distress that results from breast surgeries. That is not to say that some women are not immediately ready for reconstruction. For instance, some women in my sample knew what type of reconstruction they wanted immediately after they received the diagnosis. Women who are ready for immediately reconstruction should be allowed to do so; but the uncomfortable, pushy salesman experiences that some women described should not characterize the plastic surgeon consultations.

Women expected to meet unattainable expectations after reconstruction. These expectations were sometimes reinforced by reactions women got to their bodies after surgery. When women entered physicians' offices, they sometime found that their bodies subjected to scrutiny/critique, which is something predecessors experienced in their cancer experiences. For instance, when Audre Lorde wrote about her cancer experience in the 1980s, she talked about a follow-up visit to her physician's office following her mastectomy. She showed up at her appointment without her prosthesis, a visibly one breasted woman. A nurse chastised her for showing up at her appointment this way. The nurse was concerned that Lorde's one-breasted chest would bring down the morale of the office, yet she showed no concern for whether this loss affected Lorde. Lorde did not have reconstruction. Yet for some women in my sample, they still faced criticism/evaluation about optimal body proportions even after having reconstruction. Often, women were encouraged to use prosthesis or pursue additional procedures by physicians and other individuals they met within their cancer centers.

Fortunately, in romantic relationships, women rarely reported feeling scrutinized by their partners. When women did experience negative reactions to their bodies from partners in particular, these interactions were stressful. Recall how Monica never thought she would as feminine as she once was before cancer. Outsiders weren't the only people to assess women's bodies, and sometimes the first critic was the woman herself, hence the name of this dissertation.

The classed experience of breast surgeries and reconstruction. Comparative analyses focusing on both middle class black women and men show the nonequivalence of class based on race and ethnic variations. Thus, another contribution of my work lies in the variation among black women in my sample by class. In the context of breast cancer, lower SES profiles of diagnosed black women do account for significant variation in mortality, yet controlling for SES does not explain away the mortality gap in breast cancer when black women are compared to white women. Black women of different classes had different experiences with treatments for breast cancer. One stark difference between lower status and middle class participants occurred around surgeries. Low status women were far more likely to get infections. In my sample, no middle class woman reported an infection at the site of the mastectomy or reconstruction. The reported infections may result from a number of factors ranging from poor medical treatment and risky personal health behaviors.

There were also patterns in treatments that were affected by race for women of all classes. For instance, across class category, some of my participants complained that physicians did not adequately consider the threat of keloids forming at surgical sites. These keloids were most often unsightly, but also sometime painful requiring further surgeries to remove them.

I also observed potential differences by insurance coverage. Breast cancer is universally covered; however, for the publicly insured, treatment can be different and subpar. Andelle's case of infection is the most troubling if related to differences in services available by insurance type. Ideally, physicians should practice best care regardless of the type of insurance formulary that covers each patient. However, I am not an idealist, and think a more tangible solution would be to encourage lower class women to take more agency within appointments. These women should be educated about the option of the second opinion. Like middle class women, they too have the right to seek second opinions. For instance, Andelle was suspicious of her (alcoholic) plastic surgeon, but she felt she had no choice and decided to continue her treatment with this particular surgeon. She also did not pursue any legal or civil case against the physician or practice after it was discovered that her surgeon was sent to rehab.

The findings from my class analysis demonstrate that not all black women have the same experiences with illness. Within this group of women, differences in class explain variations in patient-physician interactions, health behaviors, morbidity following surgical procedures, and access to breast reconstruction. In my hair chapter, findings also support the salience of class/status in breast cancer experiences. These findings also somewhat challenge traditional connotations of class which describes an individual's access to resources. Hair texture, while not directly associated with class differences in my sample, was associated with prestige—a physical characteristic that affords advantages to women in terms of community standing. Hair texture was also a way for women to categorize among and differentiate themselves from other black women.

Racialized beauty: *good* hair is not a harmless term. In Chapter 2, I committed to writing a story about femininity and hair from a less explored perspective: that of black women facing breast cancer. I wanted to iterate that black women face dilemmas about hair similar to those faced by white women, as hair possesses power in relationships (especially romantic ones). Yet black women's experiences are nuanced because of how expectations for hair fit within dominant racial ideologies. All the while, these women face the impending threat of death for which the loss of hair serves as a precursory, damning omen. I was unprepared for how important notions of racialized beauty would be to women's perception of hair regrowth. The theme of good hair from chemotherapy was an unexpected topic in my interviews, but a topic that has many troubling social implications.

I am not condemning the use of certain straightening techniques,[68] as I believe black women have the right to modify and accessorize their hair. However, that some women find their natural hair to be unacceptable without the influence of a powerful chemical is problematic. Hair texture is biological, race is not; yet racial standards are upheld to judge the fitness—or better yet, the femininity—of one's hair. The good hair rhetoric that women discussed is symptomatic of underlying Eurocentric notions of beauty. Moreover, black women's decisions to go natural were heavily influenced by the perception of a new, finer hair texture. Even months or years later, women still practiced these hairstyles due to what they perceived as more

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[68] I must be honest, I personally do not support perming and relaxing. These chemicals are harsh and there is no research on the side effects of these chemicals. Colloquially, over the years, it strips many black women's hair, especially around the edges of the scalp. If these chemicals can stop hair growth, then what else are they systemically doing to the body?

easily manageable hair that resulted from chemo. However, how long do the effects of chemo linger?

Additionally, my research indicates that hair work is part of gender socialization processes that begins early for black girls, albeit differently than their white counterparts.[69] Many women indicated that they had been using straightening techniques and chemicals since childhood. Some women revealed a disconnection between the memories of their natural hair textures and what they perceived as good hair after chemo. Do women really know their true hair texture if they have been using straightening techniques since childhood?

Researchers should pay greater attention to hair texture to understand variations in ways that are similar to how Verna Keith explores variations in experiences by skin color. Hair texture is a phenotypic characteristic that is salient in defining racial categories and prestige within minority communities, yet it gets little attention within research, especially health literature.

