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UNTHINK PINK: MASTER NARRATIVES AND COUNTERSTORIES OF BREAST  
CANCER

By

Jessica C. Hume  
B.A. Bellarmine University, 2005  
M.F.A Spalding University, 2007

A Dissertation  
Submitted to the Faculty of the  
College of Arts and Sciences of the University of Louisville  
in Partial Fulfillment of the Requirements  
for the Degree of

Doctor of Philosophy in Humanities

Department of Humanities  
University of Louisville  
Louisville, Kentucky

May, 2017

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A Dissertation Approved on

April 17, 2017

By the following Dissertation Committee:

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Dissertation Director: Nancy Nyquist Potter, Ph.D.

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Committee Member: Annette Allen, Ph.D.

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Committee Member: Nancy Theriot, Ph.D.

---

Outside Reader: Rita Charon, M.D., Ph.D.

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## ABSTRACT

### UNTHINK PINK: MASTER NARRATIVES AND COUNTERSTORIES OF BREAST CANCER

Jessica C. Hume

April 17, 2017

This work examines the construction and impact of the master narrative breast cancer which is supported and reified by the contemporary breast cancer awareness movement. I contend that historical problematic constructions of the female body were interwoven with the beginning of the movement around the turn of the twentieth century. As a partial result, the female body with breast cancer is abject, and therefore subject to policing and discipline. The master narrative of breast cancer, through pinkwashing, enacts this policing and discipline. The master narrative expresses several distinct messages which may be exclusive of the experiences of many people, causing those dealing with breast cancer to struggle to reconstruct their identity in the wake of the illness, and potentially creating epistemic injustice in which the moral agency of those subject to the master narrative is reduced. Through counterstories of breast cancer which resist and replace the master narrative, those who are subject to the master narrative attempt to be included in public discourse, reconstruct their identities, and restore moral

agency. I argue that, for this reason, we, as a culture, must bear witness to these counterstories.

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## INTRODUCTION

Early on a chilly morning in October 2009, my mother and I walked from our parking spot on Witherspoon Street toward the massive crowd, mostly women, gathering at Waterfront Park for the Susan G. Komen “Race for the Cure.” We came, for our first walk, to celebrate her anniversary: five years since she'd had a single mastectomy; five years since she'd spent months getting chemo on Fridays so she'd be in decent shape to teach again on Mondays; five years since she'd spent hours on the phone with her insurance company, driven to tears, because they refused to cover a decent wig; five years since we'd celebrated my 21st birthday sitting in her bed at home, because she was too weak to get up. It was five years since my stepfather had disappeared into the garage after her diagnosis, and reappeared later, his head—eyebrows, hair, beard—completely, nakedly, shaved bald; five years since I'd called to check on her and all she could do was cry because the side effects caused by her meds were so painful; five years in remission from breast cancer. In this place, I thought, the reality of her struggle would be acknowledged. With these people, the complicated physical and emotional responses associated with breast cancer wouldn't get swept under the rug or misunderstood. Here, I reasoned, she would feel supported, safe.

Even from the distance, we saw a large pink ribbon-shaped mass ballooning above the crowd several stories in the air. “Is that a breast cancer hot air balloon?” I asked. “Oh,

God,” she responded, her sarcasm deeply apparent. I couldn't help but wonder, What does a hot air balloon have to do with breast cancer? All around us, people gathered in little clusters, teams, with matching shirts in all variations of pink, in honor or in memory of women they'd known with breast cancer. Most men wore “Save the ta-tas” shirts, and one little girl, barely a toddler, boasted a shirt which said, “Save my ta-tas before I grow them.” Even I wore a hot pink t-shirt of my own creation, bearing the slogan, “This one's for THE GIRLS,” with the words “THE” and “GIRLS” strategically placed on my right and left breasts.

As we neared the registration tables to pick up her special, pink “SURVIVOR” hat, we noticed a stretch Humvee, parked ostentatiously across the entrance to the event, painted the special shade of Komen pink. “Is that a breast cancer Hummer?” I asked, my incredulousness rising. “MMMMM, HM!” My mother intoned, with the long “MMM” and short, sharp, “HM!” she generally reserves for affirmative response to the question, “Has somebody pissed you off?” “Oh, c'mon, Mom!” I laughed, “nothing says 'I survived breast cancer' like a vehicle that pumps more toxins in the air than any car on the road!” “Mmmmmm,” was all she said. After we'd found my brother and affixed our race tags to our shirts, we waited for the race to begin, standing in a patch of sunlight to ward off the October chill. All around us, festivities surged on, culminating in a brief, pre-race parade around the park, with the survivors grouped by order of years in remission. Local D.J.s posted near the inflatable, arch-shaped starting gate announced the groups: “Less than one year!” “One year!” “Five years!” “Go on, Mom,” I said, “don't you want to be in the

parade?” knowing she would find it silly. “Parade?!” she exclaimed. “What do I need a parade for? All I did was keep breathing and waking up every day. You want to give me a parade, give me a parade for raising you as a single mother.” I sensed that she felt that the other accomplishments of her life—raising two children, teaching for nearly forty years—diminished, dwarfed by the fact that she was a “survivor.”

As the morning wore on, moments like these continued; we looked around, seeing and hearing things, looking at each other, saying, “What does that have to do with breast cancer?” It all seemed so bizarrely removed from the experience my mother had. I wondered, how did all these women get from the brutal experience of breast cancer, to this? It seemed so generic; so commercial; so, to use a marketing term, branded. I didn't know it at the time, but what we felt was pinkwashing, in action.

From that point, I began my research on the ways in which our cultural perceptions of breast cancer interact with, and are influenced by, the contemporary breast cancer awareness movement and its strategies. Moreover, I was curious about the ways in which our cultural perceptions of the breast cancer experience (which are so closely tied with the ubiquitous pink breast cancer awareness movement) accurately reflected patient experiences and stories, and whether they had any impact on people dealing with breast cancer, treatment, or recovery. Over the course of several years, my research, which I will detail below, has led me to the conclusion that the contemporary breast cancer awareness movement, motivated by profit, has generated a cultural narrative about breast cancer which excludes the narratives and experiences of many people with breast cancer (or in

remission from breast cancer). This exclusion is accompanied by a whole host of negative effects for those people, including marginalization, silencing, injustice, and potential for poor health outcomes.<sup>1</sup> We need to resist the profit-driven breast cancer culture and make room in our cultural discourse about breast cancer to acknowledge the narratives which differ from the oversimplified depiction of breast cancer circulated by the contemporary breast cancer awareness movement. In order to understand how I arrived at these conclusions, it's best to begin with the early questions that initiated my concern with these issues and guided my research.

My great-grandmother, Edna M. Teevans Conroy, died of breast cancer, which had been untreated, in 1947. At least one of my grandmother's maternal cousins had suffered breast cancer and cervical cancer. My mother was diagnosed just shy of her fiftieth birthday. At thirty, I was labeled by my doctor as high risk. I knew that one day, I too, might lose my own breast(s), go bald, vomit for days on end, put my career on hold, only to hope to come out on the other side feeling half-human again. Still, my statistical odds of survival might be fairly good. But the story of breast cancer I saw in all the cutesy t-shirts, the sappy movies, the emphasis on breast restoration and looking "normal," the effeminate pink, wasn't necessarily a narrative that matched my worldview (nor does it now). From the time I went to my first "Race for the Cure" with my mother, I knew there had to be other people out there feeling the same way I did.

As a writer, I had always accepted as a given the fact that the stories we tell, both

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<sup>1</sup> All of these potential effects will be thoroughly examined in later chapters.

individually and collaboratively, defined our cultural and our individual selves, and that our culture shaped our personal narratives as well. When I started my research, I began to wonder about the cultural story we were telling about breast cancer. Why did these stories almost always depict people who caught cancer early through mammograms, and were able to fight it like heroes and warriors? Why did it appear that those diagnosed with breast cancer came out on the other side better, stronger, happier, more enlightened? Why were most of these heroes white and heteronormative? What about the people with Stage IV, those who couldn't run races or go to galas? What about the people who die, no matter how hard they fight? What about the stories of queer people and lesbians? The stories of those who chose non-traditional family structures, or simply hated pink? Where were the stories of whose lives were radically altered by breast cancer? Why did all of this seem absent from our cultural discourse around breast cancer, and in what ways was this apparent exclusion affecting the people whose stories get excluded?

That questions prompted my research on illness narratives, and then specifically, illness narratives of breast cancer, and I discovered that the study of illness narratives of breast cancer existed at the interdisciplinary intersection of several fields. In order to understand the ways in which the female breast cancer body was culturally constructed, and the ways in which those constructions still come to bear in our cultural experiences of breast cancer (such as the "Race for the Cure"), I would have to examine the history of anatomy and medicine, feminist body theory, popular culture, and bioethics and phenomenology. There were two primary histories, though, that knew must take

precedence. To understand the function of narrative in illness, I would need to research the development of illness narrative and narrative theory. To expose and understand the ways in which cultural constructions may alter or inhibit the important function of lived or written narrative, I would have to examine the narratives themselves, starting with the earliest modern breast cancer narratives. Below is my analysis of the development of scholarly work on illness narrative and its theories, interwoven with a historical review of breast cancer narratives.

Before the 20th century, there were very few detailed narratives of breast cancer, and the extant ones were originally intended to have loved ones as their only audience (rather than be published for the consumption of the general public). Frances Burney, the novelist, wrote of her experience (one that lacked a refined surgical plan, anesthesia, and antiseptic) to her sisters and nieces in 1812, several months following her surgery.<sup>2</sup> She recounted for them the months in which she and her husband harbored fears about the lump in her breast (all the while, warning them that if they are similarly afflicted, they should not wait as long as she). Burney lived another 29 years, and her account is the only widely-known one from this time period.

Just over 100 years later, in 1915, Katherine Lee Bates wrote and distributed an account of her partner, Katharine Coman, and her experience with breast cancer.<sup>3</sup> Like

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<sup>2</sup> Burney, Frances. Manuscript letter in the Henry W. and Albert A. Berg Collection, New York Public Library. Text found online.

<sup>3</sup> See Leopold, Ellen. *My Soul is Among Lions: Pages from the Breast Cancer Archives*.

Burney's, the memoir was intended only for circulation among loved ones, as Bates explains on the title page when she says it is “for Katherine Coman's family and innermost circle of friends...only for the eyes of those who have love's right to see” (Leopold *My Soul is Among Lions* 14). The two women, both professors at Wellesley, were involved in what was then called a “Boston marriage,” in which women chose not to marry and simply lived together. There is no evidence as to whether their relationship was sexual or not, but there's no doubt that they were incredibly devoted to one another, as we see in Bates' description of her companion's illness: “As I look back on Katharine's martyrdom, I see no longer pain and death; I see only the shining of her spirit,” (Leopold *My Soul is Among Lions* 21). In her analysis of the narrative, Ellen Leopold notes that, while for many women with breast cancer diagnosis during that time, “the need to collude with the demand for secrecy must have added terrible distress to the physical pain women already faced. Coman seems to have been spared this additional suffering...such openness must have been incredibly rare,” (Leopold, 19). Leopold also notes, however, that that openness only extended so far, because Bates is careful not to ever name the disease or to identify “the powerful medicine which [Coman] had been taking to prevent recurrence of her trouble” (23). Whatever freedom Coman and Bates did have to discuss Bates' illness, even if they could not name it or discuss it specific detail, would remain incredibly rare for another sixty years.

Narratives like those of Burney and Bates are sparse before the mid-late 20th

century. The revolutionary environmentalist Rachel Carson was investigating her own case, and writing privately to Dr. George Crile (a national advocate for modified mastectomy and lumpectomy), but she refused to bring her case into the limelight for fear it might damage the credibility of her book, *Silent Spring*, in which she essentially proposed that pesticides cause cancer.<sup>4</sup> Writing about the breast cancer experience did not enter public discourse until second-wave feminism helped to break public silence about many women's health issues, and Betty Ford and Happy Rockefeller spoke in the news about their diagnoses. In that era, medical journalist Rose Kushner published her book, *Breast Cancer: A Personal History and Investigative Report*, which was one of the early comprehensive narratives of a woman's experience with breast cancer which also included some of her journalistic research on the subject of diagnosis and treatment options.<sup>5</sup> But even at the start of the movement, a tension existed between various public depictions of breast cancer narratives. Betty Ford and Happy Rockefeller sought to put on brave public faces, becoming model heteronormative breast cancer patients.<sup>6</sup> So began tension between the model breast cancer patient--one who listened to her doctors, complied easily, recovered quickly, and went back to being a "normal woman"--and women like Kushner, who demanded answers and wanted to engage in reciprocal

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<sup>4</sup> See Knopf-Newman, Marcy Jane. *Beyond Slash, Burn, and Poison: Transforming Breast Cancer Stories into Action*.

<sup>5</sup> See Kushner, Rose. *Breast Cancer: A Personal History and an Investigative Report*.

<sup>6</sup> See the section titled "The Ideal Breast Cancer Patient," in Chapter 3, for more details about Betty Ford's depiction as a breast cancer patient.

decision-making in treatment, rather than be pressured to return to femininity.

The media was drawn to the public heroism of women like Ford and Rockefeller, but there were others like Kushner seeking to complicate the public's understanding of breast cancer patients and their experiences. Audre Lorde was also diagnosed in the late 1970s, and by 1980 she had published *The Cancer Journals*, a manifesto and call for social action which revealed her experience of breast cancer as a woman of color and a lesbian.<sup>7</sup> While second-wave feminism had opened up several discussions and sparked several changes regarding women's health, the voices of the movement were predominantly middle-class, white women who were heteronormative (people who performed femininity as prescribed by traditional, binary gender roles). Lorde identifies this discrepancy in *The Cancer Journals* when she describes her encounter with a well-meaning middle-aged woman, a representative of the Reach for Recovery program, who comes to visit her in the hospital to encourage her to use her lambswool prosthetic breast: “The woman from Reach for Recovery who came to see me in the hospital... certainly did not speak to my experience nor my concerns. As a 44 year old Black Lesbian Feminist, I knew there were few role models around for me in this situation, but my primary concerns two days after mastectomy were hardly about what man I could capture in the future, whether or not my old boyfriend would still find me attractive enough...My concerns were about my chances for survival. Would I be able to maintain

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<sup>7</sup> Lorde, Audre. *The Cancer Journals*.

the control over my life that I had always taken for granted?” (Lorde 175). Despite the fact that it is nearly 40 years old, Lorde's work remains one of the very few which highlights experiences with breast cancer from the perspective of a non-white, non-heteronormative woman. The women's movement by which her books were so well received, focused much of its effort on reproductive rights and other women's health issues. In the 1980s, The breast cancer awareness movement was taken up and dominated by big fundraising organizations like Susan G. Komen and, though it became much more a part of public discourse, it also lost some of its feminist influences. Breast cancer awareness was marketed, branded, and sold to the public.

In the interceding years, hundreds of breast cancer stories, in the form of film, books, poetry, and interviews, flooded popular culture. Though some of them exposed the public to new experiences of the illness, most of them depicted demure, compliant heroes who were embodied mainly by their identities as wives and mothers. The popular 1983 film, *Terms of Endearment*, for example, brought to light some of the ways in which breast cancer was shrouded in secrecy and silence, and was one of the first Hollywood films to do so, but overall it reinforced standards of the white, middle-class heteronormative female and exploited breast cancer to make profit for movie studios.<sup>8</sup> The main character, Emma, is depicted via her primary identity as a wife and mother: when she visits New York City with a friend, she encounters working women who are

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<sup>8</sup> See Brooks, James L., et al. *Terms of Endearment*.

depicted as judgmental pant-suited villains. During her illness, when her doctor gives her a poor prognosis, he advises that she decide who should raise her children—she is, in fact, married to their father—and she must choose between her best friend, Patsy, or her mother. When her husband easily agrees to this arrangement, she smiles, forgiving him for this and all his past transgressions, in a scene which glorifies her as a long-suffering hero. When her two boys come to say their final goodbyes to their mother (notably, there is no scene in which she bids farewell to her daughter), she literally puts on a brave face, having Patsy apply bright and cheerful pink makeup. Like Betty Ford, she is demure, compliant, heroic, and hetero.

By the late 1980s and early 1990s, powerful pink marketing campaigns had become the loudest public voice in breast cancer awareness. Susan G. Komen for the Cure had begun partnering with other large corporations to encourage pink ribbon branding and marketing. Companies used the color pink or the pink ribbon to aid in generating profits or good PR, but didn't actually do much (if anything) to help raise funds or awareness (“Think Before You Pink”). In some cases, they claimed to be raising breast cancer awareness through their pink products--which ranged from Yoplait yogurt to Ford Mustangs--but the products themselves (or the processes by which they were created) actually caused cancer. As the pink ribbon was adopted by more and more corporations, the pink ribbon became a marketing powerhouse, capitalizing on the image of heroic breast cancer patients to sell products. The overpowering and ubiquitous nature

of pink marketing resulted in the proliferation of pink-washed breast cancer narratives which also made use of the inspirational warrior-hero image.

There was, however, some resistance to the depiction of breast cancer spread by the corporate-driven breast cancer awareness movement. In 1986, Jackie Winnow and Carla Dalton founded the Women's Cancer Research Center (WCRC) in San Francisco (Klawiter 164). Winnow and Dalton had noticed a gap in resources for Bay Area women with cancer: there were very few educational and support services. WCRC was designed to fill that gap. In 1989, Winnow delivered the keynote address Conference for Lesbian Caregivers and AIDS epidemic, in which she paralleled women's cancers with the AIDS epidemic and, according to Klawiter, "galvaniz[ed] a women's cancer movement," (Klawiter 164). In 1990, Elenore Pred, Susan Claymon, and Belle Shayer founded Breast Cancer Action (BCA), an activist organization which modeled itself after the AIDS movement's ACT UP activism group. According to Klawiter, this group "learned how to make sense of articles in medical journals, how to apply pressure to pharmaceutical companies and government agencies, and how to chain themselves to the fence if all else failed," (173). Organizations like these were the first groups to resist the portrayal of breast cancer circulated by groups like Susan G. Komen and others, as Klawiter notes: "Feminist breast/ cancer activists...drew attention to the false promises and misrepresentations of the cancer establishment," (175). Breast Cancer Action began the "Cancer Sucks" campaign in 1997, in hopes of countering the oversimplified cheeriness

of the pink ribbon (Klawiter 175). Later, BCA coined the term “pinkwashing” to refer to corporate exploitation of breast cancer in order to sell products which may contain known carcinogens (“Think Before You Pink”). The term was part of their “Think Before You Pink” campaign, and they remain a watchdog organization, calling out companies guilty of pinkwashing and trying to raise awareness of the phenomenon (“Think Before You Pink”). Similarly, Terry Tempest Williams sought to resist oversimplified notions of the experience of having breast cancer, trying to encourage awareness of, and resistance to, these ideas. In 1991, she published her book, *Refuge*, in which she revealed her suspicion that the women in her family had developed breast cancer because of the atomic bomb testing which took place near their home.<sup>9</sup> It unabashedly showed her sadness, anger, and internal conflict, such as in the final essay of the book, titled, “The Clan of One-Breasted Women.” The current, revitalized trend of resistance to the commercialization and exploitation of breast cancer began, and continues, with groups like WCRC, BCA, and writers like Williams.