Black Women and the Activation of Social Support

Cancer can be a fatal disease and a cancer diagnosis brings about a lot of uncertainty and isolation. Thus, women needed both instrumental and emotional support to deal with the stress of having cancer. Most women in my sample had high levels of support from their close relationships with others. Because of the high married percentage of my sample, most women I interviewed could turn to husbands for support. Variation existed, however, for the most part, spousal support was salient. With that said, other family members played important roles for

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[69] I commend Mattel's recent efforts to diversify the hair types of Barbie in recent years. There's now a cute Barbie with a fro in their numbered collection that celebrates diversity in body types, phenotypes, and facial features. But still, this does not feel like enough as white notions of beauty are still pervasive in little girls' experiences.

women across marital and class status. Additionally, my research on the activation of family support reveals important and interesting patterns related to gender in social interactions. On average, women were more likely to receive both instrumental and emotional support from women family members. In general, men offered less support and if they did, this type of support was more likely to be tangible (or instrumental).

One source of support that was commonly missing as women recounted their stories was support from professional psychological counselors or psychiatrists. Women were highly skeptical and distrustful of this type of service. Frankly, it’s understandable given the insensitive treatment my mother (a skeptic) received when she visited her first psychologist. Also, there seems to be some tension between women’s spirituality and the idea of psychological counseling. To combat these phenomena requires education of both women and practitioners. First, outreach programs should stress the importance of psychological counseling for overall wellbeing. For instance, Kroenke and colleagues (2013 a, b) find a positive association after cancer diagnosis between psychological and physical wellbeing. Some studies show that women who seek psychological counseling also have better 5 year survival rates. Given that both research and my demographic population support the links between spirituality and health, could integrating the two be an effective way of increasing utilization rates among black women?

My work also shows a need to increase counseling among black men. Black men have some of the lowest rates for using psychological counseling services. Yet, they are a group that experience high levels of trauma and face racist obstacles to achieving the American standard of manhood and masculinity (e.g. breadwinning). These hardships can be reflected in relationships between spouses and with other family members, and may explain the lack of emotional support many women complained about.

Black women and the family. Family dynamics for black women are important for understanding the salience of this institution for coping support. Also these dynamics can elucidate mechanisms of stress exposures for this particular group of women. However, my findings about social support in particular extend past the contexts of disease and health determinants. My research provides insight into how black families function. Based on my observations, black families are often matriarchal in structure when it comes to household responsibilities and the heavily reliance on mothers by children both young and adult. Moreover, black women in my sample provided a lot of emotional support for individuals around them, even when loved ones were reacting to their own sicknesses. Black women, especially mothers, were often the thread that held families together. When black women are for some reason incapacitated to fully fulfill their roles, then many in the family unit were often strained or distressed (e.g. recall how LaToya and Jorie talked about the effects of their illnesses on children and husbands).

The prominence of the black women in the family was a common thread across variations like social class and marital status. With that said, although some married women in practice had family structures that were matriarchal, they often did not articulate this level of power and authority in their interviews. For instance, many married women deferred—or better yet, gave credit for deferring—to their husbands for decision-making that affected the family. Interestingly, as was the case for Jesse and Yolanda, for example, even though they said they sought their husbands' advice or guidance, core informational and support systems were made up of women, namely sisters, mothers, daughters, and close friends. Additionally, some women relied on extended family like cousins and aunts. This heavy reliance on women may also point to other gender dynamics that happen in this sample of black families. Many women felt the need to shield men from negative emotions, indicating that black men may hold a protected status in the black family. In other words, black women often do a lot of emotion work to protect black men from distress, whether these men are husbands, sons, fathers, or brothers.

APPENDIX I:

DESCRIPTIONS OF PARTICIPANTS

I describe the women I met based on my interactions with them at the time of their interview. I conducted interviews 2014-2016.

Ramona is a 45 year old, 15 year breast cancer survivor. She found a lump in her right breast during a self-exam and decided to consult her OB-GYN. Ramona reports that prior to her diagnosis she had had a benign (painful) tumor removed from the same breasts when she was in her teens. She has a Master's degree, which she was working on at the time of her diagnosis. She is currently married and a mother to two children. She now works in the engineering profession. She and her family are middle class. At the time of diagnosis, she was dating her current husband and completing her education. She relied heavily on her parents, new boyfriend, and family members during her experience of breast cancer.
When Ramona was 17 years old, she noticed a painful lump in one of her breast. Her parents took her to a physician and a surgeon removed the benign mass. After physicians taught her how to do breast exams, and encouraged her to incorporate this practice into her normal routine. Over 10 years later, she found a lump during one of her self-exams and reported the lump to her OBGYN. This (female) physician referred her to a breast center where they did ultrasounds. However, after Ramona returned to her OBGYN to report the results from the breast center were said to be benign, her OBGYN was not satisfied and told her to get a second opinion. During this "second opinion" appointment, the doctor decided to do a biopsy. The results of this biopsy determined that the mass was breast cancer. Ramona was 29.

Thomasina is a 64 year old, 19 year breast cancer survivor. Her cancer was discovered from a routine mammogram. She also reports that she had ovarian cancer two years prior to her breast cancer diagnosis. She lives alone in a home she is leasing to own. She has three adult children and six grandchildren. At the time of her diagnosis, she was a single mom. She relied on help from family and did have some financial hardship during her breast cancer treatment. She worked for an insurance company for which she was terminated while on leave for treatment. Currently, she works in a support position for public schools. She has some college experience, and her husbands finished high school. I would consider her of working class status.
Thomasina was diagnosed with ovarian cancer twelve years prior to her breast cancer diagnosis. Because of that illness, Thomasina "faithfully" went to the doctor, and got routine pap smears and mammograms. Her cancer was found on one of those routine mammograms.

Andelle is a 53 year old, 8 year breast cancer. Her cancer was found resulting from a routine mammogram. She has 3 children and 1 grandchild, who are all adults. She lives in an apartment, seemingly alone but perhaps lived in by one of her children. She has qualified for disability for several years and does not work. She talked about several comorbid conditions during her interview. She is of lower socioeconomic status. She experienced both pain, infection and a botched reconstructive surgery (see chapter 1 for details). Andelle's cancer was found during a routine mammogram. It was then biopsied where it was formally determined to be a cancerous mass.

Keisha is a 52 year old, 9 year breast cancer survivor. She has two adult sons and at least 2 grandchildren. Her first child was born while her husband, ex-military, was stationed overseas. She has a bachelor's degree and her husband has a degree from a 4-year university as well. Keisha gave a rather obscure answer, and would not say whether she owned a home. She described herself as having a house and an apartment when I asked her that question. I suspect she may rent. Keisha is lower middle class. She works as a patient scheduler and her husband works at a tire company. Keisha's cancer was found during a routine mammogram. Four years after that diagnosis she was diagnosed with colon cancer.

Ester is a 54 year old, 7 year breast cancer survivor. She has been married for 30 years and has one (young adult) son. She reported having symptoms and impairment from other chronic conditions aside from cancer. She didn't specifically say that she had financial hardships, but in her interview she mentioned not pursuing reconstruction because she couldn't afford it. Either she didn't know whether it was covered or other costs posed hardships. Her husband has a high school degree and owns a lawn care company. She is an administrative assistant. Esther is working class and owns a home she describes to be in a regular working class neighborhood. Esther's cancer was found during a routine mammogram. The radiology technician spotted a concerning mass and then diagnostic testing was done.

Olivia is a 49 year old, 8 year breast cancer survivor. She has one adolescent and one adult daughter. She is a single mother whose only marriage ended in her early 20s. She completed some college and works as a receptionist at a medical office. She described having some financial difficulties, but her family stepped in to help. Olivia is working class, and owns a home in a neighborhood which she described as having some violence. Olivia said one day she was bending over, "scolding" her pre-school age daughter, when she felt a pull in her breast. She touched the spot and felt a lump. She then scheduled a mammogram, and after diagnostic testing, it was determined that she had cancer. She did not remember the stage, but she did remember that her cancer was triple negative.

Shaunte is a 38 year old, 5 year breast cancer survivor. She has no children and has never been married. She was a supervisor at a phone company at the time of our interview, and during her diagnosis, she was an assistant manager in retail. She has some college education. She currently rents an apartment with her mother. Her mother is also a breast cancer survivor. At the time of diagnosis, they lived in a house that was seized in foreclosure soon after they moved in. Shaunte is working class. Right before her 33rd birthday, Shaunte was planning a trip with her friends and happened to put her hand on her chest. She felt a lump, figured it would go away, and went on the weekend getaway. When she returned home, the lump was still there so she made an appointment with her doctor. Physicians performed diagnostic testing, and Shaunte was diagnosed with a Stage II cancer.

Monica is a 57 year old who was diagnosed with breast cancer twice. The first diagnosis was 8 years prior and the second diagnosis was one year prior to our interview. The first time, her breast cancer was discovered after she was having pain in one of her breast and made an appointment with a doctor. Her reoccurrence was discovered on a mammogram. Monica has been on disability for many years and was not employed. She had public health insurance and had difficulty getting services covered during her reoccurrence in the years prior. She had been cohabitating with her partner for 17 years. She said he was far more supportive the second time around than he was the first. However, Monica's story stuck out to/struck me as she had a unique experience in terms of support from her partner. She had significant hardship paying bills and maintaining routines and had to take out payday loans for routine expenses, such as for feminine needs. Her partner increased his nights out and began looking at other women after her mastectomy. Monica wept a lot during her interview. Monica has two children and one grandchild.

Florence is a 65 year old survivor of over 30 years. She experienced the earliest treatment in my sample, during a time where treatment options were far more limited than currently available. She knew of a bump in her breast, and she was prompted by a physician—aware of her family history of cancer—to seek further attention. She underwent a radical mastectomy—losing much chest and shoulder muscle mass—which is unique to compared to other women in the sample. At the time she was married and raising 4 young children. She was a housewife that did real estate part time 2 afternoons a week. At the time of interview, she had recently divorced her husband of over 40 years. She comes from a family of performers. Florence's interview was a bit less structured than others and her answers were free-flowing and unprompted. She has 4 adult children. She reports having both grandchildren and great-grandchildren, although we did not discuss the number of "grands." During a routine checkup, her doctor suggested that she get a mammogram because Florence has a family history of breast cancer. Her cancer was first detected during that mammogram, and afterwards she had follow-up diagnostic testing.

Jesse is 66 year old, 13 year survivor. She has been married for over 40 years and is currently a retiree from social work. She and her husband are both into health and fitness, as he—now in retirement from civil service—is now a personal trainer. She has her master's degree and was born into a middle class family. Jesse is middle class. A week after Christmas, Jesse felt a lump in her breast and made an appointment with her doctor. A mammogram was performed, followed by diagnostic testing. Since Jesse had fibroids, she asked that her mastectomy and hysterectomy be done the same day.

Eden is 60 year old 9 year survivor. She is working class and has some college experience. Since her diagnosis she has worked in various service position for retail industries. She currently rents an apartment, but at the time of diagnosis and treatment, she lived with her parents. She has never been married and has 2 adult children (and grandchildren). Eden was lying in bed when she felt a knot in her breast. She called her doctor and made an appointment the next day. The doctor felt the knot as well and referred her to get a CT scan. A month later, it was confirmed that Eden had cancer.

Beatrice is a 63 year old divorcee who was married at the time of her diagnosis 21 years ago. She has 2 adult children. She is retired now and works part-time at her church, but before, that she worked as an engineer for a telecommunications industry. She is middle class. Beatrice found a lump in her breast just a couple of months after she had her routine mammogram. She made an appointment with her doctor, who referred her to specialists for further testing.