Around the same time—the late 1980s and early 1990s—writers in various fields such as medicine, sociology, psychiatry, anthropology, psychology, and ethics began to examine and discuss stories of illness and the ways in which they influenced patient experiences. Arthur Kleinman's landmark book, *The Illness Narratives: Suffering, Healing, and the Human Condition*, discussed the ways in which illness can have social and personal meaning, and claimed that those meanings should be examined, understood,

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<sup>9</sup> See Williams, Terry Tempest. *Refuge: An Unnatural History of Family and Place*.

and empathized with by healthcare professionals.<sup>10</sup> In the early 1990s, the renowned sociologist and illness scholar, Arthur Frank, published a book on illness theory, *The Wounded Storyteller*, in which he substantiated that authentic narratives of illness were critical to the patient's identity in recovery; he observed that it's crucial to allow those diagnosed with illness to recount their stories without those patients being colonized by either social expectations or the power of allopathic medicine.<sup>11</sup>

Though she made no reference to the scholarly rise of the examination of illness narratives and their meanings, independent scholar Ellen Leopold seemed to have an inherent sense that public discourse about the meaning of breast cancer, in social and personal contexts, needed diversifying if it was to do justice to a variety of women's experiences. In 1996, Leopold published an essay entitled "Body Language," in which she identified one of the problems with popular warrior-hero breast cancer narratives of the 90s<sup>12</sup>: "The journey chronicled by many of the newer cancer diaries...sends the message that, given the right attitude, women can take charge and overcome breast cancer. By implication, those who fail (i.e. those who die...) demonstrate a lack of moral courage, perseverance, and all those virtues associated with a 'go ahead' attitude," (Leopold *My Soul is Among Lions* 110-111). She claimed these approaches were "Pollyanna-ish," (111) and called for a more complex vision of the contemporary breast

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<sup>10</sup> See Kleinman, Arthur. *The Illness Narratives: Suffering, Healing, and the Human Condition*.

<sup>11</sup> See Frank, Arthur W. *The Wounded Storyteller: Body, Illness, and Ethics*.

<sup>12</sup> See Leopold, Ellen. *My Soul Is Among Lions: Pages from the Breast Cancer Archives*.

cancer narrative. In the late 90s, she published *A Darker Ribbon: Breast Cancer, Women, and Their Doctors in the Twentieth Century*, a book which compared a selection of letters between the famed surgeon, William Stewart Halsted (creator of the Halsted radical mastectomy, which was considered the gold standard in breast cancer treatment from the 1890s until the 1970s) and a patient of his, to a selection of letters between the mid-20th century doctor, Dr. George Crile, and his famous patient, Rachel Carson.<sup>13</sup> The book revealed the roots of some of the hegemonic power in breast cancer treatment and the resistance to change in thinking about breast cancer treatment on behalf of the American public and the medical profession. And so, some discourse about breast cancer stories began aligning with the feminist discourses of new groups like WCRC and BCA.

In the late 1990s, scholarly work on illness narrative theory also began taking new directions, diversifying and expanding. In 1997, English professor Thomas Couser published *Recovering Bodies: Illness Disability and Life Writing*,<sup>14</sup> in which he claimed that stories of illness are one way the ill could reclaim their bodies, and in which he examined specific literary aspects, such as plot and narration, in illness stories. In the same year, Hilde Lindemann Nelson edited the collection, *Stories and Their Limits: Narrative Approaches to Bioethics*,<sup>15</sup> in which Nelson and others in the field (such as

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<sup>13</sup> See Leopold, Ellen. *A Darker Ribbon: Breast Cancer, Women, and Their Doctors in the Twentieth Century*.

<sup>14</sup> See Couser, G. Thomas. *Recovering Bodies: Illness, Disability, and Life-writing*.

<sup>15</sup> See Nelson, Hilde Lindemann. *Stories and Their Limits: Narrative Approaches to Bioethics*.

Arthur Frank) examined the ways in which illness narratives interacted with and influenced the ethical sensibilities of caregivers. One shared theme of the movement to understand illness through narrative became clear: narrative had the power to shape or reshape identity in illness or in the wake of illness, and also the power to create empathetic relationships between those writing them and those reading them.

The empowering facet of illness narratives was not evident in many of the breast cancer stories of the early 2000s, which continued to oversimplify the experience. Narratives written by women about their breast cancer experiences got a bit sassier, with clever titles like Margaret Lesh's, *Let Me Get This Off My Chest*, or modern formats Marisa Acocella Marchetto's graphic novel, *Cancer Vixen*, but they still worked within narrow confines that present the breast cancer body as marginalized, subtly invoking language (“so and so 'lost her battle' with breast cancer,” for example) which blamed the victim, and they utilized and reified problematic constructions of the female body and the breast cancer experience. And they still, for the most part, elided the experience of women of color, or women of the LGBTQ community.

Simultaneously, however, breast cancer activists and scholars in sociology, medicine, bioethics, and women's and gender studies began to publish significant works on this phenomenon. In 2003, Barron Lerner published, *The Breast Cancer Wars*, in which he examined the history of breast cancer in the United States, particularly the relationships between patients and biomedical institutions, and the legal and ethical

complications associated with treatment. In her 2004 book, *Beyond Slash, Burn, and Poison: Transforming Breast Cancer Stories into Action*, Marcy Jane Knopf-Newman presented detailed stories of four famous women—Rachel Carson, Rose Kushner, Betty Ford, and Audre Lorde—in order to demonstrate the ways in which their individual narratives and bodies were politically situated.<sup>16</sup> Knopf-Newman examined the influence these women’s experiences had on the 20th century medical practices, health law, and popular discourse of breast cancer. In this notable book, she revealed the ways in which breast cancer stories are political, and that how we respond to them is an ethical concern (notably, this observation about ethics coincides with Nelson's association of illness narratives to ethics). Maren Klawiter’s 2008 book, *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism*, in which Klawiter traced the breast cancer movement throughout the 20th century, identified the ways in which breast cancer treatment is medically managed.<sup>17</sup> It also identified the discrepancies in treatment for people of color and those who are not heteronormative, and introduced readers to new, grassroots activism about breast cancer, the purpose of which was to resolve inequity and dismantle hegemony. In 2011, Samantha King published one of the first full-length texts which examines pinkwashing extensively and analyzes its effects: *Pink Ribbons, Inc.: Breast Cancer and the Politics Of Philanthropy*. In this text, she exposes several ways in

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<sup>16</sup> See Knopf-Newman, Marcy Jane. *Beyond Slash, Burn, and Poison: Transforming Breast Cancer Stories into Action*.

<sup>17</sup> See Klawiter, Maren. *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism*.

which breast cancer has been commercialized, and points out the exploitation, exclusion, and harm which pinkwashing causes.

While these scholars began work to address specific issues raised by several women's experiences with breast cancer, and also the political and ethical nuances of the 20th century breast cancer awareness movement, others continued to bring analysis of illness narrative to the fore. Nelson published *Damaged Identities: Narrative Repair*,<sup>18</sup> in which she described master narratives: “the stories found lying about in our culture which serve as summaries of socially shared understandings,” (6). She observed that master narratives are archetypal and sometimes oppressive, and contrasted them with what she called “counterstories,” which she claimed “identify fragments of master narratives that have gone into the construction of an oppressive identity” and “aim to alter...on oppressed person's perception of herself,” (7). Master narratives of illness can be harmful to the ill person. As we shall see below, my argument is that the current construction of breast cancer experiences in our cultural discourse, particularly in pinkwashed discourse, qualifies as a master narrative and potentially harms people with breast cancer. I will discuss the impacts of that qualification more fully in Chapters 3 and 4.

Just a few years later, Rita Charon, published her major work, *Narrative Medicine: Honoring the Stories of Illness*,<sup>19</sup> in which she advocated for healthcare providers to use the narrative skills of “recognizing, absorbing, interpreting, and being

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<sup>18</sup> See Nelson, Hilde Lindemann. *Damaged Identities, Narrative Repair*.

<sup>19</sup> See Charon, Rita. *Narrative Medicine: Honoring the Stories of Illness*.

moved by the stories of illness,” (4). She also claimed that the concept of intersubjectivity was critical to the function of illness narratives. Intersubjectivity, according to Charon, meant that narrative required not only a teller but also a listener, and the relationship between the two created a kind of communion (52). According to Charon’s text, illness stories needed witnesses in order to be of help to those experiencing them.

In 2015, Mary K. DeShazer produced what is possibly the only published book to apply illness narrative theory directly to stories of breast cancer, specifically. She brought us new language to talk about breast cancer narratives when she published her book, *Mammographies: The Cultural Discourses of Breast Cancer Narratives*,<sup>20</sup> which is one of the few books to incorporate queer theory and anti-pink discourse. DeShazer’s book seems to be the only extant work which brings together all these concepts in order to emphasize the importance of alternative breast cancer narratives while also questioning hegemonic discourses about breast cancer and the female body. To date, however, there is not any published work which specifically identifies and analyzes the rhetoric of the breast cancer awareness movement as a master narrative. The discourse may benefit from an analysis the way in which the master narrative of the movement, supported and reified by the practice of pinkwashing, marginalizes those with breast cancer and potentially causes injustice and harm. Additionally, the discourse may benefit from discussion on how to resist the master narrative through counterstories, which I have done below.

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<sup>20</sup> See DeShazer, Mary K. *Mammographies: the Cultural Discourses of Breast Cancer Narratives*.

This research into illness narrative and the culturally constructed female body of breast cancer has currently led me to four central claims which build on one another. First, the master narrative of the modern breast cancer awareness movement was constructed from a foundation of problematic beliefs about the female body in which the female body has been pathologized. Second, the breast cancer body is construed as abject and therefore subject to discipline and policing; this discipline and policing is enacted through the master narrative. Third, the master narrative is utilized and reified by the practice of pinkwashing, and generates several archetypal messages which may obscure or over-determine the narratives of those with breast cancer who do not fit into the master narrative. Fourth, our culture's engagement in the messages of the master narrative may result in epistemic injustice<sup>21</sup> and poorer long-term outcomes for those with breast cancer; therefore, we need to work to pluralize the master narrative in order to acknowledge the stories of those whose lives do not match the current master narrative.

Chapter 1 provides a foundational understanding of the problematic historical understandings and constructions of the female body. Through analysis of anatomical and medical history, I demonstrate the ways in which the female body is historically pathologized. Particularly, I focus on the ways in which that pathologization relates to female body parts. Then, I analyze the ways in which that pathologization and other

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<sup>21</sup> Here, I refer to the work of Miranda Fricker, in which she identifies epistemic injustice as injustice in which “someone is wronged in her capacity as a knower,” (*italics hers*) (20).

problematic perceptions of the female body as inherently ill become part of the foundation of the modern breast cancer awareness movement at the start of the 20th century. Finally, I use examples of breast cancer narratives, such as those of Fanny Burney and Audre Lorde, in conjunction with historical information about the advancement of breast cancer medicine, to expose the ways in which that pathologization became a subtext of the early history of breast cancer. That pathologization became a springboard for the master narrative of breast cancer.

Chapter 2 utilizes current feminist theory as a lens through which to analyze several contemporary breast cancer narratives. Analysis of these unique narratives demonstrates the ways in which the breast cancer body is currently conceptualized as abject and monstrous. I use Foucauldian theory (or, more precisely, a feminist appropriation of Foucault) to expose the ways in which this abject, monstrous breast cancer body is subject to policing and regulation. This policing and regulation manifests itself through the master narrative of breast cancer, and is enacted through pinkwashing. The master narrative becomes a method by which we self-police and regulate one another, and pinkwashing becomes a system which reifies that behavior and perpetuates the master narrative.

In Chapter 3, the main messages of the master narrative of breast cancer are fully laid out and explored. I use examples from the pinkwashed marketing campaigns of the contemporary breast cancer awareness movement, as well as accounts from people with

breast cancer, to demonstrate their active presence in our social discourse and regulation of one another. This analysis brings to light four oversimplified myths expressed by the master narrative of breast cancer: that early detection always means a cure; that primary power lies in the hands of allopathic medicine; that those with breast cancer are expected to be heteronormative; and that those with breast cancer must perform the role of the ideal, heroic breast cancer patient. For each of these aspects of the master narrative, I use examples from contemporary breast cancer narratives to show the ways in which they contribute to the policing and regulation of the breast cancer body. Synthesis of illness narrative theory, and analysis of the ways in which narrative contributes to the construction of the self, shows that these messages expressed by the master narrative may be detrimental to the ill person's construction of identity in illness. Feminist theories, combined with bioethics and phenomenological analysis, support the claim that these messages, by virtue of their exclusion of the stories of many people with breast cancer, create injustice.

This work culminates in the fourth chapter, when I argue that, beyond the fact that the master narrative is detrimental to people's construction of identity in illness, and beyond the fact that it creates injustice, it may be the factor which leads to poorer long-term outcomes for those with breast cancer. Psychological research, combined with illness narrative theory and evidence from illness narratives of breast cancer, demonstrates that those who feel their stories of breast cancer are acknowledged and

witnessed<sup>22</sup> by others may have a likelihood of improved outcomes for certain aspects of their health. Therefore, I argue, those whose narratives of self in breast cancer are not embraced and acknowledged by our culture may be potentially subject to injustice and poorer health outcomes. Finally, I present and analyze examples of what Nelson calls “counterstories,”<sup>23</sup> which resist the master narrative of breast cancer. These stories demonstrate the ways in which our cultural understanding of breast cancer should be pluralized, and give readers a sense of the richness and depth which can be integrated into our cultural understanding of the experience of breast cancer.

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<sup>22</sup> I will address and define the specific concept of witness in Chapter 4.

<sup>23</sup> This concept will be fully elaborated in Chapter 4.

## CHAPTER ONE

### “YOU MUST EXPECT TO SUFFER”: THE FEMALE BODY AND THE EARLY HISTORY OF BREAST CANCER AWARENESS

Before we begin to understand the structure and implications of the modern breast cancer awareness movement, it's important to examine the context in which that movement was created and the underlying structures of knowledge of the female body onto which it was grafted when it began in the early 20th century. A brief examination of the problematic historical representations of the female body leading up to the early breast cancer awareness movement will demonstrate the ways in which those constructions were exploited, overused, and then codified by the movement. In Chapter 2, we will see the way in which those representations construed the breast cancer body as abject, and therefore subject to discipline and policing. In Chapter 3, we will discover how those representations developed into a multi-faceted master narrative of the contemporary breast cancer awareness movement.<sup>24</sup> At the beginnings of western

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<sup>24</sup> Scholar Hilde Lindemann Nelson defines master narratives as “stories found lying about in our culture that serve as summaries of socially shared understandings,” (6). In Chapter 3, we will explore the construction of master narrative of breast cancer. For now, all we will discuss are the constructions of the female body which set the stage for the development of the master narrative of breast cancer.

medicine, the female body was perceived as an inferior version of the human body. Medical men like Hippocrates and Galen believed that men and women were two sexes in two different body types: “ a single anatomical form containing both sexes,” (Libbon 80). This is what’s known as the “single-sex” model (80). To be clear, the Greeks did not believe that the human body was hermaphroditic, but that the female body was perceived as an inferior version of the male body, as Stephanie Libbon notes. Aristotle concurred: “Woman is literally a monster: a failed and botched male who is only born female due to an excess of moisture and of coldness during the process of conception,” (as cited in Ussher *Managing the Monstrous Feminine* 1). Men were a superior version of women by virtue of their excess heat.<sup>25</sup> Here, notably, the female body is construed as doubly inferior: the female fetus is an inferior version of the male, but the mother is incapable of managing her pregnancy such that she can produce a male. During this same historical era, the term “hysteria” (originally meaning “wandering womb”) was coined to apply to women who suffered from (or appeared to suffer from) a vast array of nervous problems, based on the belief that a panoply of problems could be caused by a woman’s womb becoming unanchored from its location and traveling around her body. Her anatomy (specifically, her uterus) makes her inferior to men (by virtue of the male body as the normative and highest standard). The part of her anatomy which is perceived as

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<sup>25</sup> According to Libbon, who cites Galen’s *Body*, the Greeks devised a spectrum on which life forms were ranked, from hottest at one end, to coldest at the opposite end. Hotter life forms were designated as superior to those colder than them. On this spectrum, men had more heat than women and were therefore superior (80).

non-normative, her womb, must therefore be causing her symptoms. Having a uterus makes a women susceptible to a number of undefined conditions to which men are not.

Much of how western society understands anatomy, specifically female anatomy, was undefined until after the beginning of the Enlightenment. From the time of the Greeks until the Middle Ages, arguably little progress was made in understanding human anatomy generally; medicine stagnated, languishing in the theories of Galen and the four humors. Additionally, standards of modesty prevented physicians from examining living women physically, and birth was something managed by female midwives, not physicians (Kukla 8). So, the female body, particularly during pregnancy was, in comparison with the male body, understudied. Female anatomy was a secret, private space, to which doctors rarely had access, and of which they had a much more limited understanding than that of the male anatomy. By the late seventeenth and early eighteenth centuries, because of the growing frequency of post-mortem human dissection, surgeon-anatomists in Europe were making great strides in understanding human anatomy; however, access to human bodies was still difficult well into the early 19<sup>th</sup> century (MacDonald 12-13). In England, the Murder Act of 1751 provided that any murderer could be used for dissection after being hung. At that time, dissections after death were considered "murder after death," because it deprived the person of the

possibility of religious salvation in the afterlife<sup>26</sup>; thus, dissection was only suitable for those who had committed the grave sin of murder. Often, the bodies studied were those of criminals fresh from the gallows (so, not women). Pregnant bodies were rarely available for dissection; when they were, it was only at the express permission of the family (often for purposes of autopsy). Though knowledge of human anatomy and disease progressed overall, female bodies remained far more mysterious.

As general exploration of human anatomy in western medicine progressed during the 18th century, anatomist-surgeons began to distinguish themselves from barbers, quacks, and charlatans; British anatomist John Hunter, for example, became surgeon to King John III. The legitimization and professionalism of the study of anatomy which took place during the 18th and 19th centuries meant that European social and cultural views about dissection of the human body shifted gradually away from the “murder after death” mentality, and those seeking to advance the study of anatomy had more opportunity to do so. Because of the dearth of knowledge about female bodies, the human womb and its workings were the coveted final frontier for early anatomists like John's brother, William Hunter, who published his findings in his 1774 work, *The Anatomy of the Gravid Uterus*. This move in anatomical history was important because, as Rebecca Kukla notes, “...mother’s bodies become peculiarly public in several ways. Their insides, formerly tucked away behind modesty and ignorance, became objects of rigorous scientific

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<sup>26</sup> For more information about the Murder Act and related phenomena, see Sugg, *Murder After Death: Literature and Anatomy in Early Modern England*, for a detailed history.

surveillance and attention,” (66). Rapidly, the most private and feared parts of women were revealed to western medical practitioners and to the public, making them subject to scrutiny and fetishization. For example, 35 years following Hunter's work, Sarah “Saartjie” Baartman, also known as the “Hottentot Venus,” would appear in public forums in Europe. According to Frith, Baartman was a South African native of the Khoekhoe population who was brought to London by a doctor named Alexander Dunlop and a showman named Henrik Cesars.<sup>27</sup> She was displayed, according to Frith, mostly nude, for visitors view: “her silent displays — complete with animal skins, face paint, and a tight body stocking — fueled European myths about people from Africa: They were primitive. Close to nature. Exotic. Hypersexual.” Frith also notes that her body—particularly her bottom—was an object of scientific fascination and an oddity, and her genitalia were the subject of much speculation. While Baartman's case serves as a troubling example of fetishization and hypersexualization of native African women, it also demonstrates the ways in which advances in anatomical science and growth of the power of medicine spawned attempts to colonize, display, and exploit the female body.

On the note of female bodies being subject to empirical observation and scrutiny, it's essential to acknowledge Foucault's observations about the shift in medical knowledge at this time. He observes that during the era of the French Revolution, the clinical gaze changed the way in which medical knowledge of the human body was

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<sup>27</sup> For more information, see Frith, Susan. “Searching for Sarah Baartman.” Johns Hopkins Magazine.

constructed:

...clinical experience sees a new space opening up before it: the tangible space of the body, which at the same time is that opaque mass in which secrets, invisible lesions, and the very mystery of origins lie hidden. The medicine of symptoms will gradually recede, until it finally disappears before the medicine of organs, sites, causes, before a clinic wholly ordered in accordance with pathological anatomy. (Foucault *The Birth of the Clinic* 151)

According to Foucault's theory, anatomical dissections and advancement meant the body would eventually become an entirely objective, empirical thing, its ailments measured only by anatomical changes, reducing the sick person to a pathology or set of pathologies. Prior to this era, physicians had been forced to base their knowledge of an illness on a patient's subjective experience of the illness, primarily the patient's symptoms, but with increased access to the body through anatomical study and surgery, the doctor would observe and understand the body in a way that would change perception of the human body irreversibly:

What is modified in giving place to anatomy-clinical medicine is not, therefore, the mere surface of contact between the knowing subject and the known object; it is the more general arrangement of knowledge that determines the reciprocal positions and the connexion between the one who must know and that which is to be known. The access of the medical gaze into the sick body was not the continuation of a movement of approach that had been developing in a more or

less regular fashion since the day when the first doctor cast his somewhat unskilled gaze from afar on the body of the first patient; it was the result of a recasting at the level of epistemic knowledge itself. (Foucault *The Birth of the Clinic* 169-170) <sup>28</sup>

According to Foucault, through the eyes of the physician the patient becomes an object, merely a body, a disease or set of diseases. This perception is what Foucault calls the "clinical gaze." At this point, it is helpful to clarify the definitions of "illness" and "disease." Nancy Theriot, in her work on women's voices in medical discourse, offers definitions derived from Arthur Kleinman,<sup>29</sup> which are applicable here. She defines illness as "a self-defined state of less than optimum health," while "disease is a scientific representation of illness that involves both a sorting of symptoms into discrete entities and a theorizing about causation and cure...disease is not discovered but created," ("Women's Voices in Nineteenth Century Medical Discourse" 3). Applying these definitions to Foucault's theory of the clinical gaze in the late 18th century, we can say that the clinical gaze means that rather than sharing a reciprocal relationship in which they must establish together their knowledge and understanding of the illness, the doctor now relied more on knowledge of the body and its workings to understand the way in which the body is diseased. Medical practitioners and anatomists perceived the body through the lens of pathology—the causes, effects, origins, and nature of an illness—and

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<sup>28</sup> We shall return to the discussion of epistemic knowledge in Chapters 3 and 4.

<sup>29</sup> For more information, see Kleinman, Arthur, *Patients and Healers in the Context of Culture*.

considered the human body an object. Knowledge of pathology was the purview of these medical professionals, and the general public did not have education about, or access to, information regarding disease and pathology. Because the knowledge regarding the primary means of understanding illness now lay with the health care professionals, the individual's personal or socio-cultural experience and knowledge regarding the illness became secondary. The human being's social, cultural, and personal experience while diseased became a separate aspect of illness, an aspect that was less legitimized by biomedical professionals. This phenomenon is the “recasting...of epistemic knowledge” to which Foucault refers above. The premier “knowers” about the body became not the people with bodies, the people with illnesses, or their cultural leaders, but the people who generated and held knowledge of anatomy and pathology.

Some have argued that, with the advancement of anatomization which took place in the late 18th and early 19th centuries, clinicians were launched to a position of power over the body such that the subjective experience of the patient fell to the wayside and was overwhelmed by the seemingly objective, empirical, and omnipotent authority of medicine. Arthur Frank observes that this era is the one in which we see the shift from pre-modernism in medicine, to modernism, claiming that a defining feature of modernism is that, “The story told by the medical professional is the one against which others are ultimately judged true or false,” (5). Frank's observation intersects with Foucault's at the point that both of them acknowledge the shift of power from the afflicted person to the perception of the medical professional. To Frank, though, what's critical here is *story*.

Prior to this era, the story was one of illness, created by the patient through the patient's cultural language and beliefs; once pathological knowledge begins to dominate medical knowledge, the story generated is one of disease (of pathology), rather than illness (a story which includes not only pathology but the human experience of the illness). The ill person is expected to give up authority of experience in favor of the pathology narrative generated by the medical professional. Frank calls this phenomenon narrative surrender: "...the ill person not only agrees to follow the physical regimens that are prescribed; she also agrees, tacitly but with no less implication, to tell her story in medical terms," (6). While the language used to describe the experience of being sick may shift from one which defines disease, rather than illness, Frank uses the word "surrender," which seems to indicate a lack of agency.

Theriot, however, takes up Barbara Duden's challenge that, "historians...find ways to connect the medical discourse defining individuated body-selves with patients' constitution of themselves both as physical *objects* of medical science (bodies) and as individual *subjects* participating in treatment," (italics Theriot's) ("Negotiating Illness: Doctors, Patients, and Families, in the 19<sup>th</sup> Century" 349). Theriot claims that, in the 19<sup>th</sup> century, patient case studies indicate a level of reciprocity in patient-physician dialogue:

Much of this literature can be read as a double narrative, as the physician's interpretation of the symptoms and examination results and as a physician-shaped account of the patient's story...The patient's history, as told by the patient or family member...was recorded/reported as part of the as-yet-unexamined data

from which the physician would weave her/his interpretation. (351)

For example, Theriot cites a gynecologist, Ernest Hall, who records one patient's complaints with attention to the way in which she articulated her symptoms: "she expressed herself as feeling blue, and unable to overcome periods of despondency, objected to being left alone, and very nervous," (353). While the primary record and primary voice of the account is that of the physician, we can see that the doctor is careful to incorporate her perception, interpretation, and even phrasing, of her experience. Thus, the narrative is one constructed by the two of them, and shaped by the physician, as Theriot notes. She is careful to explain further that constructions of disease for women in this era were not solely those of medical practitioners: "extra-medical" factors such as specific practices, professional politics, and often women themselves, through their illness narratives, contributed to the construction of their diseases. So, perhaps Foucault is accurate to note a shift in epistemic power regarding anatomical knowledge taking place in the 17<sup>th</sup> through 19<sup>th</sup> centuries; and Frank is right that language shifted to the use of medical jargon; but those changes may not necessarily have meant that all of the patient's narrative (or agency) is entirely surrendered. The patient's agency was, to some extent, maintained in the exercise of constructing her own history with the medical professional. Culturally, those living under the auspices of western, allopathic medicine still deal with the residual effects of these linguistic and epistemic structures of power; however, they, too, may have some authority over their narratives of illness. This will become important to bear in mind later in this work, so we can observe the ways in which

women enacted agency in the creation of their narratives of illness.<sup>30</sup>

According to Libbon, around the start of the 19th century, the female body was viewed by scientists and philosophers as the opposite of the male, as we see in the work of German surgeon Philip Franz von Walther: “The feminine is purely negative, existing only in contrast to and through the masculine,” (as cited in Libbon 84). Later in that century, Johann Heinroth defined women as a “necessary complement” to men (85). By mid-century, two German scholars, J.J. Sachs and Carl Michelet, had expanded the theory, noting the ways in which women also have complementary social roles, as we see in Michelet’s work: “Woman leads more of an emotional life...The inner order of the familial circle completely consumes the moral significance of woman...Woman is the born enemy of law...the productivity for the general welfare is accorded to the man exclusively,” (as cited in Libbon 86). Women who did not fulfill the social role of that era, according to Libbon, would therefore “threaten not only the contemporary definitions of womanhood, but in so doing, destabilize those of manhood,” (86). Because the western world was, in essence, a patriarchy, destabilization of the definitions of the sexes and genders could result in increased power for women and fueled a fear of decreased power for men. It could change the structure of politics, law, culture, and domestic life. Sex and

<sup>30</sup> In Chapter 3, we will establish and examine the archetypal master narratives of breast cancer which are sometimes fueled by the linguistic and epistemic authority of allopathic medicine; in Chapter 4, we will analyze examples of what Nelson calls “counterstories,” which resist these standard power structures and their problematic features and allow and encourage women to enact agency in their experience of the illness.

gender were inextricably linked; the problem was that, prior to the invention of the speculum, much was still unknown about female sex organs.<sup>31</sup> Thus, the medical community sought to scientifically define acceptable social behavior in order to avoid destabilization of the concepts of gendered behavior they had identified.<sup>32</sup>

In the nineteenth century, the medical community still believed that sex and gender were co-extensive, and thus attempted to medicalize gendered behavior. According to Theriot, gynecologists aimed to build their profession around the “otherness of woman” and so connected all of her symptoms and illnesses to her female organs (6). The normalized depiction of an ideal woman included, delicacy, passivity, dreaminess, and capricious emotions, and that description was legitimized by scientists like Freud (Bordo 16). According to Libbon, in 1793, John Miller claimed that women were the “moral barometer and the vanguard that improved society,” and by 1870, Nicholas Cooke said that if women’s rights increased “she will cease to be a gentle mother, and become an Amazonian Brawler,” (as cited in Libbon 86). Female organs and their functions were associated with behavioral abnormalities. Ussher cites the medic, Edward J. Tilt, who claimed that menopause brought on irrational, immoral, and sometimes illegal behavior: “During the change of life the nervous system is so unhinged that the management of the

<sup>31</sup> In her article, “Women’s Voices in Nineteenth Century Medical Discourse,” Theriot notes the ways in which specialization in gynecology, along with the invention of the speculum, “encouraged an anatomical representation of women’s complaints,” (6).

<sup>32</sup> Libbon claims it was, specifically, sexologists who began discussing women in pathological terms (86).

mental and moral fibers often taxes the ingenuity of the medical confident...the disturbance can cause normally moral women to act without principle...steal...leave their families...brood in melancholy self-absorption,” (*Managing the Monstrous Feminine* 128). Phyllis Chesler observes the close association between women and madness in public discourse: “By the end of the nineteenth century...the portraits of madness, executed by both psychiatrists and novelists were primarily of women,” (32). Elaine Showalter notes that the terms “feminine” and hysterical” become almost synonymous during the nineteenth century (129). Women were defined by their physical differences from men, and those physical differences had been assumed to be the cause of illness, as Theriot notes: “The practice of gynecology...encouraged male practitioners to define their specialities to include all of women’s problems and therefore to define woman as inherently pathological,” (“Women’s Voices in Nineteenth Century Medical Discourse” 6).

By the end of the 19th century, Western biomedicine had conflated gender and sex. The female body had become pathologized. Because behavioral abnormalities (those behaviors which are not typically “female” like those named above) could indicate illness, a woman's body, as well as her behavior, was subject to scrutiny and attempted regulation.

#### 1. The Early History of Breast Cancer and the Awareness Movement

Once we understand the ways in which the pathology of the female body is historically established, we can see the ways in which that construction of the female

body influences the early modern cultural history of breast cancer throughout the 19th century. It's important to note, too, that the perception of the female body as pathologized coincided with the professional rise of the surgeon (who had, in centuries past, been relegated to the leagues of barbers and dentists, a mere step above animal butchers). The professional legitimization of surgeons and the increase in frequency of surgery was specifically bolstered by two key developments in the 19th century: anesthesia (mid-century) and antiseptic (late 19th century), both of which changed surgery from an excruciating last-ditch effort which often resulted in death from a gruesome infection, to a viable option which could spare the patient agony and also had a relatively good expectation of success. In fact, these developments gave surgeons an important and powerful position in the cultural hegemony of western medicine. The political scholar and intellectual Antonio Gramsci generated the primary definition of cultural hegemony, which is "the 'spontaneous' consent given by the great masses of the population to the general direction imposed on social life by the dominant fundamental group; this consent is 'historically' caused by the prestige (and consequent confidence) which the dominant group enjoys because of its position and function in the world of production," (12). Surgeons already held a certain cache of epistemically significant knowledge about the human body (as we have seen from Foucault's observations above). The invention and frequent use of antiseptic and anesthetic meant that surgeons gained the prestige and confidence noted in Gramsci's definition, because they could suddenly offer safe and painless methods by which to extirpate tumors, growths, and limbs which caused illness

or debilitation. Increasingly, the masses in need of medical attention deferred to surgeons and physicians by default, making them the “dominant fundamental group” in the context of health care. Additionally, as we have established above, medical professionals were in a position of authority to investigate and regulate female behavior. Because medicine generally exercised more influence over the female body via its potential to scrutinize or regulate behavior, surgeons were uniquely positioned to perform more surgeries on women who were interested in that option. It’s important to note that the shift of medical professionals to the top of the cultural hegemonic structure took place gradually, over several generations, and was multifactorial and complex; for the purposes of expediency, it has been somewhat distilled in this context. We should be careful to remember that medical professionals are not one-dimensional, and each doctor’s relationship to each patient is unique and complicated. It’s also important to note that while medicine, specifically surgery, was enjoying a golden era of power, women enacted various types of agency in their health care, as we shall see with writer Fanny Burney, who is both pathologized by her doctors but also empowered through her illness narrative.

The narrative of Fanny Burney, the English writer, and her “cancer of the breast” diagnosis and subsequent surgery<sup>33</sup> is one of the earliest modern narratives of breast cancer widely published. Burney began to feel symptoms in 1810, which she reported to her husband, who then retained the services of a famed accoucheur (man-midwife)

<sup>33</sup> Burney, Frances. Manuscript letter in the Henry W. and Albert A. Berg Collection, New York Public Library. Text found online.

named Dubois. Upon his initial examination and early diagnosis, Dubois offered her a prescription (the chemical composition of which is undisclosed in her writings) and “uttered so many charges to me to be tranquil, and to suffer no uneasiness, that I could not but suspect there was room for terrible inquietude.” Dubois’ urgings for Burney to remain calm and avoid distress are not at all unusual for the time. John Rodman, a Scottish surgeon, believed that fear of cancer was a possible cause for cancer, according to his publications in 1815. He claimed that “fretfulness of temper and superfluous anxiety, which sharpen the mental feelings, are not uncommon as maternal legacies,” (as cited in Aronowitz 23). He also believed, according to Aronowitz, that “the physician’s most important role [was to actively intervene] in this causative cycle of cancer fear and worry,” (23). Further, Rodman claimed that fear of cancer, and thus, cancer itself, could be spread between women via their sympathy and compassion for one another: “many feel afflictive sensations of concern whenever they heard of another being distressed with a mammary tumor named cancer...and brooding over ideal miseries unhinges the mind, till the frame is disturbed, and disorder commences in their own breast,” (as cited in Aronowitz 23-24). In the claims of Dubois as well as Rodman, we can see reflected the beliefs of Buchan and Tilt, that it is the very femaleness of the body (be it the anatomical parts themselves, in this case breasts, or the feminine disposition, which causes illness) that is capable of threatening the populace through its femaleness; that it is the duty of the medical man to use his authority to prevent the female body from becoming unruly and endangering women, families, and society. Also, by virtue of the fact that a woman’s own

behavior can ostensibly cause or exacerbate the illness, she can then be held accountable should the illness get worse. In these moments (Burney's retelling of her diagnosis and Rodman's publications), we see the power of the medical professional both in private consultant and as public advisor, and the way in which the medical man begins to use that authority to develop the expectations of the ideal breast cancer patient: she is calm; she is enduring; she does not burden other women with the stress of her illness; and she does not burden or frighten society with it either. Her emotional responses to her illness are regulated; if she does not respond appropriately, she must bear the consequences. Not only she, but others as well, might be affected by the consequences of her behavior and her illness, as we have seen above from Rodman; it was common to believe that a woman could be accountable for spreading her cancer simply through exciting the sympathies and emotions of others. Here, as Burney notes via her suspicion that there was "reason for inquietude" she, like so many women of the era is stuck in an incredibly difficult catch 22: she cannot allow herself to suffer from or exhibit emotional distress—she risks worsening her illness or potentially spreading it to others—but her doctor has just given her news which should almost inevitably bring on such distress. This conflicted position, of being stuck between socio-cultural expectations for behavior and desiring to express genuine responses to illness, will be (and continues to be) a common experience for women with breast cancer in the 20th and 21st centuries.

The belief of the pathological link between illness and emotion is corroborated by the behavior of Burney's second doctor (for she finds Dubois intolerable), Larrey. While

he is much more empathetic and tender in his treatment of her, and her condition appears to be improving, he too believes that her condition is worsened by emotional states. When she receives the news that Princess Amelia has died, and that King George III is ill, she is deeply upset.<sup>34</sup> Her response to these incidents are not out of line; it's reasonable for any constituent to be shocked and saddened by the death and illness of her country's leaders. In this case though, for women, health is linked to emotional distress; her emotional response becomes a diagnostic lens through which her illness is perceived. Larrey's inquiry about her emotional state is immediately followed with a diagnosis that her tumor has worsened, as we see from her letter: "The good M. Larrey, when he came to me next after the last of these trials, was quite thrown into a consternation, so changed he found all for the worse...and presently, sadly, announced his hope of dissolving the hardness were nearly extinguished. M. Ribe was now again called in—but he only corroborated the terrible judgement..." In this passage, we see that not only Larrey but a third health professional (an anatomist) associates her emotional response over these incidents with the depreciation of her health and the worsening of her cancer.

Burney endured several diagnostic sessions throughout 1810 and 1811, which she describes in letters to her sister and nieces, and in which she recounts the fact that she finally capitulated to the surgical option (which would have meant surgery without anesthesia, since anesthesia did not come into common use until around 1846). Burney

<sup>34</sup> The complete text of the letters can be found online. See Burney, Frances. Manuscript letter in the Henry W. and Albert A. Berg Collection, New York Public Library.

writes that Dubois (who is brought back on the scene at the request of Larrey) tells her forthrightly, “You must expect to suffer, I do not want to deceive you—you will suffer—you will suffer very much!—” Roughly a hundred years later, during the time of “benevolent deception” physicians withheld diagnostic and treatment information from patients in an effort to avoid confusing or agitating them (Skloot 63). This strategy, in which there is a lack of transparency, will become a problem with 20th century medicine. However, as we see from Dubois' remark above, that is not the case in his communication with his patient. He has been abundantly clear about the pain which will accompany her treatment. We could argue that he is merely being direct with his patient. However, this remark, taken in context with his previous exhibitions of carelessness about, or lack of consideration for, her feelings in other parts of Burney's letters, and with the fact that she essentially fired him once for that type of behavior, indicates a pattern of lack of consideration, rather than a directness of rapport out of respect for his patient. He has already blamed her for exacerbating her illness by waiting so long to report her condition to physicians, and makes no pretense of attempting to minimize her pain or anxiety. More importantly, it synthesizes one aspect of the view of the medical hegemony about a woman's experience of the illness, and it aligns with previous pathologization of the female body: because of her very femaleness, a woman may be expected to endure a great deal of pain. This expectation is the foundation for the expectation of the ideal breast cancer patient as one who willingly endures the painful procedures prescribed by her doctor, and is held accountable if she is not demure and quietly enduring.

Her response to the surgeon's lack of empathy is made clear in her letters. Burney describes her reaction to him as he enters the room to prepare her for the procedure:

My distress was, I suppose, apparent...for M. Dubois himself now softened, and spoke soothingly. “‘Can you,’ I cried, ‘feel for an operation that, to You, must seem so trivial?’—‘Trivial?’ he repeated—taking up a bit of paper, which he tore, unconsciously, into a million of pieces, ‘oui—c’est peu de chose—mais’—(‘Yes—it’s a small thing—but’—) he stammered, and could not go on.