Cassandra is 69 year old 16 year survivor. She has three children and some grandchildren. She and her husband have been married over 40 years (although they did divorce for a short period of time in the 1980s). She worked in a support staff position for metro schools during her time of diagnosis and has since retired. She is married to a civil service officer. She describes her insurance status as being ok—she had a supplemental cancer policy—however, she and her husband took out loans to make ends meet during her treatment. Cassandra and her husband are working class. Her cancer was found after a routine mammogram.

Doreen is a 40 year old, 4 year survivor. She is divorced—and was at the time of her treatment—and has a young child (or 2 check this). Her mother is Jesse. Doreen tells me she has had breast issues since high school, when she first had fibrocystic lumps removed. She and her mother discovered that they carry one of the BRCA gene mutations. Doreen is middle class, has her master’s degree, and works as a health practitioner. Doreen had benign tumors in her breasts since the age of 17. Her cancer was discovered after a routine mammogram.

LaToya is a 53 year old 7 year survivor with 2 children. She is currently married to her second husband and was at the time of her treatment as well. She lives in public housing, and was unemployed at the time of her treatment. She is still unemployed but working on her craft business. She tells me that she applied for public assistance resources aside from Medicaid, and that she and her husband still struggle to pay for bills they owe for her treatment. My interview with her was fairly free-flowing in nature. LaToya felt a large knot in one of her breast while getting dressed for bed. She called her doctor to make an appointment. They did diagnostic testing and diagnosed her with cancer. She found the lump “less than a year” from her last mammogram.

Irene is a 66 year old, 1 year survivor. She is divorced with 2 adult children. She has her GED and has earned other professional certificates. She has been disabled for the last 15 years and does not work. Irene struggled a lot during her treatment. She was unaware of resources that provided assistance, so she told me she was forced to borrow money from friends and family, and many times couldn’t eat after chemotherapy and other treatments. She was on public insurance at the time. She owns her home, but feels unsafe in her neighborhood. Irene’s cancer was found after a routine mammogram. A few year prior, she had colon cancer. She also had a number of other comorbid conditions.

Yolanda is a 59 year old, 3 year breast cancer survivor. She has some college credits and works as a customer service supervisor for a government service company. She is married to her second husband who is disabled and former military. They have 3 children and are lower middle class. Yolanda had not had a mammogram for about two or three years when she felt an “itch” in her breast. She consulted her doctor, who did not find anything in the physical exam, yet still referred Yolanda to specialists for further testing.

Bebe is a 51 year old, 7 year survivor. She has never been married, but at the time of her diagnosis was in a long-term relationship with a man who died tragically (and abruptly) about 3 years after her diagnosis. She has two bachelor’s degrees. At the time she worked as a project manager, and now she works as a specialist in child services. She is middle class. She owned her home during her treatment, but after losing her partner tragically, she decided to downsize and rent an apartment. Bebe found a lump while changing into a sports bra. She ignored it at first, because she thought she had pulled a muscle. When the lump did not go away, she scheduled an appointment with her doctor. The physician referred her to specialist for further testing.

Marie is a 57 year old, 9 year breast cancer survivor. She has her master’s degree and worked as a principal. She has since changed her occupation, but still is employed with public schools. She is married and the couple have 2 children. She is middle class. Marie found her cancer during a routine self-exam. She scheduled an appointment with a doctor and then was referred to a breast center.

Kerrie is a 48 year old survivor of 18 months. She has never been married and has no children. She has her master’s degree and works as an accountant. She is middle class. Kerrie had a mammogram months prior to a self-exam that she found a lump. She then contacted her doctor and more testing was done.

Bethanie is a 42 year old, 1 year survivor. She has her associate’s degree and is married to a prominent active community member. They are middle class and just moved into a new home down the street from where they lived when she was diagnosed (It was her home she bought before their marriage). She has 2 children. She worked as an administrative assistant for at a corporation/institution and experienced job insecurity because of her treatment and diagnosis. She sought legal counsel because of the treatment she experienced at her job. Bethanie’s cancer was detected during a routine mammogram.

Lenore, 61. My mother had a twin sister who was shipped away to Paris when she was an infant. There were just too many mouths for her parents to feed. This baby remained the family secret for years. Her name was Lenore (or maybe Lenora at some point in the story) and my mother was the only one who communicated with her. Grandmama even forgot her. Sometimes Lenore would come visit before bedtime and bid us goodnight in her strong Parisian accent. Now, my dear, you always get to be your fantastic, alter-ego: the super chic, vogue Lenore, who—looked and smelled like you, but—happened to live in Paris most days. Thanks for the story. I hope you are living it up!

Gretchen is a 53 year old survivor who was 16 months out from her diagnosis when we talked. She was widowed and divorced at the time of her treatment. She has her bachelor’s degree and worked in a contracted position for an insurance company at the time of her diagnosis. This company did not provided individual health care insurance, so she was covered under the ACA. However, she had her treatment rescinded during the middle of her treatment (because of tax errors), and struggled to continue to pay for radiation. She still experiences a lot of financial strain because she lost her insurance. She now works in for a community/grassroots organization and is a caregiver to her mother. She is of working class status, and experienced significant declines in her economic resources because of her cancer treatment. Gretchen's cancer was found after a routine mammogram.

Brielle is a 43 year old, 6 year survivor. She recently relocated to a new city for her husband's new managerial position in security. She has been married for over 20 years and has 2 children. At the time of her diagnosis, she worked as an administrative assistant but at the time of interview, was looking for a job in her new city. She has her associate's degree as well as a professional licensure. She is lower middle class. While on vacation, Brielle felt a lump under her arm. She thought it was nothing (just a cyst), but still decided to schedule an appointment. For precautionary reasons, her physician sent her to have a mammogram and ultrasound.

Simone is a 41 year old, 2 year survivor with 3 young children. She has her master's degree and works as a research associate. Her husband also has a master's degree in a mathematical discipline. She describes her continuing payments for her treatment as "residual income" for the hospital, as she feels this bills are never-ending. While she and her husband didn't necessarily struggle during the treatment, all was not covered by insurance and they are on long term payment plans with the treatment center. She is middle class. Simone was doing a self-exam, when she noticed a discharge from her nipple. She scheduled an appointment and was referred for further testing.