Here, we see how Burney felt the gravity of her situation minimized by her surgeon’s language even though, as we see from the following passage, she describes the surgery itself as quite severe: “...so excruciating was the agony...the air that suddenly rushed into those delicate parts felt like a mass of minute but sharp and forked poniards, that were tearing the edges of the wound...describing a curve—cutting against the grain...while the flesh resisted in a manner so forcible as to oppose and tire the hand of the operator, who was forced to change from the right to the left—then...I thought I must have expired.”

Burney’s description of her surgery is especially telling when compared with that of an 18th century German surgeon named Lorenz Heister, as he describes the ways in which various female patients handle the operation: “Many females can stand the operation with the greatest courage and without hardly moaning at all. Others, however, make such a clamor that they may dishearten even the most undaunted surgeon and hinder the operation...the surgeon should be steadfast and not allow himself become

discomfited by the cries of the patient,” (as cited in Mukherjee 49). Heister claims that women who are brave are quiet during surgery (this equating of bravery with quietness would not necessarily have held true for men), implying that women who cry out, thus distracting their doctors, are somehow misbehaving. They are less than ideal. In this passage, we can see the suggestion of the expectation of the ideal patient to be one who endures torturous pain without complaint or “moaning.”<sup>35</sup> Women were expected to be passive, demure, and quiet, not loud or self-indulgent, and an ideal breast cancer patient should have endured her pain in silence and bravery.

During the time of Burney’s diagnosis and treatment, the surgeon had begun a rise to the top of the medical hegemonic structure, but surgery was still considered a last resort as far as treatment, and a dangerous one at that. Doctors were pessimistic about surgery as far back as the Hippocratic oath, which stated that “it is better to give no treatment in cases of hidden cancer; treatment causes speedy early death, but to omit treatment is to prolong life,” (as cited in Aronowitz 25). Burney’s account of Dubois’ feelings about surgery seem to match the apprehension of the ancient Greeks<sup>36</sup>: “M. Dubois had given his opinion that the evil was far too advanced for any remedy; that the cancer was already internally declared; that I was inevitably destined to that most

<sup>35</sup> At this time in history, the expectation that the “ideal patient” be quiet and stoic was not limited to women; however, as we have seen above, it was incumbent on women to keep their emotional reactions and responses to a minimum, lest they risk inciting sympathy in others and potentially spreading their illness.

<sup>36</sup> See Burney, Frances. Manuscript letter in the Henry W. and Albert A. Berg Collection, New York Public Library.

frightful of deaths, and that an operation would but accelerate my dissolution.” In that era, women did not recognize breast cancer as easily and readily as we do know, and often waited a long time to see a doctor for treatment, by which time the disease had progressed too far to be helped. Then, treatment was often palliative (Knopf-Newman 3). Buchan, on the other hand, claimed that after other treatments—bleeding and compression of the breasts among them—were exhausted, surgery should be the next viable option: “either by knife or caustic...the sooner it is done, the better,” (Aronowitz 26). Robert Aronowitz rightly notes that Buchan’s commentary is an early 19th century example of the “do not delay” rhetoric which will become dominant in the latter half of the 19th century. Over the course of the 20<sup>th</sup> century, the “do not delay” concept morphed into the “early detection means a cure”<sup>37</sup> message and remains dominant today. Regardless of the individual physician's opinions about surgical treatment, one fact held true: during the early 19th century, surgery was a frightful and high-risk option until the advent of major advancements which took place in the mid-1800s. By the end of the century, breast cancer surgery would go from a nearly hopeless, last-ditch effort, to the first and primary option for treatment. This change initiated nearly a century of debilitating surgical procedures for breast cancer in which the “early detection means a cure” rhetoric would become codified as breast cancer law.

The mid-19th century saw two major shifts in medical practice which resulted in

<sup>37</sup> The “early detection means a cure” message, as part of breast cancer awareness, will be discussed thoroughly in Chapter 3.

significant changes in thinking about, and treatment of, breast cancer. In 1846, surgical anesthesia became widely popularized and came into common usage in western medical applications. Anesthesia, of course, meant that patients could be unconscious during surgery and thus unaware of the pain, making many patients more inclined to surgical options. According to Marci Jane Knopf-Newman, it also made ablation a viable option for treatment (8). In 1869, Joseph Lister used carbolic acid as an antiseptic while he removed a tumor from his sister-in-law's breast on her dining room table (Mukherjee 58), and by the 1870s, antiseptic practices of various stripes were commonplace, cutting down a great deal on dangerous post-surgical infections. This advancement meant not only that patients could be made unconscious for surgery, but that it was something they had a real chance of surviving. Rapidly, surgery became a much more viable option for the extirpation of breast cancer tumors but, as Aronowitz points out, it brought to light many more questions about the causes and nature of breast cancer, and the effectiveness of surgery at various stages of the development of cancer of the breast (54). Particularly, these advances set the stage for the popularization of the Halsted radical mastectomy procedure, a controversial procedure which would later serve as an important symbolic catalyst of the modern breast cancer awareness movement.

While it was visibly evident to doctors that surgery was an effective way to remove breast cancer tumors (and thus, it seemed to them, an effective option overall), the fact remained that women continued to relapse or die from what appeared to be the same illness, even after surgery had been performed. Aronowitz claims that this phenomenon

supported the theory that breast cancer was a constitutional illness. According to O'Toole, to understand an illness as constitutional meant that it had something to do with “the make-up or functional habit of the body, determined by the genetic, biochemical, and physiologic endowment of the individual, and modified in great measure by environmental factors.” The term “constitutional” encompassed many possible speculated causes of breast cancer other than localized tumors: stress, hysteria, chronic irritation of the breasts (such as that which occurred from corsets and laces), possible hereditary factors, “sympathy” between organs which caused the cancer to spread, or the general weakness of the female constitution. While some physicians believed in the constitutional theory of the cause of cancer, others believed that cancer was localized in the specific tumor locations. Commitment to the belief in localization, as Aronowitz recounts, was popular among surgeons, because it supported their primary method of dealing with illness, as William Jenner noted: “You are not to believe it because it is true, but because it is necessary in order that you should operate,” (as cited in Aronowitz 59). But at that point, both concepts were merely theories and the empirical data had not been collected to fully justify either one. Doctors and surgeons simply drew on their own anecdotal knowledge and that of other professionals (Aronowitz 59). In the late 1870s, the Pathological Society of London reached the compromising consensus that while the illness may be constitutional in its general origin, it is primarily local (Aronowitz 57). This compromise was made more specific by the definition and application of the word *metastasis* which, in its application to cancer, then came to mean “the transmission of the

physical matter of cancer...cancer cells,” (Aronowitz 60). According to Aronowitz, the acceptance of the constitution as causation could then explain the process by which a cancer metastasizes, but called into question the effectiveness of surgical options: “What good was surgery if tumors may have already spread throughout the body in a latent way?...surgeons began...asserting that there existed a discrete time interval in the natural history of cancer during which latent metastasis had not yet occurred,” (61). In essence, the assertion meant that breast cancer followed a predictable, logical progression, the final stage of which was metastasis. Breast cancer had a simple timeline from beginning to end—a timeline which Aronowitz identifies as its “natural history”—and that patients who were vigilant could catch their cancer early in this progression and simply stop it from worsening or spreading. By the time the Victorian era had begun, surgeons encouraged the belief that patients had a limited amount of time in which to extirpate cancer before it began to metastasize, though they had very little reliable evidence to support the rhetoric.

This theory of the natural history of breast cancer was handy for surgeons to encourage the use of their services: patients who found the cancer for which they were so vigilantly watching, could just come have it removed. But the natural history theory also had another effect: where previously accountability for illness was laid at the feet of women via accusations of distress, hysteria, corset-wearing, or other constitutionally-based ideas, in this new era in which the idea of a natural progression from local to metastatic was supported, women could still be held accountable for their

illness by virtue of the accusation that they had waited too long to seek diagnosis and treatment. The work of Buchan, in the early 19th century, was a precursor to this phenomenon: “the unhappy patient conceals it too long...after the disorder has arrived at a certain height, it generally sets all medicine at defiance,” (as cited in Aronowitz 26). We can see the real effects of the natural progression theory in the 1891 account of Alice James, sister of Henry and William James, regarding her breast cancer diagnosis:

Ever since I have been ill, I have longed and longed for some palpable disease, no matter how conventionally dreadful a label it might have, but I was driven back to stagger alone under the monstrous mass of subjective sensations, which that sympathetic being “the medical man” had no higher inspiration than to assure me I was personally responsible for...” (as cited in Aronowitz 71)

Alice had experienced a whole host of illnesses and symptoms, so her breast cancer took time to diagnose; by the time she was diagnosed, there were no options but palliative measures (Knopf-Newman 3). It’s clear from this passage from her diary though, that her doctor made her feel that she is to blame for the advanced progression of her illness. This shift in the 19th century sets the stage for the “early detection equals a cure” rhetoric that would become so much a part of the 20th century discourse around breast cancer. It also forms the foundation for the subsequent phenomenon of blaming women who are diagnosed with breast cancer: the woman who waited too long for treatment put her own life at risk, but also risked the well-being of the family for which she was responsible. Had she only come in sooner, she could have been cured. Therefore, she was responsible

for the outcome. Finally, the “early detection equals a cure” message also empowered and supported the common use of the Halsted radical mastectomy, the surgery which would become the “gold standard” or breast cancer treatment until the 1970s, and which would disfigure many women.

In the 1870s, William Stewart Halsted was already a well-known and successful surgeon who had studied in Europe and worked at Bellevue Hospital in New York and Johns Hopkins in Baltimore. Because of his successful surgical practice and the amount of patients through his doors on a consistent basis, Halsted earned himself the moniker, “Jack the Ripper” during his early career (Imber 122). During his research trip to Europe, he had learned about a German surgeon named Volkmann using increasingly aggressive surgeries to treat breast cancer tumors; but he also knew that many patients had experienced relapse (Mukherjee 64). The extensive and aggressive surgeries appeared to have a limited effect. Halsted was also aware of the work done by Charles Moore examining the margins around the excisions for breast cancer tumors, and Moore’s observation that the tumors seemed to recur around these margins, indicating the possibility that not all of the cancerous tissue had been removed (64). Additionally, he knew of evidence that cancer spread through the lymphatic channels and that cancer was often found in the pectoralis major and pectoralis minor muscles (Imber 121). All this research led Halsted to one conclusion regarding the best surgical treatment of breast cancer: the surgeon must remove the breast, the pectoralis muscles, the lymph nodes, and even a section of the collarbone in order to reach the lymph nodes beneath it (Imber 121).

Because they involved the removal of significant portions of chest and arm muscle, and sometimes bones, his surgeries often left his patients recovering for months or years, often permanently disfigured or debilitated (Mukherjee 65). Many suffered ongoing weakness, chronic pain, or even loss of use of their arms on the side of their bodies where the surgery occurred. Additionally, because allopathic medicine had taken up Benjamin Bell's Enlightenment-era claim that part of a good recovery included a speedy path from diagnosis to surgery, surgeons performed the biopsy and then surgery (if necessary) in the same operation (Knopf-Newman 7).

To compound matters, Halsted subscribed to the belief of "benevolent deception" articulated earlier in this chapter, in which physicians withheld diagnostic information from their patients (relatively standard practice at this time), ostensibly for their own good. As we saw with Burney, there was some sense on behalf of physicians that extremes of emotion could exacerbate a malignancy; many women were not even told they had cancer. Many of Halsted's patients underwent this whole procedure never having been told their diagnosis (Aronowitz 127). Women went into surgeries not knowing what their affliction was (although their families were often informed and consulted), and woke to find all of their breast and a good portion of their chest missing and that their arm had very limited function, though there was no solid evidence of the benefits of the Halsted over other methods.

Epidemiologists began gathering data to support the success of Halsted's procedure, and the data appeared to indicate that the Halsted method was the best option: "Those

statistics reinforced the early 20th century belief that a woman could choose between the Halsted radical mastectomy and death,” (Knopf-Newman 8). In 1894, Halsted published a paper in which he claimed that of 50 cases he had treated, only three exhibited local recurrences, which was a 6% recurrence rate (compared to 50% recurrence rate found in other surgical methods) (Imber 124). Women came rushing to Halsted for their procedures (Imber 123) and it quickly became the standard method for treating breast cancer. But a closer look at the reasoning behind the statistics reveals that its effectiveness was misconstrued. First, Halsted de-emphasized the idea of metastasis and instead focused almost solely on local recurrences. He believed that metastasis subsequent to surgery was basically irrelevant to surgery: “By positing the distinct and separate clinical course of local disease and metastatic disease, Halsted rationalized his emphasis of the complete operation by the absence of local recurrences rather than saving his patients’ lives,” (Aronowitz 95). So, Halsted’s “successes” for the radical procedure were measured by how many women did not have local recurrences after their surgery, and some of those successes include women who died years later of metastatic breast cancer (96). By 1898, Halsted’s own evidence had begun to demonstrate the lack of true effectiveness of the procedure. He presented data at a conference of the American Surgical Association of New Orleans which claimed that his method was much more successful than any other at preventing local recurrence, but that over 76 breast cancer patients who had originally undergone the Halsted radical mastectomy, 36 had died within three years of surgery (Mukherjee 68). That’s a mortality rate just over 47%.

During his career, Halsted admitted that he had performed surgery for what he termed “moral reasons,” which meant that he would perform his surgical procedure on women in order to preserve their hope (Aronowitz 96). This idea of the importance of the preservation of hope in the face of breast cancer would remain a part of cultural thinking about breast cancer throughout the 20th century (as we shall see in later chapters).<sup>38</sup> However, Halsted was also careful to note that he never considered cure the goal of surgery. Which begs the question, what exactly did he suppose he was offering women hope for, if not a cure? If the goal of radical surgery is not a cure, what else could a reasonable goal possibly be? Perhaps, since doctors hypothesized that women’s emotional states could exacerbate their physical conditions, Halsted believed performing the surgery could offer some emotional consolation, some semblance of control, which might allow the patient some more time, or might alleviate pain. Regardless of the evident problems with the Halsted procedure, it became the “gold standard” for breast cancer treatment, and the structure of health insurance in the early 20th century continued to support this ascendancy: extremely invasive procedures offered the most financial benefit to healthcare providers and doctors because the insurance company paid more for them (Knopf-Newman 10).

Notably, while female and feminist writers seeking to explore the effects of the Halsted procedure, and the possible glorification of Halsted’s views on cancer treatment,

<sup>38</sup> The emphasis on hope is still prevalent. See Ehrenreich, Barbara. “Welcome to Cancerland.” Harper’s Magazine.

have often found great fault with Halsted and his work, contemporary male scholars writing on Halsted tend to take an apologist approach, including the famed author of *The Emperor of Maladies*, Siddhartha Mukherjee: “William Stewart Halsted, whose name was to become inseparably attached to the concept of ‘radical’ surgery, did not ask for that distinction. Instead it was handed to him without almost any asking...Halsted didn’t invent radical surgery, He inherited the idea from his predecessors and brought it to its extreme and logical perfection...” (60). Further, Aronowitz (who, like Mukherjee is male and an M.D.) implies that Halsted has been unfairly judged: “breast cancer activists in recent decades have often vilified Halsted and the ‘Halsted mastectomy’ which has been depicted as a mutilating operation imposed on women by patronizing and insensitive male surgeons,” (86). Though he makes an attempt to appear objective in his summation of the controversy over Halsted, Aronowitz also calls him an “icon” and does not acknowledge the fact that Halsted knowingly continued to perform a surgery which he knew was debilitating and for which he had little to no evidence of decreased mortality. Aronowitz does not acknowledge or include the perspectives and observations of women who have undergone the surgery. These very recent reflections on Halsted’s work also focus on his story and his successes and achievements: the remarks demonstrate the paternalistic power of the medical hegemony still present in modern cultural discourse of breast cancer and glaze over the lived narratives of the women who were subject to the genuine brutality of breast cancer treatment. While it’s important to acknowledge Halsted’s body of work objectively, we should bear in mind that remarks like these may

feel marginalizing to many women who feel their stories of pain, struggle, and lifelong debilitation may go widely unheard, even by scholars like Mukherjee who is widely acclaimed as having written a comprehensive cultural history of cancer.<sup>39</sup>

As if the threat of surgery (which had become the primary treatment option by the late 19<sup>th</sup> century) wasn't enough, the Victorians feared breast cancer because they had come to revere the breast as a symbol for home and hearth (Knopf-Newman 6). The breast, as a symbol of the woman's own sexuality and vitality, was far less important than the breast as representative of the maternal nurturing of the nuclear family. Ellen Leopold notes this occurrence: "Any pleasure a woman might take in her own body or her own life was deemed inconsequential to the culture...what did matter was the preservation of family life. Inescapably, breast cancer put this at risk," (*A Darker Ribbon* 31). The breast was representative of a woman's responsibility to her family; therefore, the destruction of the breast threatened by breast cancer symbolically endangered the woman's obligation to her family. Moreover, any individual woman's desires, wants, or feelings about her own sexuality, her own perception of femininity, or the treatment of her body, was secondary (or even tertiary) to cultural needs to preserve women's roles as mothers and domestic caretakers, rather than individuated, sexual beings. These ideas were the foundation for the expectation that women with breast cancer maintain heteronormative bodies and behaviors. Jackson defines "heteronormativity" as "institutionalized, normative

<sup>39</sup> For this reason, we need to expand our cultural understanding of the experience of breast cancer, and culturally acknowledge the vast variety of experiences many women have with the illness, as I shall elaborate in later chapters.

heterosexuality” (105). In the context of this definition, heterosexual relationships are considered the norm, and gender roles within heterosexual relationships are considered the definitive roles. In heteronormative thinking, women are identified as wives and mothers in nuclear families, and they perform traditional gender norms of femininity. Women with breast cancer were expected to forego their own complex feelings about their bodies, their illness, and their treatment in order to maintain heteronormativity, and expectation which remains with us today, and which we shall explore in later chapters.<sup>40</sup>

The symbolic importance of the breast was one salient factor which catalyzed breast cancer awareness. Another factor was the spread of the belief in the natural history theory of breast cancer. The spread of natural history theory led to widespread beliefs that women who went to the doctor immediately after finding a lump could (and inevitably would) be cured of their cancer. This was an oversimplification: “cure” was a rather deceptive word, because many physicians defined “cured” as having had the tumor extirpated from the body. They did not take into account the later recurrences or metastasis which were probable. The emphasis on the breast as a symbol for healthy homes and families (which we saw above), coupled with the ostensible need for immediate diagnosis and treatment of breast cancer, served as a catalyst for growing awareness about, and discussion of, breast cancer. However, it also became the foundation for the notion that women had a responsibility to see their doctors as soon as

<sup>40</sup> In chapter three, we shall also discuss the LGBTQ community in the context of the expectation of heteronormativity for breast cancer patients.

they were aware of symptoms, and that they could be held accountable for failing to do so, as we shall also see in later chapters.