Angela is a 56 year old, 8 year survivor. She is twice divorced, but was married at the time of her diagnosis. She has moved from the large home she lived in with her husband, and now owns a smaller place on her own. She has a master's degree and other professional licensures, and has worked as a research associate for years. She has one child. She is middle class, but had more resources at the time of her diagnosis and treatment because of her marriage. Angela felt a lump while putting on lotion after a shower. She contacted her physician, especially since her younger sister had recently been diagnosed with breast cancer.

Catherine is a 53 year old, 13 year survivor. She is married to an entrepreneur. She has no biological children and one step child. She has her master's and works in the field of social work. She is middle class. Catherine is a very fair skinned black woman, which is of importance in our interview and in her responses. Catherine felt pain in one of her breast while laying on her side. She also said she felt an itch in her breast as well. She contacted her physician.

Naomi is 46 year old, 2 year survivor. She has her master's degree and works in a managerial position in Human Resources. She is married with 4 children. Naomi shopped around for her treatment, and settled on the Cancer Centers of America for her treatment. This location was hours away and posed some financial difficulties and relationship strains on the family. Naomi took her youngest children with her when she stayed for her treatments. She and her husband still struggle to pay bills and make ends meet 2 years after. Naomi's breast cancer was found during a routine mammogram.

Dominque is 61 year old, 16 year survivor. She completed her master's a year before her diagnosis and works as a health practitioner. She was also divorced less than a year prior to her diagnosis. She has one child, who was a teen at the time of her treatment. She is middle class. Dominique found a lump during her routine self-exams. She then contacted her physician and was referred for further testing.

Essence is a 44 year old, 4 year survivor. She has never been married and has no children. She has her master's degree. She works as a health practitioner now, but during her treatment was a manager for her a community enrichment. She got her job only weeks before being diagnosed, and her boss terminated her since she was on a probationary period at her job. Essence's cancer was detected during a routine mammogram.

April is a 64 year old, 1 ½ year survivor. April (whom I debated calling Apricot) was my favorite interview. She was a welcomed and refreshing break from the mundane (and depressing) at this point in the research, and we, literally, had fun. She is previously divorced and is now in a same-sex marriage. She has 3 biological children and one step. She has some college credit, and Associate's degree and she works as an administrator in Human Resources. Her partner has a doctorate. She is middle class. April had a routine mammogram, and got negative results. However, she felt something was not right and insisted on a follow-up with her PCP. He felt a small "pebble-sized" lump behind her nipple. She was sent for further diagnostic testing.

Monique is a 45 year old, 1 ½ year survivor. She is married with one child. She has a master's and works in a technological field as a developer. She didn't report financial strain, but they are still in the midst of making payments for her treatments. She is middle class. Monique performed a self-exam in the shower one day and noticed a lump. After monitoring it for three weeks, she decided to schedule an appointment with her physician. As a precautionary measure, her physician sent her for to get a mammogram.

Drita is a 56 year old, 17 year cancer survivor. She works in an upper level nursing position. Now she is divorced, but she tells me that she got married the same month she was diagnosed with breast cancer. She has no children. She recently completed her master's degree about a year ago, and loves her current position. She is an activist and leader within her community. She is middle to lower middle class. During an annual visit, Drita's gynecologist thought she felt something and told Drita she should have mammogram. Drita had just turned 40.

Terrin is a 35 year old, about 1 ½ year survivor. She had been married for 3 months at the time of her interview, but she and her husband had been cohabitating for several years. Sadly, the couple's young son died some months after her treatment. She has her master's degree and works as a supervisor for a social services foundation. Her husband works in banking, but was unemployed at the time of her diagnosis. They reside in a two bedroom apartment. She is working class, even though she is educated. Terrin was doing a self-breast exam and thought she felt something "funny." She called her gynecologist who referred her to a breast specialist. At this appointment, the breast specialist immediately did a biopsy.

Deanna is a 67 year old woman who was sort of in the midst of her treatment during our interview. She had been diagnosed 6 months prior. She told me that she may have to have an additional surgery in the future. She has been divorced for a few decades. Deanna has both an associate's and bachelor's degrees and professional licensures. She is the mother to three children-two adopted. Her (biological) son died several years prior. She is working class. Deanna's cancer was found during a routine mammogram.

Shelita is a 66 year old, 11 year breast cancer survivor. She has been married to her second husband for the last 29 years. She describes her education as having some college credits and that she got certificates in "key-punching." Her husband is a construction worker. They are working class. Shelita has 4 stepchildren and no birth children. Her step children were adults when she and her husband were married. She considers herself close to godchildren and nieces/nephews. She worked as an insurance underwriter at the time of her treatment and has since retired. Her cancer was discovered during a routine mammogram. She did mention that it was weird that three other women in her office were diagnosed with breast cancer around the same time, as if it was "contagious."

Sheree is a 56 year old, year and a half survivor. She has been divorced for several years. She has her master's degree and works in administration at civil/social service organization. She owns a large home in a "demographically changing" neighborhood and she is middle class. She had no children, but is very close to her godchildren. Sheree said about 4 years prior to her diagnosis, physicians found something on an ultrasound and had the area biopsied. It was benign and they recommended that Sheree come in for diagnostic mammograms over the next couple of years. In 2014, after being cleared and taken off the diagnostic mammogram, technicians found an area of concern on a routine mammogram. She then was formally diagnosed after a diagnostic MRI.

Mary Jill is a 66 year old, 11 year breast cancer survivor. She is married (not sure for how long), and I think she has 2 children. Mary Jill's interview was fairly free flowing, and she did not always follow my prompts. I am not sure what level of education she completed, but she did mention that she has certifications for clerical work. Mary Jill is low class/poor. Her husband has about the same level of education as well. I'm not sure how Mary Jill's cancer was discovered, but I suspect a mammogram. Intuitively, she thought she had breast cancer because of a family history and past environmental traumas (planes dumping pesticides). She also told me that she had seen a witch doctor in her home state, who prescribed a special tea because of her suspicions about cancer. She felt that the elements of the tea attacking the cancer could be seen on her diagnostic mammogram or MRI.