In 1913, the American Society for the Control of Cancer formed with the primary purpose of spreading awareness about cancer prevention and treatment (Knopf-Newman 16). In fact, Aronowitz claims that spreading the “do not delay” message was the “raison d’être” for the society (144). Often, the “do not delay” message made use of the the presumed importance of the female body to her husband and family in order to impress its message upon women. An ad published by the New York City Cancer Committee, for example, tells the story of a young newlywed man whose wife has detected a lump. She is resistant to visiting the doctor, a family friend, but her husband tells him and he comes to dinner: “The doctor confronts the newlywed...tells her to take off her blouse, pays ‘no attention to her hysterical attitudes,’ examines her, and sends her...to the hospital where she immediately has an operation,” (146). The woman in the ad is understandably alarmed and made anxious by the fact that her husband has planned a dinner that is tantamount to an ambush, and that her family friend orders her to remove her blouse for an exam, and yet her response is labeled “hysterical” by the male doctor. Because she has not behaved in a way that fulfills her social expectations--abiding the advice of her husband and medicinal professionals to get checked—she is labeled as “hysterical.” This word is key because, since the time of ancient Greek medicine, it has been associated with mistaken assumptions about the ways in which female biology (specifically, the “wandering womb”) affects behavior. This woman is doubly dismissed by the use of the

word: first, the word implies inappropriate levels of irrationality. This woman's resistance to her doctor's dinner ambush seems objectively rational and reasonable, yet she is labeled with a word that dismisses her emotional response. Second, the etymology of the word tells us that it has long been used to (mistakenly) associate female biology with illness, to pathologize women simply for their femaleness. While we could argue that the husband is well-meaning and concerned for her health--there's no evidence to the contrary--it's important to note that he does not respect her privacy. Against her wishes, he tells the doctor, and neither man seems to acknowledge the deeply intrusive nature of what happens during dinner. Finally, the story of the illness, which is uniquely female, is narrated by two men. And yet, the oversimplified "do not delay" message persisted.

The ASCC launched a program called the Women's Field Army in 1933, and the program recruited women to work in community groups to raise awareness and spread the "do not delay" message (Knopf-Newman 16). The "do not delay" message stemmed from belief in the late 19th century theory of the natural history of breast cancer, the idea that breast cancer followed a predictable, orderly timeline of growth and metastasis. A quick Google search by any layperson reveals dozens of posters for the movement, many of which emphasize early detection, such as one which reads "'Early' is the watchword for cancer control." According to Karli Jane Cerankowski, many of these advertisements also claimed that cancer could be cured if patients only made it to their physicians in time for proper treatment. Both of these strategies reified the belief that early detection was tantamount to a cure, even when evidence did not support the message. The public

latched on to the oversimplification that “early detection means a cure,” believing, essentially, that as long as breast cancer was detected and attended to at early stages, that it not only *could* be cured, but that it *would* be cured. On its face, the concept of encouraging the populace not to delay in treating an illness seems fairly innocuous, but in the case of breast cancer, the message is complicated when it intersects with other messages and strategies of the early movement. By this simplified logic, any woman who is not cured of her breast cancer simply didn’t detect it early enough or get medical attention early enough, a behavior for which she can be held accountable. Additionally, mammograms had not come into use yet, so treatment and removal of breast cancer was fairly primitive: early detection meant surgery nearly every time. Many women with early stage cancers may have undergone unnecessary surgeries. Some of the lumps may not even have been breast cancer, and many women who did have cancer had recurrences or metastasis anyway. Very little was known about the types and stages of breast cancer at that time: sending the “early detection equals a cure” message was an overreach on behalf of the campaign.

The advertisements added to their urgency (and played on the patriotism generated by the war efforts of World Wars I and II) through the usage of war metaphors and battle language. Women were encouraged to “enlist” in the group (Knopf-Newman 16) and posters often encouraged women to “fight cancer” and pictured strong female figures wielding swords. At this point, the breast cancer awareness movement took on the role of spreading public messages about breast cancer. The perpetuation of the “early detection

means a cure” message, along with the usage of battle metaphors, creates problematic cultural connotations of breast cancer that we still deal with today. The “early detection means a cure” message implies that those who do delay are responsible for the outcome; the battle metaphor implies that those who “lose the battle” to cancer simply didn’t fight hard enough. Both support and encourage the problematic victim-blaming which we saw in the 19th century. This implication of the message is still prevalent today, and the problematic nature of its usage will be discussed and developed in later chapters.

When it came to breast cancer, the young awareness movement continued to emphasize the importance of the breasts as symbols, a focus which had begun with the Victorians at the end of the 19<sup>th</sup> century. Breasts continued to represent the ultimate manifestation of femininity: motherhood. They represented a woman’s ability to create and nurture a nuclear family, contributing to the social welfare. The movement exploited that symbolism by implying that women who did not engage properly in the construction of such a family, got breast cancer as punishment. Knopf-Newman notes this phenomenon in her mention of a 1935 medical report (which initially appeared in the work of Leslie Reagan) which called breast cancer “the penalty women pay for failing to bear and...nurse children,” (18). This reportage, according to Knopf-Newman, “suggested that women had to succumb to their biological destinies as wives and mothers,” (18). It’s important to note that now, we do know of substantial research to demonstrate that bearing children, particularly before 30, can lower a woman’s risk for breast cancer. However, this research had not yet been conducted in 1935. Also, this kind of advertising

again creates an oversimplification of a complex situation. It assumes that women are not only biologically “destined” to be mothers but also to be wives (implying that un-wifely behavior is risky, too). This assumption is also potentially hurtful and unnecessarily frightening to women who can’t bear children for medical reasons. In 1953, a woman named Terese Lasser partnered with the ACS to form an organization called “Reach for Recovery,” which was meant to help women deal with the loss of a breast. While this organization did much good work for many women, one of its early problems was that it reified heteronormativity. Lasser, for example, when asked about the reasons she began the “Reach for Recovery” organization, responded: “The first thing you think about is whether or not you’re going to live...And then the second thing you think about is how the man in your life is going to react,” (Klemesrud 46). While it’s reasonable to assume that many women’s first thoughts after diagnosis would relate to their own mortality, the pairing of these two things appears to imply that a person’s physical well-being is related to person's ability to perform heteronormativity, that the person should focus on the “man in [her] life” and a role in the nuclear family and household. If we relate a person’s mortality to the ability to perform heteronormatively, we also risk the implication that the person is responsible if they get cancer—because that person didn’t perform the proper role. Or, at least, that person is accountable for whether or not their spouse still finds them attractive after surgery.

While their methods may have been somewhat ill-conceived, the ASCC (later the American Cancer Society) and the Women’s Field Army, had begun to spark public

awareness about breast cancer and self-examination. However, by the time the famed author and environmentalist, Rachel Carson, was diagnosed with breast cancer in 1960, it was not an illness which offered women an opportunity to discuss a shared experience; they did not speak to one another of their experiences with breast cancer (Leopold *A Darker Ribbon* 114). Adrienne Rich, in her poem, "A Woman Dead in Her Forties," notes the significance, the burden, of this silence: "I want to touch my fingers/to where your breasts had been/but we never did such things," (Rich 53-58.). Part of the social expectation of polite, demure women, an expectation which had been common for several decades, was that they not discuss or share their illnesses with one another. Leopold notes this expectation in her commentary about the experience of Katherine Coman in the early 1900s: "Women who had to endure breast cancer surgery often hid their disease, even from members of their own families. It was not uncommon for children to be kept in the dark," (Leopold *My Soul is Among Lions* 18-19). It was still an illness mostly shrouded in secrecy and mystery, and not one for which women found many venues of acceptable discussion. This atmosphere enforced the social expectation that well-behaved women did not discuss their cancer; they fulfilled the expected social role, and the role of ideal patient, by enduring silently. It should be observed, additionally, that members of the LGBTQ community would not generally have discussed their sexual identity publicly, either, and so were doubly silenced by social norms if they acquired breast cancer.

Carson, however, rebelled against many of these conventions, enacting agency and demanding a reciprocal relationship to her doctors. She insisted that full disclosure of her

diagnosis be given to her so that she could investigate options and participate in treatment decisions (Leopold *A Darker Ribbon* 116). It was through her investigation of these options that she came across Dr. George Crile, Jr. Like Carson, Crile, too, flew in the face of his peers when it came to their beliefs about breast cancer. In his book, *Cancer and Common Sense*, he claimed that the Halsted mastectomy was overly radical, not necessary, and ineffective. Further, he encouraged women to insist that their doctors be transparent with them regarding their diagnosis and treatment outcomes: “Do not be afraid to ask your surgeon to tell you the truth...If you do not ask him, he may evade the issue,” (Leopold *A Darker Ribbon* 117). A survey of medical professionals around this time reveals that, with regards to cancer diagnosis, 90% still applied the concept of benevolent deception, and chose not to tell their patients about their diagnosis of cancer (122). They avoided the word “cancer” itself and, when pressed, used euphemisms like “lesion” and “mass,” arguing that this choice was in the patient’s best interest (Leopold *A Darker Ribbon* 122-123). Conversely, a report by the Canadian Cancer Society reveals that when women were asked if they would want to know their diagnosis, two-thirds claimed that they would (123). Notably, 20th century physicians rationalized the choice to mislead patients using very similar logic to that of their 19th century counterparts: the patient might become depressed, emotional, or despondent (123). While this evasiveness on behalf of physicians would have been fairly normal behavior with regard to all cancer diagnoses (not just breast cancer), it’s important to understand the context and atmosphere in which Crile was voicing his opinion. His book was specifically directing women,

breast cancer patients, to utilize their voices, empower themselves, and demand transparency (Knopf-Newman 10-11). The phenomenon of note here is not the benevolent deception which, shocking as it may seem to us now, was fairly standard; rather, it was that Crile flew in the face of that professional standard, specifically when it came to breast cancer treatment, and that that flouting of professional standards was one of the major actions which earned him the ire of agencies like the American Cancer Society, the American Medical Association, and the National Cancer Institute (Knopf-Newman 10). As Leopold notes, Crile's work angered his peers in the medical field, as one fellow physician noted: "The trouble with Crile is that he advocates so many goddamn different things...He has introduced a sense of chaos into breast treatment. Now any surgeon can do anything he please for breast cancer and call upon Crile as his authority," (*A Darker Ribbon* 117). What this man may have been identifying as "chaos" is an upset of the male-dominated medical hegemony to which so many physicians had become accustomed. Additionally, in his work, Crile exposed the fact that the structure of health insurance meant that extremely invasive procedures offered the most financial benefit to healthcare providers and doctors, and therefore health insurance inadvertently supported the frequency of such a procedure, which also didn't gain him much popularity among his peers (Knopf-Newman 10). The American Cancer Society, the American Medical Association, the National Cancer Institute, and the American college of surgeons all took issue with his revelations, citing their belief that he should not have shared his theories with the laypeople (Knopf-Newman 10). Though Crile's arguments were

well-reasoned and supported by evidence, his peers in these prestigious and renowned agencies all took sides against his disclosures, which might be a maneuver on behalf of the medical hegemony to retain some of its power.

Carson had read Crile's work, so she got in touch with him. She had already undergone a Halsted radical mastectomy, but her prognosis was not good and she sought further advice from Crile (*Leopold A Darker Ribbon* 118-119). Carson's action, pursuing a second opinion (and doing so without using one's husband as an intermediary or representative) was rare for women (118-119). Carson, sadly, died of complications related to breast cancer in 1964 and, though Crile stopped performing the Halsted procedure (and instead favored modified radical mastectomies or lumpectomies) and a few surgeons followed his lead, the majority of doctors continued to use the Halsted into the 1970s. Many doctors continued using the Halsted procedure throughout the mid and latter 20th century because they were simply resistant to change or had grown accustomed to the lucrative nature of such a procedure, even though there was little to no evidence that it was more effective than other procedures. In the case of the Halsted mastectomy, we see that biomedicine has a great deal of power with regard to breast cancer treatment. While some women—like Burney—had been enacting agency in their own ways for many years, the imbalance of power between medicine and patients would really begin to dissipate during American second-wave feminism in the 1970s, when the women's health movement began to encourage women to seek further agency and empowerment in their diagnostic and treatment processes.

By the late 1960s, the power of the medical establishment had begun to change. Mukherjee elaborates: “By the late 1960s, the relationship between doctors and patients had begun to shift dramatically. Medicine, once considered virtually infallible in its judgement, was turning out to have deep fallibilities—flaws that appeared to cluster pointedly around issues of women’s health,” (199). In the late 1960s and early 1970s, America was in an uproar as various groups resisted hegemonic power structures like the military, medicine, and government. Women began to seek more and better options with regard to their health care, rather than accepting the status quo. Women with breast cancer, for example, specifically, sought to eliminate the “one-step” procedure (in which women went under anesthesia for a biopsy but, if a malignant tumor was found, also had a Halsted radical mastectomy performed in the same procedure). Rose Kushner, a journalist who had also had breast cancer, advocated against this procedure through an article in *The Washington Post*, in which she asked, “Why do surgeons feel they have the right to make the decisions for their unconscious patients? Why not allow them to wake up, be told the diagnosis, and the alternatives and options available?” (as cited in Knopf-Newman 89). According to Barron Lerner, Kushner also took on the American Cancer Society by criticizing Terese Lasser’s “Reach for Recovery” program: she claimed that it distracted women from their pre-surgical options. Lerner notes that the ACS, predictably, took a stance against her. Kushner, like Crile, also objected to the Halsted radical mastectomy, and some physicians had begun to believe likewise, such as Bernard Fisher who, as chairman of the National Surgical Adjuvant Breast and Bowel

Project, began research to demonstrate the lack of efficacy in the procedure (Mukherjee 200).

First Lady Betty Ford's experience, and her intersection with activist Rose Kushner, offers much to consider with regard to women's simultaneous agency and oppression. In 1974, Betty Ford, wife of then-President Gerald Ford, was diagnosed with cancer. Ford made her diagnosis public eighteen days after her husband pardoned former President, Richard Nixon, in an effort to divert the public's gaze from that event (Knopf-Newman 59). Though her overt intent was to distract from what may have been perceived as a scandal, a side effect of her disclosure was that suddenly breast cancer was a matter for public discussion. Because of her position, Betty Ford was able to effectively break the public silence about breast cancer.<sup>41</sup> In this way, the First Lady demonstrated some use of her privileged position: as a public figure, she had the power to open the discussion for other women which had not been previously open to them. However, though she may have been going against the tradition of silence, it would be inaccurate to say that she became a full-fledged breast cancer rebel. In fact, according to Barron Lerner, Rose Kushner attempted to use private contacts to get in touch with the First Lady to inform her of her options and discourage her from having a radical procedure but was told "that the President had already decided that his wife would have the one-step radical procedure." So, in this case, First Lady Betty Ford's body was subject not only to

<sup>41</sup> Knopf-Newman analyzes this phenomenon thoroughly in *Slash, Burn, and Poison: Transforming Breast Cancer Stories into Action*, pages 72-76.

presidential politics, but also to the legacy of medical power.

Ford's position in the public eye meant that her behavior in response to her breast cancer would have been widely scrutinized; she was expected to perform the role of the ideal breast cancer patient. And that she did, as we see in several examples, not the least of which is story told by the picture taken of herself and her husband shortly after she has had her radical mastectomy surgery (Knopf-Newman 74-75). The President and First Lady are at a Washington Redskins game and the team has signed a football for the President to give to the First Lady. In the picture, President Ford has just thrown the ball to her, and she is pictured, right arm aloft and reared back, holding the ball and about to toss it back to her husband (75). This physical movement following a Halsted procedure would have been, at worst, nearly impossible, given the muscle removal and nature of the injuries; it would have been, at best, incredibly painful. And yet, First Lady Ford smiles and throws the ball, at once fulfilling and reinforcing the concept of the ideal breast cancer patient (by enduring her pain without complaint) and the good wife (by standing by her man and making him look good for publicity). Ford may have been integral to breaking the silence so that women could start to speak with others about breast cancer, but the long-standing cultural norms and expectations surrounding the illness were still highly influential and a part of many people's experience.

The shift in use from the Halsted procedure to the modified radical mastectomy or the lumpectomy was the result, primarily, of the coinciding of the second-wave feminist movement of the 1970s with open discourse about breast cancer and its treatment; the

standard procedure changed because patients advocated for change with their doctors. Finally, in 1981, physician Bernard Fisher published a definitive study that included 1,765 patients. The study divided women into three groups: those who had been treated with Halsted radical mastectomies; those who had been treated by simple mastectomy; and those who had been treated with surgery and radiation (Mukherjee 201). The study revealed that there was no difference in rates of recurrence, relapse, death, and distant metastasis for any of the three groups. While the Halsted fared no worse than other procedures, by this measure, it also fared no better; its more invasive method was proven no more effective than any less radical treatments (201), which means that the most debilitating aspects of the procedure, such as removal of arm muscle and chest muscle, were unnecessary. After nearly 100 years of medical science clinging to the procedure, the Halsted mastectomy finally fell out of practice.

By the late 1970s, Kushner's work and the public discussion of Betty Ford's breast cancer had meant that many women had begun to voice their concerns about radical surgery, and that many had begun to resist it. Audre Lorde, the black, lesbian, feminist poet, was one of those women. In an era in which women had only recently begun to speak publicly about breast cancer, and in which they still struggled mightily to get out from under the power of allopathic medicine, Lorde came forward to claim space in the discourse about breast cancer, but also to attempt to stake a claim in that space for black women and lesbians, too, as she writes: "For...women of all ages, colors, and sexual identities who recognize that imposed silence about any area of our lives is a tool for

separation and powerlessness, I have tried to voice some of my feelings and thoughts...” (*The Cancer Journals* 7). Lorde scrutinized and criticized the major trends which may impose silence on people about their breast cancer. She resisted the power of medicine by demanding a two-step procedure, in which those with breast cancer could be biopsied, come out of anesthesia, consider options, and then schedule another procedure if necessary (Knopf-Newman 110). The ideal breast cancer patient is demure, quiet, and defers to medical authority; Lorde calls into question the problematic role of the ideal breast cancer patient by refusing to wear a prosthetic breast in her doctor’s office after a nurse told her that it was “bad for the morale of the office” (60). Lorde observes the expectation that breast cancer bodies return to heteronormative femininity through her criticism of the reach for Recovery organization. When the representative comes to her hospital room to show her how to wear her prosthesis, Lorde wonders how her lover will react to her altered body (Lorde 42-43). She also notes that she cannot relate to this woman: “I ached to talk to women about the experience I had just been through...But I needed to talk with women who shared at least some of my major concerns and beliefs and visions, who shared at least some of my language,” (42). Lorde’s emphasis on language here shows her feeling that her experience is not represented in the contemporaneous discourse of breast cancer. She is not looking for voices exactly like her own, necessarily, but she is craving voices which “share some of [her] language.” She is seeking more plurality in which to identify an experience, a voice, to which she can relate. Finally, Lorde dismantles the victim-blaming inherent in the “early detection

means a cure” mentality by noting that the cultural reaction to breast cancer bodies may cause those with potential breast cancer to delay: “...for the incidence of early detection and treatment to increase, American women must become free enough from social stereotypes concerning their appearance to realize that losing a breast is infinitely preferable to losing one’s life,” (63). Here, Lorde points out that women are still subject to the emphasis on the importance of the breast and appearing normal, and that appearing abnormal is still so highly stigmatized that it may threaten a person’s ability to seek help. The cultural prevalence of heteronormativity, and the stigma which accompanied non-normative appearance or behavior, may have endangered people's lives.

Lorde’s empowerment in telling her own story was a major leap forward on behalf of those with breast cancer. However, her story still remains one of the few widely known breast cancer narratives from both people of color and lesbians.<sup>42</sup> It opened the opportunity for some to speak out and reveal their own experiences, and it sparked some revolutionary thinking in small pockets, but would take decades for larger contingents of people to profoundly consider breast cancer in the way that Lorde had. In the meantime, the dominant hegemonic discourse, always bolstered by the authority of medicine and further supported by the burgeoning pharmaceutical industry, would give rise to the contemporary breast cancer awareness movement, the pink ribbon, and series of narratives which perpetuated the problematic construction of the breast cancer body.

<sup>42</sup> In Chapter 4, we will identify and explore works by other women of color and other non-heteronormative women. We will also identify areas in which current discourse about breast cancer is still lacking diversity.

In 1981, inspired by her sister's experience with breast cancer, Nancy Brinker founded the Susan G. Komen for the Cure Foundation and began speaking publicly about her sister's experiences with the illness and her own. She very quickly became the public face of the contemporary breast cancer awareness movement. By the beginning of the 1990s, she had led Komen to partner with Estee Lauder to begin the pink ribbon marketing campaign to raise awareness (and money). According to Sandy M. Fernandez, Pink ribbons were given away at Susan G. Komen events and distributed to customers at Estee Lauder sales counters. From the very beginning, the pink ribbon was associated with corporate fundraising and the promotion of feminine, middle-class white women.

Fernandez<sup>43</sup> recounts the story of the ribbon's inception and rise to fame. First, in 1979, Penny Laingen, inspired by the song “Tie a Yellow Ribbon Round the Old Oak Tree,” tied a yellow ribbon around a tree in her yard to represent her wish that her husband, a hostage in Iran, would come home safely. The trend caught on, and in 1990, when Jeremy Irons wore a red loop on his lapel to the Tony Awards to represent AIDS awareness, the use of lapel ribbons to represent causes took off . In 1991, according to Fernandez, the Susan G. Komen Foundation, already distributing pink visors at their “Race for the Cure” events, distributed pink ribbons at the New York City race.

Simultaneously, *Self* magazine editor-in-chief, Alexandra Penney, had stumbled upon the concept of creating a pink ribbon, and enlisted Evelyn Lauder, Estee Lauder executive

<sup>43</sup> In her piece, “The History of the Pink Ribbon,” originally published in MAMM and reprinted via Breast Cancer Action, Sandy M. Fernandez gives a detailed history of the pink ribbon, which I have summarized, here.

and breast cancer survivor, to help with production and put the pink ribbons at cosmetic counters around the country. Penney then heard about Charlotte Haley, a 68-year-old woman who had started a small, grassroots movement creating peach ribbons in her home. Fernandez notes that each ribbon came with a card which noted the small amount of National Cancer Institute funding directed to cancer prevention, and requested that citizens contact their legislators to encourage further funding for breast cancer research. Penney contacted Haley about collaboration, and Haley refused for two reasons: *Self* wanted her to relinquish the concept of the ribbon to them, and because the *Self*-Estee Lauder venture was too commercial. Penney contacted attorneys, who advised her to simply choose another color.

According to Fernandez, it is unknown who made the final color choice, or why, but the 1996 comments of Amy Langer, Executive Director of the National Alliance for Breast Cancer Organizations, may shed some light on the subject. When asked about the choice of pink for the ribbon, she responded, “It’s about body image, it’s about nurturing, it’s about femininity...” Thus, the famous pink ribbon was born, and has since skyrocketed to stardom in the breast cancer movement. The story of the creation of the ribbon makes evident its historical roots in corporate involvement, and its investment in traditional ideas of femininity as a means of furthering its message about breast cancer.

With the rise of the breast cancer awareness movement and organizations like Susan G. Komen, and the advent of the famous pink ribbon, breast cancer and its accompanying narratives occupied more and more space in the public discourse of

women's health. Still, most of these narratives circulating in the popular discourse are tidy tales which could be easily categorized as “inspirational,” or “self-help.” They often include saccharine moments meant to encourage those with breast cancer to endure their ordeal bravely (echoing early beliefs that those with breast cancer should endure breast cancer without expressing their emotional or physical distress). The majority of that discourse continued to focus on the ways in which women could restore themselves to healthy, stereotypical femininity, like the ribbon itself. Langer's quote above makes this rhetoric evident. This quote is frighteningly reminiscent of Victorian mentalities about the importance of the breast and breast health which found their way into now-antiquated materials put out by the Women’s Field Army. The word “nurturing” demonstrates the remnants of that era’s connection of the breast to home, hearth, nuclear family. Through its identification of the pink ribbon and breast cancer with femininity, this language places a major emphasis on the expectation that those with breast cancer represent traditional social constructions of female, and on the female’s role in the nuclear family. This rhetoric does not apply to those who choose not to present as stereotypically female and heteronormative, marginalizing several segments of diverse women and trans\* people from the movement. Organizations like this which allege that their purpose is to help those with breast cancer may actually be hindering the conversation by investing in and supporting deeply-rooted hegemonic and patriarchal values.

Few public discussions of breast cancer (if any) address the complicated legacy of

factors which could be a cause of breast cancer, or the experiences of non-heteronormative people, or the ways in which breast cancer treatment and awareness emphasized (and still does) the value of breast as a sexual and symbolic object over the value of a person's life. Many narratives of breast cancer demonstrate (but don't explicitly articulate) the ways in which their authors are made to feel marginalized and abject by these discussions (or lack thereof) of breast cancer. Conversely, many narratives also support and encourage oversimplified narratives and hegemonic values like the ideas of "nurturing" and "femininity" encouraged by organizations like the Komen foundation.

We know that, by the beginning of the modern movement, the female body was pathologized, and that that pathologization, coupled with other factors (like the professional legitimization of surgeons and specialists) contributed to specific messages sent about breast cancer and women with breast cancer in the early movement. From this chapter, we can see the ways in which historical perceptions of the female body shaped, molded, and remained present in the 20th century breast cancer awareness movement. In the following chapter, contemporary illness narratives of breast cancer will be analyzed through the lens of contemporary feminist theory of the body, and they will demonstrate the ways in which current illness narratives of breast cancer show the breast cancer body as abject and monstrous. As we shall see in Chapter 2, the abject breast cancer body is subject to Foucauldian policing and discipline, much of which is actually enacted through the oversimplified expectations for people with breast cancer set by the current breast

cancer awareness movement.

## CHAPTER TWO:

### BEYOND ABNORMALITY: BREAST CANCER BODIES AS ABJECT

In the latter half of the twentieth century, medical treatment for breast cancer has rapidly advanced, and the breast cancer awareness movement has made the topic of breast cancer increasingly accessible to the public. In the last thirty years, breast cancer has moved to the forefront of American awareness. In the late 1970s, women like Rose Kushner and Audre Lorde sought to bring to light critical questions regarding the treatment of and public discourse about breast cancer. By sharing her experiences in the media, First Lady, Betty Ford, catalyzed public discussion about breast cancer. Since the early 1980s fundraising, research, and writing about, breast cancer has increased exponentially. While much progress has been made with regards to discussing breast cancer as a medical concern, there is still room for much to be said in the discussion of breast cancer as a cultural and feminist concern: current public discourse and writing about breast cancer supports problematic constructions of the female body, as we noted in the previous chapter. Elements of those constructions are evident in contemporary discourse about breast cancer, and they create unjust expectations for the ways in which those with breast cancer should behave or manage their bodies. The presence of these

concepts in contemporary discourse, contributes to a master narrative of breast cancer.<sup>44</sup>

The ways in which these concepts lead to marginalization, policing, and discipline of people with breast cancer (as we shall see below) indicate that further exploration is necessary in order to complicate and revise them. Only in doing so can we pluralize the master narrative of breast cancer, which we will discuss in Chapter 4.

Once we see the historic problematic constructions of the female body (and how they found their way into the early breast cancer awareness movement) we have set the stage for an understanding of how the breast cancer body is constituted in the context of the current breast cancer awareness movement. Because we are analyzing contemporary constructions of the female body, it is material to apply modern feminist theory. One specific aspect of feminist theory is particularly germane: in the last few decades, scholars like Julie Kristeva, Mary Russo, and Jane Ussher have developed our understanding of the abject feminine and examined the ways in which the abject body is reified and supported by patriarchy and hegemony. They have furthered analysis of this construction by applying these concepts to contemporary feminist concerns such as the representation of the female body in media and the treatment of the female body in healthcare and narratives of illness. Application of theories of the abject feminine to contemporary breast cancer narratives reveals the ways in which some discourse about breast cancer reifies concepts of the female body retained from the early years of breast

<sup>44</sup> A definition of “master narrative” can be found in Chapter 1, but we shall also discuss the concept of the master narrative further in Chapter 3.

cancer awareness around the turn of the 20th century. It will demonstrate the ways in which some breast cancer patients are subject to these mistaken notions during their breast cancer experiences. According to contemporary feminist theory, the breast cancer body is publicly construed as abject.<sup>45</sup> If the breast cancer body is abject, it is (according to Ussher) subject to surveillance and discipline.<sup>46</sup> As we shall see in Chapter 3, that discipline is enacted through a master narrative of breast cancer which has been codified and exploited by the contemporary breast cancer awareness movement and its pinkwashing strategies. The current discussion, however, is simply aimed at identifying the ways in which the contemporary breast cancer body is abject and monstrous and therefore subject to discipline.

Narratives of illness are often called “pathographies”; scholar Mary de Shazer has coined the term “mammographies” for illness narratives of breast cancer. Analysis of a selection of these mammographies which includes stories, poetry, and visual art, brings to light the ways in which the breast cancer body is constructed as abject. That construction leads to surveillance and discipline of any breast cancer body which does not conform to established socio-cultural expectations. For our purposes, it is best to investigate a wide variety of types of narrative texts in order to show that abject breast cancer bodies are not isolated to one type of story or experience; rather, those with breast cancer are constituted as abject in several different situations and express that abjection in

<sup>45</sup> Concepts of abject and monstrous will be elaborated further below.

<sup>46</sup> Surveillance and discipline, particularly as they are laid out in Foucault’s *Discipline and Punish*, will be expanded and explored further below.

diverse narrative styles. The examples below will show abjection from two perspectives: first, when the woman identifies her own body or the body of another woman with breast cancer in a way that fulfills the definition of abject (which will be elaborated below); and second, when a woman recounts an instance in which she has been made to feel abject by people with whom she interacts.

One of the key characteristics of the abject body, according to Kristeva, is that it represents a breaking down of boundaries, a collapsing of meaning: “Abject...the jettisoned object, is radically excluded and draws me toward the place where meaning collapses...on the edge of non-existence and hallucination,” (Kristeva 2). The abject body is so “radically excluded,” so marginalized from the norm, that it blurs the boundaries between concrete, commonplace perceptions of the human body and those instantiations of the human body which are less normalized, which the brain struggles to reconcile with its straightforward, everyday perceptions of the body. Kristeva claims that this collapse of meaning is particularly represented by the reproductive female body: “...the height of bloodshed and life, scorching moment of hesitation (between inside and outside, ego and other, life and death) horror and beauty, sexuality and the blunt negation of the sexual,” (155). Here, it may help to imagine that Kristeva is speaking specifically about childbirth. In most daily instantiations of the human body, we think of it as representing life or death, inside or outside, horrific or beautiful. In the moment of childbirth, however, the female body represents both sides of many binaries at once: death through bloodshed, and life through the new life of the child. The body represents inside and outside because the

infant is, at the moment of birth, literally inside her and outside her. She represents horror because the process her body is going through can be shocking, unpleasant, or even brutal, but the power of what her body can do, has done, is also beautiful. She represents sexuality because a baby is a product of sex, but negates sexuality because childbirth is generally perceived as a sexually unappealing moment. Kristeva extrapolates that belief further, though: the female body, not merely in the moment of childbirth but because of its symbolic representation of being capable of childbirth, represents this collapsing of boundaries. For Kristeva, the abject body is the body which is radically marginalized, living in the space where critical existential binaries—life/death, horror/beauty, inside/outside—collapse into one another. The female body, in its potential to give birth, collapses meanings of life/death, inside/outside, horror/beauty in this way. For Kristeva, the female body, capable of reproduction, is the primary site of abjection.

Ussher concurs with Kristeva, and uses her definition of abject to note the ambivalence with which society has viewed the abject fecund female body: “Central to this positioning of the female body as monstrous or beneficent is ambivalence associated with the power and danger perceived to be inherent in woman's fecund flesh, her seeping, leaking, bleeding womb standing as a site of pollution and a source of dread,” (*Managing the Monstrous Feminine* 1). Ussher's definition may add some clarity to Kristeva's comment that the abject is “radically excluded and...on the edge of non-existence and hallucination.” Ussher's observation that the fecund female body is both monstrous and beneficent, both powerful and dangerous, parallels Kristeva's claim that the body

collapses meaning and boundaries. Ussher, however, simplifies the concept of the fecund female body existing in our minds “on the edge of non-existence and hallucination”; she notes that we confront this collapsing of boundaries with ambivalence, dreading the mental conflict with which it presents us. Ussher's observation of the power and danger of the fecund female body recalls the ancient Greek belief that women were responsible for the sex of their fetuses in the womb: they were meant to keep the womb warm enough to create a male child (which was considered superior). The womb, then, improperly managed, had the power to “pollute” the fetus, making it female, an occurrence which may also be dreaded. Many other cultures, throughout history, have revered, feared, or misunderstood the female reproductive organs in a variety of ways. As we saw in the last chapter, the female reproductive organs were, throughout the 18th and 19th centuries in the western world, one of the long-standing mysteries of human anatomy. While we must be precise with our terms and note that historical pathologization is not equivalent to the current definition of abjection, early pathologization of the female body may have contributed to its current construction as abject.

Ussher expands the definition of “abject” further, claiming that fecundity of the female body associates it with excess: “Women's bleeding, and the embodied changes that come with pregnancy, birth, and menopause, are irrevocably connected to the discursive positioning of female fecundity as a site of danger or debilitation, with these signs of fecundity standing as signifiers of feminine excess,” (*Managing the Monstrous Feminine* 4). All the features, characteristics, and cycles of the female body which allow

her to reproduce also represent the physical “too much-ness” of a woman who is growing another person inside her. Her entire body represents excess by virtue of the fact that it can create and grow its own additional person. This level of physical excess is dangerous because it cannot be controlled: it is not an experience which falls into binary categories or labels. Rather, it collapses them. Female bodies are perceived as debilitated because they are out of control. This notion of women as debilitated by their reproductive organs harkens back to the late 19th century pathologization of the female body, when their behavioral abnormalities were associated with their female organs or reproductive cycles. Behavior which might be considered “excessive”—staying out late, too much reading—might have been either the cause or the symptom of some malfunction in those organs or cycles. Women, because of their fecundity, are inherently excessive and prone to being out-of-control; they are therefore debilitated. So, we can see how historical pathologization of the female body may have paved the way for our current construction of the abject, as in this example of excess as a characteristic of abjection.

In a 2015 study, Parton, Ussher, and Perz offered further nuance to our understanding of the abject. They applied Kristeva's definition to women with various types of cancer, expanding the definition of abject to include bodies which they call “beyond abnormality.” Citing a number of previous studies on female cancer patients, they point out evidence that “bodies affected by cancer and cancer treatment can be constructed as out of control, breaching the material and symbolic boundaries which

position bodies as ‘normal.’”<sup>47</sup> They note that in their current study, “the abject body refers to embodied experiences that were positioned outside the norms of bodily functioning...the use of such language suggests that the body is constructed not only outside discourses of normality but that these bodily experiences are unfamiliar” (493). Finally, they observe that women with cancer use language which alternates between positioning their bodies as subject and positioning them as object (492). So, we know that abject can also mean bodies which are beyond the literal and figurative standards of functioning, and for which the bodily experience feels personally abnormal<sup>48</sup> and that this abjection can be demonstrated by self-positioning which fluctuates between subject and object.

From these works, we can conclude overall that connotations of the abject feminine include collapse of the boundaries between life and death, horror and beauty, inside and outside; seeping, pollution, and excess; and existence “beyond abnormality,” sometimes indicated by a change in subject position.

Ussher notes that the problems created by the construction of the fecund female body as abject are evident when we incorporate Judith Butler's theory that (to borrow Ussher's paraphrase) “gender is a performance, discursively constituted, something one does rather than what one is,” (*Managing the Monstrous Feminine* 3). Butler's theories

<sup>47</sup> See Parton, Chloe, Jane M. Ussher, and Janette Perz. “Women's Construction of Embodiment and the Abject Sexual After Cancer.” *Qualitative Health Research*.

<sup>48</sup> In this case, we would define “personally abnormal” as any occurrence which is different from the way that person's body typically functions.

mean that “gender” (in this case, female gender) is a performance which a female body is expected to execute. We know from the last chapter that, by the end of the 19th century, problematic constructions of the female body had resulted in the conflation of gender and biological sex. All people who were identified as biologically female would have been expected to perform specific features of female gender roles (such as being representatives of domesticity, of home, hearth, and family). This conflation of biological sex with gender, and the subsequent expectation that biologically female bodies perform female gender roles, is an oversimplification which persisted throughout the 20th century, and from which we are still attempting to extract ourselves, socially, culturally, and academically. It is also a problem which surfaces in the contemporary breast cancer awareness movement, when specific socio-cultural expectations for women’s behavior during or after breast cancer are based on stereotypical female gender roles.<sup>49</sup>

According to Ussher, who draws on Butler and Mary Douglas, failure to properly execute the performance of femaleness results in disruption of the social order: “...the fictions framed as facts that circulate about the fecund body are central to the definition and maintenance of social order...the limits of the social are defined by that which is 'out of place'--substances deemed dangerous and polluted, which threaten the symbolic sense of order,” (*Managing the Monstrous Feminine* 5). Proper execution of femininity supports the social order in our society; improper execution of femininity results in a

<sup>49</sup> In Chapter 3, we will identify and examine these specific socio-cultural expectations and their implications.

threat to the social order. Abject female bodies do not properly perform femininity, and thus threaten the social order. Threats to the social order must be controlled. Thus, “women who fail this control, who fail to perform femininity within the tight boundaries within which it is prescribed at each stage of the reproductive life cycle, are at risk of being positioned as mad or bad and subjected to discipline or punishment,” (4). The presence of this risk of “being positioned as mad or bad” and therefore subject to discipline, appears to be a residual effect from the late 19th century construct that a woman needed to follow certain behavioral guidelines in order to keep herself well; if she exhibited alleged behavioral abnormalities—abnormalities which, Ussher would likely note, are failures to perform the prescribed definition of femininity—it was assumed that she was mentally or physically ill. The basic idea that those with breast cancer are expected to follow certain behavioral guidelines (and are subject to discipline if they fail to do so) is one that also appears in the modern breast cancer awareness movement. For example, the socio-cultural expectation for those who have had a mastectomy is that those people will, generally, make an effort to restore their breasts to their appropriate feminine appearance through reconstructive surgery or the use of prosthetics. Those who cannot do so, or choose not to, are subject to stares, whispers, judgment, and possible ostracizing by others.