Cora is a 68 year old, 8 year cancer survivor. She has been married twice and has 1 child (adult daughter) and two grandchildren. She has her GED and "trade" certificates. Her current husband is a high school graduate who works part-time at a car company. At the time of our interview, Cora was retired, but during her diagnosis she worked as a senior processor for an insurance company. She owns a home that she has lived in for decades. She is working class. Her cancer was discovered during a routine mammogram.

Brandy is a 49 year old, and was diagnosed with cancer at the age of 40. She has three children with ten years between each sibling (2 boys and a daughter). She has been married to her high school sweetheart for 30 years. She has her associate's degree and is a secretary for metro schools. Her husband is in law enforcement. She and her husband own a small 3 bedroom, 1 bath home. Brady is working class. Brandy was folding clothes, and placing them on top of her large breasts, when she accidently grazed a spot and noticed a spot "right near the surface." She asked her husband to feel, and he noticed the spot too. She made an appointment with her gynecologist, who referred her to a breast center. They "aspirated"—or better yet, biopsied—the spot and Brandy was told that would contact her. She felt that the lump was gone. After 21 days, Brandy felt reassured that she had heard no news from the breast center. However, a co-worker told her that she should follow up, because Brandy told her she felt like the lump had come back. When she make contact, she found out that the diagnostic lab had faxed over results to her gynecologist and no one from that office had contacted her. Later, the physician assistant admitted to taking the records off the fax machine and putting it in Brandy's file without contacting Brandy (or telling her gynecologist). The results of that biopsy indicated that Brandy had cancer.

Miriam is a 71 year old, 16 year breast cancer survivor. She has two adult children and has been married to her husband, a professor, for over 40 years. Miriam has her master's degree and worked as a librarian at the time of her diagnosis. Both she and her husband were retired at the time of our interview. Miriam is upper middle class. Her cancer was found during a routine mammogram.

Sue is a 64 year old, who was diagnosed 4 years prior to our interview. She has two children (a son and a daughter), and she has been married two her husband (a pastor) for nearly 40 years. She has a granddaughter. Sue and her husband own a home which is located in what she calls the "hood, not the ghetto, but the hood." She has a master's degree, was an insurance contractor, and recently helped support her husband as he got his doctorate in ministry. Sue is working class. Sue told me that she was diagnosed at Stage 0, but did not want to be treated with "poisons." So she tried an alternative route for a year and decided to forgo conventional treatments. As a result her cancer grew, and she was diagnosed with Stage 2 cancer after her year of alternative therapy.

Pearl is a 47 year old, 9 year breast cancer survivor. She has two teen children, a son and daughter. Pearl had divorced since her treatment (about 4 years prior) and did not want to talk about her husband. Pearl is middle class. She worked as a business manager at the time of her treatment and when I interviewed her she was a recruiter and an insurance agent. About 14 years ago, Pearl was actually undergoing another surgical procedure, when she asked to her surgeon to check out a lump she discovered while at home. He took out the lump, found out it was benign, but recommended yearly mammograms. Then in 2007, shortly after he mother had been diagnosed with breast cancer, Pearl's routine screening revealed that she had cancer in her breast. She found out while returning home from her mother's surgery.

Vivien is a 50 year old, 11 year breast cancer survivor. She has a son and daughter. She is a physician who practices in a high paying, specialized field. Her husband is also a physician, with an MD and MPH. They met in medical school. Vivien is upper middle class. Years prior to her diagnosis, she had cysts in her breast so she had been undergoing routine mammograms. Her cancer was discovered during a routine mammogram, which led to a biopsy followed by a diagnosis.

Shonda is a 70 year old, 13 year breast cancer survivor. She has 3 adult sons, several grandchildren and two great grandchildren. She has been a widow for 10 years, but prior to that she was married to her husband for 38 years. Her husband was a double amputee so she was his caregiver when she was diagnosed. Her illness prevented her from being his sole caregiver, so her husband had to be moved to a nursing home. At the time of our interview she was retired, and before that she was a supervisor at a rehab center. She has a high school degree and said that she took a nursing (LPN) course. Her husband was a college graduate, and she told me she was always so proud of what he did (and thought he was really smart). She is lower middle class. She own two homes, one she "gave" to one of her sons. Her cancer was found during a routine mammogram.

Farrah is a 71 year old, 3 year survivor. She has a daughter, she had been married for over 40 years. Her daughter started a business venture several years ago, and Farrah and her husband help run the business. Farrah has a master's degree and both she and her husband are retired, aside from working with their daughter. Farrah is middle class. When Farrah was diagnosed, her insurance was being shifted because she became eligible for Medicare. She described her insurance prior as of good quality, yet she had to take the Medicare coverage. Medicare denied coverage of certain procedures, and she was forced to delay her treatment while fighting for coverage. As a result, her cancer moved up in stage.

Gina is a 68 year old, 7 year survivor. She has two daughters, at least one grandchild, and has been married for 20 years. She had been married two times previously. Since her diagnosis, Gina completed a bachelor's degree alongside her husband. At the time of her diagnosis, she worked for the postal office and ad her husband worked construction. Since then, both she and her husband have retired. Gina is lower middle class and she owns her home. Gina did not get her mammograms regularly, although she knew she was supposed to. Then in 2008, her mother insisted they both set appointments to have mammogram. After a second mammogram, and follow-up diagnostic testing, Gina was diagnosed with an advanced stage cancer.

Lena is a 59 year old, 6 year survivor. She has three adult daughters who are all married. She is married to her third husband. Her first marriage ended in divorce, and she was widowed in her second marriage. She is a high school graduate who went on to business school and earned a certificate in data entry. Her husband has an associate's degree. She and her husband rent a two bedroom apartment. She is working class. Years prior to her cancer, Lena had benign tumors removed from her breasts. Her breast cancer was detected from a routine mammogram. Lena described her breast cancer as starting at the age of 15. That is when she had her first benign tumor removed. I am unsure of what stage Lena's cancer was because she did not understand staging. She told me that in 2010 had breast cancer had "metastasized" and that she was diagnosed with Stage IV cancer. However, her cancer was only in one breast and the size of a quarter. I can definitively say that Lena did not have Stage IV (the incurable cancer that has spread to other organs) breast cancer.