In order to understand the ways in which the abject breast cancer body is subject to surveillance and discipline, we first need to understand specifically what we mean by the terms “surveillance” and “discipline.” In his work, Michel Foucault describes Jeremy

Bentham's concept of the Panopticon, the ideal prison:

...at the periphery, an annular building; at the centre, a tower; this tower is pierced with wide windows that open onto the inner side of the ring; the periphery building is divided into cells, each of which extends the whole width of the building; they have two windows, one on the inside, corresponding to the windows of the tower; the other on the outside, allows the light to cross the cell from one end to the other. All that is needed, then, is to place a supervisor in a central tower...one can observe from the tower...the small captive shadows in the cells of the periphery. (*Discipline and Punish* 200)

Foucault claims that Bentham's concept of the Panopticon serves as a figurative representation for modern power structures such as the hierarchies found in medicine and education, but also used generally by society at large. One of the fundamental aspects of the Panopticon's functionality (as we might infer from the root word, *optic*) is the ability to see and watch the individuals who are kept inside its cells: "The panoptic mechanism arranges spatial unities that make it possible to see constantly and to recognize immediately...Full lighting and they eye of a supervisor capture better than darkness, which ultimately protected," (200). Foucault notes that the major effect of the Panopticon is "to induce in the inmate the state of conscious and permanent visibility that assures the automatic functioning of power," (201). The Panopticon facilitates surveillance, and also careful and ongoing observation of the "inmate." This observation is recorded: "It must be possible to hold the prisoner under permanent observation; every report that can be

made about him must be recorded and computed,” (249). In the Panopticon, the prisoner is not only constantly surveilled; his behavior becomes a compilation of recorded knowledge about him, and that knowledge is what gives significant power to the agents of the Panopticon and they wield that power over the inmates. In fact, Foucault claims that “surveillance and observation” and “security and knowledge” are themes of the Panopticon (249). Documentation supplements surveillance, and is integral to its power. As the allegedly deviant individual is continually and repeatedly captured on the page, the agents of the Panopticon gain more knowledge about that individual, and therefore gain more power. The idea of the relationship between surveillance and writing/documentation is important and will be discussed in later chapters; for now, we can conclude that surveillance, according to Foucault’s appropriation of Bentham, means that a person is (literally or figuratively) fully exposed and visible, and that the person is aware of this visibility, such that the person monitors their own behavior to meet the expectations of those in power who could be watching. Moreover, it means that the agents of the Panopticon record their observations about the prisoners into a compendium of knowledge which means their knowledge equals power, and that their power increases as they observe and record more. It is important to note that, Foucault’s transliteration means that the figurative societal Panopticon is one to which anyone is subject, not only prisoners. For example, if we imagine that the concept of the Panopticon figuratively represents social expectations for female body image, it’s fairly clear that those imprisoned within the Panopticon are any people who are surveilled and disciplined when

their bodies deviate from the norm perpetuated by several various agents such as the media. But those who body-shame others, for example, then represent agents of the Panopticon, because they are observing and noting whether or not people abide social expectations for body image, and then disciplining those who are deviant. These are people who have internalized the expectations and discipline of the Panopticon. As they are observed, those inside the Panopticon learn which behaviors are unacceptable and modify the behaviors in advance of being disciplined by the agents of surveillance. The monitoring and adjustment of behavior to which the people (in Bentham's literal description, the prisoners) involved in the Panopticon are subject, is known as internalized self-policing.<sup>50</sup>

Discipline, then, according to Foucault, is the type of power/knowledge system that utilizes surveillance to regulate behavior and assure that those within the panoptic system meet the expectations and follow rules of those in power. Foucault calls it a “functional mechanism that must improve the exercise of power by making it lighter, more rapid, more effective, a design of subtle coercion for a society to come,” (*Discipline and Punish*, 209). He claims that this system of discipline spread through western society in the 17th and 18th centuries, creating what he terms a “disciplinary society” (209). Perhaps most importantly—at least, for the purposes of the discussion in this work—Foucault notes that discipline, as a system, is a mode that can be utilized by

<sup>50</sup> The concept of internalized self-policing is one that will appear again in later chapters.

institutions: "...it is a type of power, a modality for its exercise, comprising a whole set of instruments, techniques, procedures, levels of application, targets...And it may be taken over either by specialized institutions...or by pre-existing authorities that find in it a means of reinforcing or reorganizing their internal mechanisms of power," (215).<sup>51</sup>

Discipline, in the context of this discussion, should be noted as a system of power/knowledge (sometimes used by institutions) which uses surveillance to trigger internalized self-policing to ensure that those within the system follow its behavioral expectations.

Here, it's important to note that Foucault also claims that power can (and should) be challenged and resisted. He notes that, while discourse can be involved in the reification of power systems, it is also key to resistance of systems of power:

Discourses are not once and for all subservient to power or raised up against it...We must make allowances for the complex and unstable process whereby a discourse can be both an instrument and an effect of power, but also a hindrance, a stumbling point of resistance and a starting point for an opposing strategy.

Discourse transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart. (*The History of Sexuality: The Will to Knowledge* 100-1)

In later chapters, we will examine the primary discourse of the power systems of the

<sup>51</sup> In Chapter 3, we will examine and elaborate on specific ways that institutions in the breast cancer awareness movement use surveillance and create disciplinary systems.

breast cancer awareness movement, the master narrative, and the ways in which it supports and reifies the power systems; however, we will also emphasize the importance of the discourses of resistance to that power, and I will argue that, by the nature of the fact that they are resistant, we should take care to incorporate them into the larger public discussion around breast cancer experiences, pluralizing the dominant master narrative. For now, though, we will focus on establishing the breast cancer body as abject and subject to discipline.

For our purposes, we will apply Foucault's theory of disciplinary society, and the use of discipline by institutions, to contemporary United States society and the institutions which are part of it, particularly those which are stakeholders in the breast cancer awareness movement. We will be analyzing the American culture as a disciplinary society, particularly when it comes to illness, and specifically when it comes to breast cancer, healthcare, and the contemporary breast cancer awareness movement.

Notably, according to Foucault, systems of discipline are generally incompatible with non-binary labels; in other words, disciplinary systems force things (or people) to be labeled according to binaries, and function better that way: "Generally speaking, all the authorities exercising individual control function according to a double mode; that of binary division and branding (mad/sane; dangerous/harmless; normal/abnormal)," (*Discipline and Punish* 199). So, those occupying subject positions which are non-binary, which are not clearly one or the other, confound the principles of a disciplinary society. As we already know from our above definition of "abject," those who occupy the abject

subject position are exactly that: non-binary. Instead, they represent the collapsing of extremes, which means that, in a disciplinary system, they risk being categorized as abnormal by default, as Foucault notes in a 1975 interview: “If you are not like everybody else, then you are abnormal,” (“Je Suis Un Artificier”).

The abject female body, according to Ussher’s application of Foucault and Butler, is one which threatens the social order and must be therefore surveilled and subject to discipline. If we can establish that the breast cancer body is abject, we will also have established that it is therefore subject to surveillance and discipline. In the next chapter, we shall see the ways in which surveillance and discipline become evident via the omnipotence of the master narrative of breast cancer. First, we must focus on substantiating that the breast cancer body is abject.

The primary way in which the breast cancer body is abject is that it collapses the boundary between life and death. We know that by the end of the 19th century, the female body had become pathologized; by virtue of the fact that the female body simultaneously represented illness and the capacity to give and nurture life, it was already collapsing the boundaries of life and death. Additionally, by way of Ussher, we noted above that the fecund female body collapses a number of binaries, including life and death, horror and beauty, and inside and outside. The female body itself, was, is, and has already been established as abject. So, what makes the breast cancer body more powerfully abject than simply the female body, generally?

The body with breast cancer is out of control, and thus needs disciplining. This

chaos is embodied by the cancer itself: cancer is, essentially, a cluster of cells which are growing out of control, to excess. The lack of control inherent in any type of cancer may be enough to qualify a body as abject, of course; but in this case, the lack of control, the excess, the representation of mortality and fatality, is happening in exactly the physical location which has come to be arguably one of our culture's most emblematic symbols of life, nurturing, and fecundity: the human female breast. For many, the breast symbolizes womanhood. It not only represents motherhood as a symbol, the nurturing of children, but it is also the exact physical location at which many women spent early months caring for, and bonding with, their children; that same location where, almost certainly, a woman experiences intimate caresses with a lover. The breast is not only a symbol; it's a body part and the symbolic locus of many important aspects of a woman's life, and the horror inherent in losing that should not be overlooked, either for the physical impacts of an amputation, or for the loss of a body part which can be so emblematic of so many aspects of womanhood and identity. When the breast suddenly becomes, not the symbol of life, but the exact cause and location of potential death, a cognitive discord occurs in the minds of the public, who see the breast as a so life-giving and womanly: how can something that is so representative of beauty, motherhood, femininity, and life also generate something—cancer—which so iconically represents mortality? The woman who is possibly losing her breast is forced to confront the cognitive dissonance her body, her breast, now creates for her. She must also confront the public's distress over the life/death breast, and to mourn her own precious body part. The breast cancer breast powerfully

symbolizes the ways in which life and death are collapsed into one bodily location; the thing which is life-giving is also the apparent cause of death.

Additionally, it's now fairly common knowledge that increased exposure to estrogen, produced by the ovaries, also increases lifetime risk for breast cancer. Many who are high risk choose prophylactic oophorectomies in order to reduce their lifetime exposure to estrogen. So, again, the biological essence of femaleness, estrogen, the ovaries, also represents the potentially fatal threat to the body in which it exists. Life and death are collapsed together again, and once again that collapse is represented by the life-giving element of female anatomy. In many contemporary mammographies, readers observe that those with breast cancer feel representative of both life and death in the course of their experience with breast cancer.

A woman with breast cancer is alive, but her breast contains a potentially fatal disease, so she represents both life and death simultaneously. Writer Joan Halperin notes feeling this way in her poem "Diagnosis": "I am a moth/ready to burrow in winter clothes/surrounded by white nuggets/Camphorized," (7). Her figurative image of herself as a camphorized moth indicates that, while she is alive, her experience causes her to feel her own mortality, to feel dead. Like the moth, she has attempted to live her life, but finds herself overtaken by a force which makes her feel euthanized. Marian S. Irwin, in her poem, "Post-Mastectomy, Week One" also describes the feeling of existing in the space where boundaries are collapsed, writing "I am my own unknown," (32). The words "my own" signify her ownership of her body, a body which was familiar to her and which may

have represented the importance of motherhood or her own sexuality, as it does for many women. The word “unknown” may connote her mortality (death is the greatest unknown), but it also indicates that, without her breast she loses herself, her identity.

In her mixed-media piece, “Physician's Report II,” Violet Murkami uses visual art to show the ways in which her body represents life and death to her physicians. Murkami has layered physician's reports with full-body bone scans, resulting in a page of handwriting about her diagnosis which is overlaid with an eerie, dark-red, x-ray image of her body, in which her bones are visible through the flesh (73). Finally, representation of the collapsing of the boundaries between life and death is most clearly exemplified by graphic novelist Marisa Acochella Marchetto in *Cancer Vixen: A True Story*. In a series of panels, the writer/artist depicts herself, young, vivacious and preparing for her wedding, but in alternating panels, readers see a faceless grim reaper sneaking into her life. Finally, we see a panel in which the reaper smashes through the doorway, accosting the heroine and screaming “Cancer your wedding! Cancer your career! Cancer your life!” (63). This series of panels demonstrates that, having been officially diagnosed with cancer, Marisa feels herself as existing in the collapsed boundary between life and death. In each of the sentences, the word cancer is juxtaposed with something that represents a celebration of life or a vital part of living, indicating the collapsing of the boundaries between life and death. The following full-page panel makes the message even more clear. Marisa is depicted in two side-by-side images, one of her in a white dress and veil, and one of her in a frumpy hospital robe. The language above the images reads: “Instead of shopping for

a wedding gown...I see myself in a hospital gown,” (65). Marisa's position as abject makes it impossible for her to perform what are considered socially normal activities (fantasizing about and then purchasing a white gown for her wedding). Again, an experience that is life-affirming occurs simultaneously with one that is life-threatening and the boundaries between life and death are collapsed. These people, in their experiences of breast cancer, feel identified as simultaneously representing life and death, thus demonstrating the abject subject position. Additionally, the potential loss of this particular body part, the breast, for Marisa also signifies the figurative death of several aspects of her identity. This image represents the death of the kind of wedding and marriage she'd envisioned for herself, of the kind of bride and wife she would be. Later, she fantasizes about saying goodbye to a fictional infant to whom she's never given birth, her potential future child (205). She acknowledges that breast cancer (and its subsequent treatments) will likely terminate her ability to bear and nurture a child. In addition to the very real threat of mortality, the experience of breast cancer, because of the importance of the breast to female identity in many contexts, can also bring about a series of figurative deaths (deaths of identity) with which a woman must cope.

Women with breast cancer also feel themselves as existing in the collapsed boundary of horror and beauty, which is another indication of their abject position. Writer Elizabeth Hurst describes the ways in which cancer is both beautiful and horrifying: “Cancer is a complicated gift, unasked-for and undeserved. Imported from the rich mines of the underworld, it sheds metaphors and ideas, as well as murderous cells.

Cancer is also a generous disease...It is time's Philosopher's Stone, and a meteor flung up from hell; a serial killer's wet dream, DNA's idea of a joke—a squirming handful of chaos which I may or may not still own," (80). Here, readers can see that Hurst identifies collapsed boundaries and binaries present in her cancer experience. It is rich and generous but also the tool of a killer. She see something beautiful—metaphors and ideas—and also something horrifying—murder. The word “generous” may be a subtle allusion to the fact that cancer cells are those which multiply, constantly giving more, but it gives too much and too chaotically. Murder and the threat of the overwhelming multiplication of cancer cells are both horrifying; rich metaphor and generosity are both beautiful. Cancer has collapsed those two binaries. Lois Tshetter Hjelmstad notes the horror in losing a part of her body which she considers beautiful: “The night before my first mastectomy, I wept as I wrote a good-bye poem to my beautiful breast,” (55). Here, we can see that the breast is vital to Hjelmstad’s identity as a woman and a person, possibly her femininity, sexuality, and motherhood. The breast itself is beautiful, and the thought of losing it is horrifying, but so, too, is the disease which has affected it. In these cases, the breast cancer body represents the collapsing of horror and beauty.

Others note the horror of undergoing such an frightening amputation, like Maxine Kumin, who says in her piece “Off” that she is “as a lamb to the slaughter,” or Patricia Goedicke, in her poem “100,000 Upon 100,000”: “One by one we are taken to the hospitals/In silence, in secret/The surgeons whet their knives,” (Kumin 18; Goedicke 61). Certainly, surgeons are not butchers, nor do they literally whet their knives in eagerness;

they actually intend to help their patients in the long run. However, the fact that these people feel this way—as though they are about to have an important, beautiful body part butchered—indicates that they occupy the abject position. Marlene Gharbo Linderman's painting, "My Surgery," visually depicts her narrative of horror regarding her mastectomy (27). The painting shows a surgeon looming large in the foreground, using a serrated blade to cruelly saw off her breasts, while technicians hang other amputated breasts on meat hooks in the background. On the hooks, the breasts are painted in soft, warm pastels and they look soft and tender, even pretty, aside from the rough, bloody edges. This image, too, shows horror and beauty collapsed. Because the breast cancer body quite literally embodies the collapsed boundary between horror and beauty, it is abject.

The female body, particularly the female body in cancer, also experiences the abject position by being placed "beyond abnormality," according to the study done by Parton, Ussher, and Perz. The study, again drawing on Kristeva, notes that, many women describe their post-cancer bodies in similar ways, but that the socially ordered structure of normal versus abnormal cannot appropriately encompass their positioning: "...women attempt to manage the abject body by positioning it outside of normality, their accounts suggest on ongoing unease around their use of this discourse," (493-94). In other words, the social order expects those with breast cancer to be able to identify themselves, and their bodies, somewhere within the accepted continuum which has the binaries of "normal" versus "abnormal" at either end. People understand this binary because it's been socially inculcated: they have a notion of what a "normal" body versus an

“abnormal” body looks like, according to the binary categories. However, when they consider their breast cancer bodies, they cannot easily categorize their breast cancer bodies into one of these binary categories, or even onto the continuum. They cannot see themselves as normal, but they also don’t fall into pre-conceived notion of “abnormal” because their experience is more extreme, more pronounced, more different, than even simply being “abnormal.” For example, the study identifies one interviewee, Christine, who describes her reconstructed breast as “odd...it still looks normal. I try to think, you know, it's okay, but I don't see it” (4). Christine feels that her normal-looking body is abnormal, but also can’t relate to her new breast as a part of herself. Being defined as abnormal would mean, at least, that her body falls into a binary category which is familiar, but it is beyond even her conception of abnormal, so far that she can't even relate to the body part. From this study, we know that a woman's attempt, in her breast cancer experience, to locate her body relative to the normal versus abnormal binary, indicates her abject position. She can't fit anywhere on the pre-determined, familiar continuum. We see an example of this “beyond abnormal” positioning in the case of Greta, when she comments on her experience during chemotherapy and radiation. First, she notes the strangeness of the changes in her taste buds: “I don't crave things like everybody else does. I just go, 'Oh, that sounds okay,'...It's painful, it burns, it's salty, and it's just bizarre,” (Abel and Subramanian 20). Further, Greta describes the specific experiences related to her female body: “That's the one that's the weirdest, the most peculiar...I went into chemo-induced menopause. It's what they call crash

menopause...And when it happens, you don't even know if it's the chemo or what's going on," (Abel and Subramanian 20). Here, Greta uses words like "bizarre," "weird," and "peculiar," to attempt to position herself relative to abnormality, but what her body is doing is even outside of her pre-conceived notion of abnormal, as we can see from the latter part of her comment, "you don't even know if it's chemo or what's going on." In both cases, she is reduced to generalizations like "bizarre" and "you don't even know....what's going on" because she can't even position herself as abnormal. Because she is experiencing something "beyond abnormality," her body is abject.

Artist Sylvia Colette Gehres uses her artwork in an attempt to position herself relative to the abnormal as well. Her work, "Reflection," a piece done in sketchy chalk pastels, shows a bald woman with one breast and her eyes closed. In her caption, Gehres says, "I had to get used to this strange new head and body, so I put it on paper. It's easier to look at the picture, which is once removed from reality. The earrings are important because they were favorites in the years 'before the cancer.' They function as the 'familiar' in the piece," (54). Gehres attempts to position herself in the ordered realm of normal versus abnormal, but rather than simply falling on one end of the spectrum into abnormal, she can't even relate to her own body and instead feels like her body parts don't belong to her, making her abject. The reference to the earrings is important because it indicates that even in attempting to position herself as abnormal, she feels unsettled about her body, and needs a familiar image. Here, in Gehres story, we also see her shift between subject and object. She is the subject when she knows she must get used to her

body and when she puts it on paper; she is the object when she says that she has a “strange head and new body” and when her own body is once removed from reality by its depiction as art. She sees herself simultaneously as subject and object.

The abject body is also characterized by its lack of control; Ussher, drawing on Kristeva, makes this point clear: “Kristeva argues that bodily fluids and emission—sweat, pus, excreta, breast milk, semen, blood—stand as signifiers of the abject, of the body without boundaries which threatens the illusion of the contained, controlled, rational subject, and as such, threatens stability and social unity,” (*Managing the Monstrous Feminine* 6). Parton, Ussher, and Perz noted a manifestation of Kristeva's theory when they interviewed several women with cancer as part of a study: “The abject body was often positioned as being out of control in the women's accounts, through corporeal experiences such as disfigurement, excess in bodily weight, menopause, a seeping wound, a stoma, or leaking excretion and urine,” (495). One survivor of breast cancer recalls her experience with having to wear a drain in public: “...I had to keep measuring and emptying that [drain], and mine got clogged a couple of times, so I had to go to the emergency room for that...I wear big clothes anyway, so I had the big clothes with the drain hanging out. And the bandages. It was kind of scary to get in the shower because I didn't know what that was gonna do. So it was the unknown, the unknown,” (Abel and Subramanian 24). This survivor's drain, the seepage of her body, socially signifies her body's lack of control: she is then connoted as a “subject which threatens stability and social unity.”