Jorie is a 71 year old, 6 year survivor. She has 3 adult children (2 sons, 1 daughter) and grandchildren. Her husband is retired with a master's degree. She completed some college and worked as a tax analyst during her treatment. Since then she has retired. She and her husband live in a 4 bedroom home. Jorie is middle class. Jorie was on a mission trip in the Caribbean when she felt a lump in her left breast. When she returned, she made an appointment with her primary care provider, who also felt the lump and referred Jorie to a breast surgeon. The breast surgeon performed a biopsy and soon after, Jorie was diagnosed with a "fairly large" triple negative tumor.

APPENDIX II:

FIGURES AND TABLES

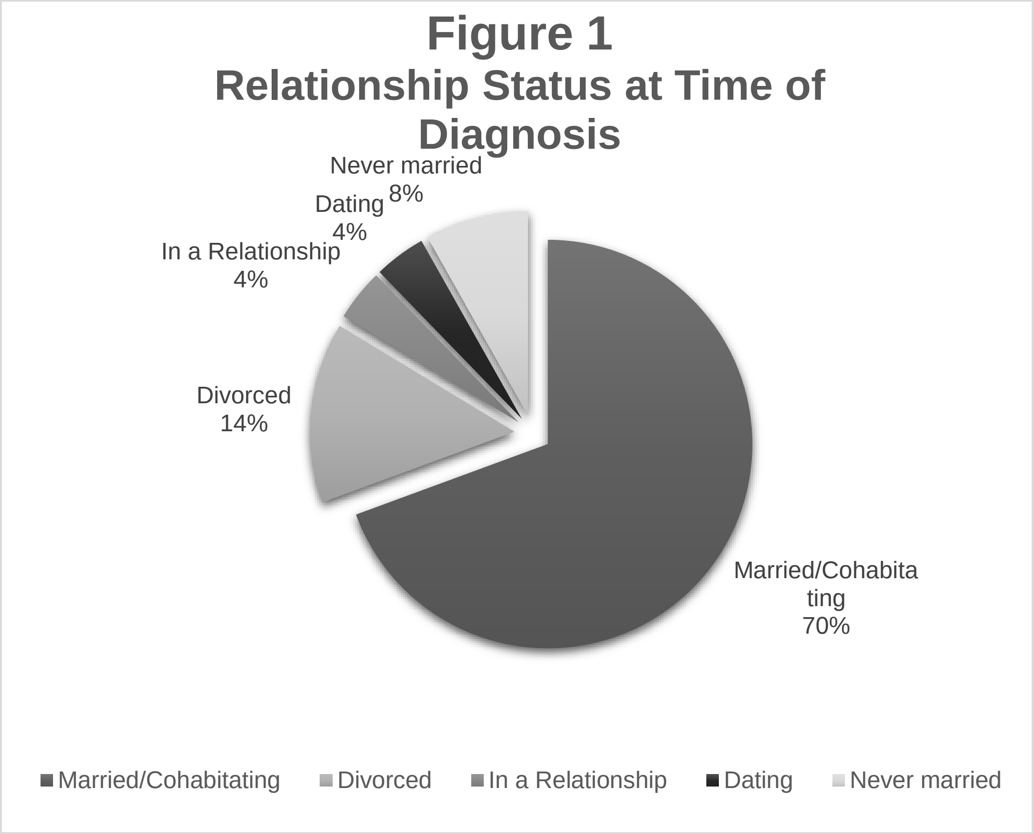

Figure 2. Age at the time of diagnosis (Dx)

				(Monica)
				April
				Cora
				Deanna
	Beatrice			Farrah
	Bebe			Gina
Brielle	Bethanie	Andelle		Irene
Doreen	Brandy	Angela		Jorie
Florence	Catherine	Dominique		Lenoire
Pearl	Drita	Esther	Cassandra	Mary Jill
Ramona	Essence	Kerrie	Eden	Miriam
Shaunte	Keisha	LaToya	Gretchen	Shelita
Simone	Monique	Marie	Jesse	Shonda
Terrin	Naomi	Monica	Lena	Sue
Vivian	Olivia	Thomasina	Sheree	Yolanda
Dx <40	**Dx 40-44**	**Dx 45-49**	**Dx 50-54**	**Dx 55+**

Age At time of Diagnosis (Dx)

TABLE 3: TREATMENT BASICS

	Lumpectomy	**Mastectomy**	**Reconstruction** Y/N(if mastectomy) f=flap; i=implant; l=lift; r=reduction	**Chemotherapy** (infusion count, does not include Tamoxifin) *=hair loss	**Radiation**
Dx >40 years old					
Brielle	L			C	R
Doreen		M	N	C	
Florence		M	Y^f		R
Pearl	L				R
Ramona		M	Y^f	C	
Shaunte		M	Y^i	C	
Simone		M	Y^i	C	R
Terrin	L			C	R
Vivian		M	Y^{fi}		
Dx 40-44					
Beatrice		M	Y^f	C	
Bebe	L			C	R
Bethanie	L			C	R
Brandy		M (double)	Y^i	C	R

Catherine		M	Y^f	C	R
Drita	L			C	R
Essence	L (2)	M	Y^f		R
Keisha		M	Y^f	C	
Monique	L			C	R
Naomi	L			C	R
Olivia		M	Y^f	C	

	Lumpectomy	**Mastectomy**	**Reconstruction Y/N(if mastectomy) f=flap; i=implant; l=lift; r=reduction**	**Chemotherapy (infusion count, does not include Tamoxifin)** ***=hair loss**	**Radiation**
Dx 45-49					
Andelle		M	Y (special case)	C	
Angela		M	Y^i	C	
Dominique	L			C	R
Esther	L				R
Kerrie	L			C	R
LaToya	L	M (double)	Y^f	C	R
Marie		M	Y^i	C	
Monica*	L				R
Thomasina		M	Y^f	C	
Dx 50-54					
Cassandra		M	Y^f	C	
Eden	L	M	Y^f		
Gretchen	L			C	R
Jesse		M	N	C	
Lena	L			C	R

Sheree	L				R
Dx 55+					
April		M	N	C	
Cora	L			C	R
Deanna	L (special case)				
Farrah	L			C	R
Gina	L			C	R
Irene	L				R
Jorie		M	Y^{fi}	C	R
Lenore		M	N	C	
(Lenore)				C	R
Mary Jill		M	N	C	?
Miriam					
(Monica)		M	N (special case)		
Shelita	L			C	R
Shonda		M	N	C	R
Sue		M	Y^{f}	C	R
Yolanda	L			C	R

TABLE 4: STAGE AND TYPE OF CANCER	STAGE	TYPE hormone positive=yes or triple negative
ANDELLE	2	unknown
ANGELA	DCIS (0)	yes
APRIL	2	triple negative
BEATRICE	2	unknown
BEBE	1 (almost 2)	unknown
BETHANIE	unknown	yes
BRANDY	2	triple negative
BRIELLE	3	yes
CASSANDRA	unknown	unknown
CATHERINE	3	yes
CORA	3	unknown
DEANNA	1 "0 to 1"	yes
DOMINQUE	2	unknown
DOREEN	2	yes
DRITA	2B	yes
EDEN	0	unknown
ESSENCE	0	yes
ESTHER	0-1	unknown
FARRAH	0→1	triple negative

FLORENCE	unknown	unknown
GINA	2B or 3	yes
GRETCHEN	unknown	yes
IRENE	1	yes
JESSE	2	triple negative
JORIE	unknown	triple negative
KEISHA	2	triple negative
KERRIE	1	triple negative
LATOYA	2	unknown
LENA	unknown	unknown
LENOIRE	1A; 4	triple negative
MARIE	2	yes
MARY JILL	unknown	unknown
MIRIAM	1	yes
MONICA	2; 1 or 2	yes
MONIQUE	1	unknown
NAOMI	2B	yes
OLIVIA	unknown	triple negative
PEARL	DCIS (0)	yes
RAMONA	2	unknown
SHAUNTE	2	yes
SHELITA	1	unknown

SHEREE	0	yes
SHONDA	3	yes
SIMONE	2	yes
SUE	0→2	yes
TERRIN	2A	yes
THOMASINA	2	yes
VIVIAN	DCIS (0)	yes
YOLANDA	2	triple negative

*some unknowns gave hints as to what type their cancer was. I (along with an oncologist) speculated what these women meant. However, I decided not to include hints or speculations in this table.

FIRST ROUND					
	Home Ownership	**Education (and/or spouse)**	**Occupation Type (and/or spouse)**	**Insurance Status and Type**	*participants needed to score yes on three of these to get considered for one of the middle SES class categories *home ownership was necessary to be considered middle class
Middle SES	Y (+description*)	college +	managerial professional entrepreneur clergy/community leader	Y through work, through spouse, private policy; good quality	
Lower SES	N Y (low SES neighborhood)	high school some college associates “certificates”	administrative/clerical manual labor unemployed disabled	N, dropped, public, denied; poor quality	

*Some of the working class owned homes. I did ask participants to describe their homes to assess the types of neighborhoods women’s homes were located. I also conducted interviews in some women’s homes and could assess their living situations myself. One middle class woman was renting, however she had just sold her house within the last year and was looking for another. She and her husband had advanced degrees, and their children attended an elite private school. Therefore, the mandatory home ownership stipulation for the middle class distinction did not apply to her context.

SECOND ROUND: Assessed financial difficulty

THIRD ROUND: Anecdotal patterns to further distinguish between women in terms of class (more relative to their purchasing power in society): poor, working, precarious middle, middle—add the need to distinguish between the two middle groups, especially the precarious lower middle. They have the credentialing and other things like homeownership but they do not have the same access to resources as what people typically think of as middle class. This category takes into account that research has found that blacks on average get marginalized returns from class proxies such as additional years of education. Reasons offered for this disparity between black and white education include differences in prestige and resources of HBCU and PWI, hiring biases that steer blacks in lower roles compared to whites of equal education education, and the trend for black Americans to pursue (advanced) degrees in community and service oriented fields (which pay less than other sectors). The PLM (or TLM) class represent a hodgepodge group. Some didn’t experience as high of returns on their education, some have low education but a long work history. This group was more likely to financially struggle, take out loans, or experience a loss in status during their treatment compared to the middle class group. For some women, the financial strain was already present because of mismatch between education and job status, financial need from other family members, dependency of adult children, caregiving responsibilities, partner unemployment or low wage, and anecdotal events that affected economic resources. Additionally, marital status sometimes factored into the distinction between lower middle and middle for some single women. (They just didn't have the *extra*, just in case)

I differentiate between the poor and the working class, which I think is important. Typically, in research, both sets of people would be considered in one lower SES because of education and occupational type, yet they have different access to resources. I also used the way women talked (especially how they could articulate the course and timeline of their treatment) to further distinguish between some individuals (especially among the lower SES categories and between lower and middle SES).

TABLE 4: CLASS DEMOGRAPHICS

Precarious Lower Middle or Tenuous Lower Middle Class	Middle Class (+ upper middle**)
Keisha Esther Yolanda Brielle Naomi* Essence Shonda Pearl (now) Gina	Ramona** Florence Jesse Beatrice Doreen Bebe Kerrie Marie Bethanie Simone Angela Catherine Naomi* Dominique April** Monique Drita Sherree Miriam** Vivian** Farrah Jorie Pearl (when diagnosed)
Poor	Working Class

Andelle Monica LaToya Irene Mary Jill	Thomasina Olivia Shaunte Eden Cassandra Gretchen Terrin Deanna Shelita Cora Brandy Lena Sue

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