The piece “Don't Touch Me,” by Arlene and Michelle Linder, profoundly demonstrates the abject, out-of-control body. The artwork is a black and white sketch of a bald woman in a hospital gown, vomiting into a nearby toilet (Linder 86). The I.V.s and other medical instruments to which she is attached are drawn at harsh, exaggerated angles, while the female figure is composed of more curved, organic forms, drawing attention to the apparent lack of control represented by her body, versus the regimented control demonstrated by medicine (86). In the background of the picture are words describing the patient's thoughts about her bodily secretions: “My bucket is my best friend,” and “I watch that green goopy stuff coming out of my mouth. I can't go on,” (86). This portrait demonstrates the extent to which the woman depicted in it feels that her body is out of control. Socially, the idea of the female body being out of control is problematic—it represents, again, the threat of excess in the female body. The “too muchness” associated with sickness, secretions and vomiting, signify frightening and threatening unknowns, and also associate that fear and threat with her symbol of femininity: her breast. Women are supposed to be well-kept and in control of their bodily functions; they are supposed to be sexually appealing to men; and they are supposed to represent idealized motherhood, the bearing and nurturing of children. A person who cannot maintain these norms has failed at enacting her expected role in society. Again, breast cancer threatens the social order, and a person who cannot keep her body in control (or at least hide the fact that it is out of control) is representative of that threat.

The breast cancer body threatens the social order by being, according to Parton,

Ussher, and Perz, “outside femininity”: “For many of the women, cancer resulted in a loss or threat to embodied signifiers of femininity...in a cultural context where women tend to be defined through bodily appearances, the loss of feminine signaled a loss of subjectivity for women, positioning their bodies as being of less value,” (494). The feeling of loss associated with femininity is demonstrated in Lois Tschetter Hjelmstad's poem, “Double Amputee”: “Strange it is to seem/A sexless child/Again,” (55). Here, the loss of her feminine signifier, her breast, makes her feel unsettled and reverted to a helpless, child-like position. Similarly, Pamela Post, in her essay “Cancer Says,” demonstrates feelings of deep loss associated with her femininity when she is faced with the possibility of a mastectomy: “It had to do with the part of me that first responded to the touch of my teenage boyfriend. It was where my two babies fed and nuzzled and drifted into sleep for the first year of their lives,” (Post 4). Post specifically identifies her breast as representative of herself as a sexual being and a reproductive female body, and implies a loss of identity as feminine by the loss of her breast. Lorraine Vernon, in her poem, “Slant,” notes that the loss of her breast makes her feel less feminine:

Or maybe I'm becoming  
(androgynous)  
precocious female—  
child woman man  
transforming Woman  
with the little

(left

(Vernon 34).

The poem's ending—the word “left” with one parentheses on the left-hand side which is never closed—is a visible, linguistic replication of the appearance of her chest, which is left with one curved left breast. The fact that that ending is preceded by the phrase “with the little” implies that Vernon feels her value as feminine is diminished by the fact that she has only one breast. Even the title of the poem itself, “Slant” indicates her feelings of bodily imbalance. The feeling of loss of value derived from loss of femininity appears in Marchetto's work when, after her single mastectomy, the grim reaper appears again, only this time, the figure is not faceless; it has a face which, though gray, harsh, and eyeless, has blond hair and a facial structure like Marisa's own; it is she. When her fiancée neglects to call immediately following her surgery and she wonders why, it lingers over her bed shouting, “I'll tell you why...you're damaged goods and he found someone better to do! Damaged goods! Damaged goods!” (Marchetto 120). The fact that Death personified looks like Marisa indicates that she has internalized messages which label her as abject—representing collapsed boundaries between life and death—and the fact that the reaper uses the phrase “someone better to do,” (in this case, “do” being a euphemism for sex) indicates that she views herself as having less value sexually, from the male perspective. Thus, Marisa has internalized the societal perspective of the definition of female sexual attractiveness. The hegemonic values which Marisa has internalized regarding her femininity are demonstrated most profoundly, however, in the series of

frames near the end of the book in which she discovers, at 44, that she will need to take Tamoxifen for five years post-surgery, and thus will not be able to have a child. After she hears this, the following frames show her, gazing upwards to a starry sky where an infant body floats. She looks at the infant: “I’m so sorry...I thought I had all the time in the world, when all I had was the blink of an eye,” and in response, the infant says “Goodbye” and disappears (205). The next few frames show Marisa and her mother crying over her loss of reproductive ability. This is certainly sad news for any woman who wishes to have children, and these feelings of loss and sadness are valid. However, her presentation of her loss of reproductive ability indicates that she feels of less value without it, that she feels ashamed for having made the decision to wait to have children. This presentation is another indication that she has internalized the reproductive value, the accepted type of femininity, which our social order attributes to her.

When the hegemonic social order is threatened by bodies which do not meet its expectations, those bodies must be surveilled and disciplined. Abject bodies, including the breast cancer body, must be surveilled and disciplined because they threaten the symbolic order. Foucault claims that this surveillance and discipline, in previous centuries, was conducted primarily through two institutions: “Religious groups and charity organizations had long played this role of disciplining the population,” (*Discipline and Punish* 212). But, he notes that “one also sees the spread of disciplinary procedures, not in the form of enclosed institutions, but as centre of observation disseminated throughout society,” (212). Ussher claims that, in modern times, one of the entities to

which disciplinary procedures have been disseminated, particularly when it comes to the female body, is medicine: “In contemporary western culture, theories of biomedical science...serv[e] to regulate the monstrous feminine...through positioning the female body as inherently pathological, necessitating rigorous application of technological investigation and intervention—with medical experts firmly in control,” (*Managing the Monstrous Feminine* 15). Because the female body has been established as pathological, it stands to reason that healthcare would be the source of surveillance and discipline for deviant female bodies; women, more than men, are expected to subject themselves to the authority of medicine. Medicine inadvertently disciplines the abject female body, as Ussher notes: “diagnostic categories...conveniently attribute female distress to the deviance of the reproductive body, legitimating medical management of the reproductive excess, and implicitly of the monstrous feminine...we are told that medical management of the fecund body is the answer for all ills,” (17). This is a rich and bold claim, which we should parse out and discuss in the context of breast cancer. First, risk factors and potential causes for breast cancer are often associated with “deviance of the female reproductive body.” Public discourse focuses on the fact that women who have children after 30, or who don’t have children at all, are at higher risk; we hear that increased exposure to estrogen, produced by the ovaries, increases risk. While both of these claims have solid scientific evidence behind them, they are overemphasized in public discourse, which implies that the cause of breast cancer lies inside the person’s own body, inevitably. We don’t hear much about potential environmental causes of breast cancer.

Instead, “medical management” is our cultural default option when it comes to this illness. While medical management is the cultural default option for many types of cancer, and even other illnesses, it is specifically problematic in relation to breast cancer because of the iconic symbolism of the breast in our culture. As we have mentioned above, the breast has always connoted motherhood, nurturing, sexuality, and idealized femininity; breast cancer and the post-mastectomy body threaten those associations and the social expectations and norms which result from them. Therefore, we are more alert to the implications of breast cancer, more uncomfortable with the discord it creates, and more emphatic that it be medically addressed. Those with breast cancer are expected to subject themselves to medical management because breasts are so socio-culturally important to our model of the archetypal woman: they can’t be risked. For example, many medical institutions recommend mammograms to screen for breast cancer. The American Cancer Society recommends that women start getting yearly mammograms at 45 and then get a mammogram every two years after turning 54 (“American Cancer Society Guidelines...”). The United States Preventative Services Task Force recommends one every year from 40-49, and one every two years from 50-74 (“Final Recommendation Statement: Breast Cancer Screening”).<sup>52</sup> That’s about 22 mammograms over the course of an American woman’s lifetime. That’s roughly 22 exposures to radiation, when medical radiation is the only thing actually proven to cause breast cancer,

<sup>52</sup> It should be noted that, at the completion of this text, these recommendations were paired with recommendations that patients consult with their doctors about potential risk for breast cancer versus risks associated with mammograms.

and causes about 2,800 cases per year (Committee on Breast Cancer and the Environment: The Scientific Evidence, Research Methodology, and Future Directions; Institute of Medicine 294). In actuality, mammograms aren't really as helpful as we may believe. In fact, a British study by Miller et al., the largest done to date on this topic, found that "annual mammography in women aged 40-59 does not reduce mortality from breast cancer beyond that of physical examination or usual care when adjuvant therapy for breast cancer is freely available." Additionally, mammograms have been shown to lead to overdiagnosis and overtreatment. According to Neighmond, one recent study showed that of 700,000 women screened for breast cancer using mammograms, 75,922 had "suspicious" mammograms that resulted in follow up treatments, but it turned out they didn't have cancer at all, and they had to deal with the anxiety and physical pain that comes with over-treatment. Mammograms, in this case, are a figurative and literal form of surveillance to which abject breast cancer bodies are subject; agencies and institutions who reify the over-emphasized belief in mammograms, are all part of the disciplinary system which administers that surveillance and assures that we meet the expectation to get our mammograms. People have internalized self-policing for this behavior as well: often, you can hear women ask each other if they're getting their mammograms; when a person is diagnosed with breast cancer, one of the first questions someone asks is whether or not that person has been getting mammograms regularly.

Maxine Kumin, for example, notes feeling subject to the disciplinary system in her account of breast cancer in the early 1990s. When her doctor, who she has previously

described as not treating her like a human, calls to tell her she has been diagnosed with cancer, he says that, “It means you have three choices. You can do nothing. You can take Tamoxifen. Or you can have a mastectomy. You'll have to come in and let me explain this to you,” (19). In this case, it is the physician who serves as the administrator of power in the disciplinary system. The fact that his options for treatment are limited and his responses are so curt indicates that he sees medical management of the abject body as the only legitimate option; the fact that he insists on being her primary source for information regarding these options supports his authority. Later, he refuses to send Kumin her pathology report at her request, even though she knows it is her legal right to have a copy of the document, and she tells him so: “Two days later, [I received] a one-sentence letter from Dr. X indicating that he would have to talk to me face-to-face to interpret the report,” (20). In this case, the medical professional exercises power over her body and her choices. He believes that the only legitimate interpretation of the report is his own; he puts himself in charge of her narrative. Other writers, in their descriptions of breast cancer, use figurative language to describe the ways in which they feel contained or controlled by medical treatment: “you stretch on a table/wondering how you got into this cage/the room with the x-ray machine,” (Kennedy 4). This poem by Terry Kennedy, called, “Mammogram,” indicates that Kennedy feels physically, bodily contained by the medicalization of her breast cancer. She is in a cage, a figurative cell, not unlike the one described in Foucault's Panopticon. She feels trapped, surveilled, and overpowered by the disciplinary system which administers the mammogram.

Medicine, in some cases, becomes the system which administers the surveillance of the abject breast cancer body. This surveillance can sometimes lead to internalized self-policing, as we see with mammograms. Policing of the abject female body, as a mode of discipline, can also be administered through other institutions or groups, as Foucault's comment demonstrates: "Discipline...may be taken over either by 'specialized institutions...or by pre-existing authorities that find in it a means of reinforcing or reorganizing their internal mechanisms of power," (*Discipline and Punish* 215). Policing of the abject breast cancer body is not always administered by the authority of biomedicine; sometimes it is administered by other groups or social structures.

Policing often takes place in the form of shaming, which publicly hurts or embarrasses those who do not behave within the system's prescribed order or expectations. After they have been publicly shamed, they are more likely to behave according to the expectations of the system in order to avoid further hurt and embarrassment. Sometimes, shaming comes from the very organizations which claim to support those with breast cancer. In the case of shaming, these organizations can represent the disciplinary system; the shaming has been internalized, and then is administered, by those involved. One example of covert shaming is the continued usage of battle or war language referring to breast cancer patients. For example, the *Susan G. Komen* website features a woman, Nikki Hammonds-Blakely, whose personal profile pivots around the repeated phrase "found her strength," and her story tells us "I have battled breast cancer for over 20 years," implying that she is a long-term fighter (*Susan*

G. Komen). Patients in treatment are often encouraged to think of themselves as “fighters” and “warriors” in a battle against breast cancer; when and if they die as a result of cancer or cancer treatment, they are said to have “lost their battle with breast cancer” or (in polite circles) to have “succumbed” to cancer. Persistent and pervasive use of this language implies that any breast cancer patient who does not take on the “fighter” mantle is a coward, and that anyone who dies as a result of breast cancer is a weak-willed failure. For example, the documentary, *Pink Ribbons, Inc.*, which is based on Samantha King's book of the same title, features a group of women who call themselves the “IV League.” (Pool, Dir.). These women are all living with stage IV breast cancer, meaning the cancer has metastasized and is terminal. They claim they feel hurt, dismissed, and marginalized by the “fighter” language often used by the contemporary breast cancer awareness movement, because it implies that they've given up, that they aren't worth acknowledging (Pool, Dir.). What is being policed, in this case, is the attitude or emotional reaction people have to their cancer publicly. Their bodies are deviant because they are both alive but actively dying, simultaneously. They don't fit neatly into the life/death binary. They are expected to fight, to behave as warriors, according to the current disciplinary system. If they don't, they are subject to this form of shaming via the use of “fighter” language. The abject breast cancer body is policed by new socially ordered expectations of how a person is expected to respond to the illness.

Readers see similar policing through a social group (as opposed to an organization like Komen) in Marchetto's, *Cancer Vixen*, when Marisa's friends learn about her

diagnosis. A full-page image, with Marisa's face at center, shows several of her friends (as floating heads around her) asking if she's taken the proper steps to start dealing with the disease. All of their questions begin with the words "HAVE YOU..." in all capital letters, emphasizing their concern with whether or not she has taken the requisite steps (73). The next page shows the same image, except that all of her friends are now united in one voice, shouting, "WHEN ARE YOU GOING TO START FIGHTING THIS THING?!" (74). The expected and condoned role of the abject breast cancer body is that of "fighter," and those who chose not to frame themselves that way transgress the expectations established by the social order.

Those with post-mastectomy bodies (sometimes called "mastectomees") must cope with the pressure, administered by these disciplinary systems, to appear physically feminine via the use of prosthetics or reconstructive surgery. Marchetto's graphic novel shows a frame in which Marisa consults a woman who has had a double mastectomy to ask if she (the woman, Hilary) is OK. Hilary responds, "I'm more than OK...Now I've got the greatest tits!" This brief segment demonstrates that Hilary has internalized the value of breasts as signifiers of femininity to the point that the most important part of her breast cancer experience is her take-home prize: great new tits. While many feel constantly pressured to alter their bodies to fit more idealized concepts of femininity through cosmetic surgery, the pressure is slightly different in the context of breast cancer: our current disciplinary system makes people feel more than pressured, obligated, to ensure that their bodies match the norms of femininity constructed for them. Because of the

symbolism of the breast as representative of life and nurturing, we are often disturbed by missing breasts: it creates the cognitive discord and unease noted earlier in this chapter. Those with breast cancer who've had mastectomies are obligated to set us at ease by wearing prosthetics or having cosmetic surgery. When people cannot adequately modify their bodies to conceal their mastectomies and signify the feminine, they feel unsettled, like one mastectomee, June, who is unnerved by her prosthetic: "...all of a sudden you've got this great big weight hanging down in your bra," (Parton, Ussher, and Perz 8). Similarly, Zona Gale's poem, "Does It Eat, Too?" demonstrates the pressure a person feels to appear feminine: "Anne's first night out/in full prosthesis/salad drops down front/laughter dissolves us/almost to tears/tension eases/after months of fear," (Gale 35). Though the woman in the poem and her friends are able to find humor in the situation, that doesn't negate the fact that she felt the obligation, even among friends, to go out publicly wearing full prosthetics. She, too, has internalized the policing of her body, feeling the pressure to ensure that she is behaving as expected within the disciplinary system. All of these people, by virtue of the fact that they choose prosthetics, are aware that their bodies are being surveilled, observed, and judged for meeting the standards of femininity.

Much progress has been made in feminist criticism and breast cancer discourse in the last few decades; however, the work of understanding the impact of breast cancer on the identities of those who are diagnosed, and the socio-cultural impact of the breast cancer awareness movement is not yet exhausted. Application of feminist theories of the

abject, fecund female body to breast cancer discourse reveals that the breast cancer body is also an abject body, and that, while people's voices in breast cancer are heard today more than they ever have been before, there are still disciplinary systems in place which surveil bodies and attempt to regulate their behavior so that it meets the system's expectations. Much current public discourse about breast cancer is influenced by the disciplinary system, and reifies its values or demonstrates that those with breast cancer feel subject to hegemonic values through the policing and regulation of their bodies. But many have resisted this public discourse, creating for themselves new and innovative narratives of self which resist to our current system, as we shall see shortly.

In the first two chapters, we established the history of the problematic constructions of the female body which the early breast cancer movement inherited, and then established the ways in which the breast cancer body is abject in current discourse about breast cancer. Further analysis of this subject is critical and will include an examination of the extent to which some people enact their agency and make choices to transgress the disciplinary system and its expectations of the abject breast cancer body, and the methods by which they do so. In the following chapter, we will build on the discussion from the first two chapters by demonstrating the ways in which public and literary discourse—particularly the discourse generated by the breast cancer awareness movement and its marketing strategies--reify and support the construction of the female body as abject. This discourse has helped to codify and foster a master narrative of breast cancer which sets socio-cultural expectations that many struggle to meet or simply refuse

to engage in. As a result, they feel marginalized, as though their experience is not reflected by (or acknowledged by) the society in which they live, and that experience can be painful and detrimental.

### CHAPTER THREE: THE MASTER NARRATIVE OF PINKWASHING AND THE BREAST CANCER AWARENESS MOVEMENT

In the last chapter, we saw that application of feminist theories of the abject, fecund female body to breast cancer discourse reveals that the breast cancer body is an abject body, and therefore subject to disciplinary systems. While public awareness of breast cancer and its resultant mortality has risen significantly over the last thirty years, disciplinary systems which attempt to regulate abject breast cancer bodies have not diminished or receded, nor has awareness of those systems markedly increased. Instead, those disciplinary systems have generated a master narrative of breast cancer, based on flawed hegemonic, patriarchal constructions of the female body.<sup>53</sup> As I will explain, that master narrative has several parts, key concepts which present themselves in the contemporary breast cancer awareness movement. The master narrative of breast cancer has become the expectation by which we judge abject bodies of breast cancer and by which people with breast cancer are policed and police each other.

The modern breast cancer awareness movement is powered by cause-marketing strategies and corporate sponsorship. Cause-marketing and corporate campaigns

<sup>53</sup> Chapter One includes a definition of a master narrative, but the definition used by Nelson will also be fully articulated below.

involving breast cancer awareness take advantage of the concepts which comprise the master narrative, using them to sell products and (ostensibly) raise money for breast cancer awareness and research. Because the marketing and corporate use of pink and the pink ribbon is ubiquitous, it massively influences public discourse about breast cancer; therefore, the master narrative, ever present in pink marketing, creates the expectations for behavior of the breast cancer body that are dominant in our society. The disciplinary systems are enacted, paradoxically, through the modern breast cancer awareness movement. This master narrative potentially silences the voices of people, those who, for a multitude of reasons, do not conform to its expectations, and that silencing has real and lasting implications for the physical and mental health of those with breast cancer. In the next chapter, I will demonstrate the potential impacts of the master narrative on those with breast cancer in order to substantiate that we should pluralize the master narrative rather than letting it dominate our cultural perceptions of the illness; I will also analyze stories which resist the master narrative<sup>54</sup> in order to demonstrate the ways in which these stories can enrich and complicate our discourse about breast cancer.

### 1. Illness Narratives and Social Identity

Several scholars in medical anthropology, sociology, and narrative medicine concur that the social aspects of illness are integral to understanding the function of stories of illness (known as illness narratives). Our lives do not happen in a vacuum; we

<sup>54</sup> Nelson calls stories which resist the master narrative “counterstories,” as we shall see later in this chapter and in Chapter 4.

are (at least to some extent) defined via our relationships to others. Additionally, illness has various socio-cultural connotations (for good or ill) that influence our experiences in illness; by the same token, in illness, we make choices and behave in ways that change the fabric of our social worlds. In order to understand the potentially deep and multi-faceted effects of the master narrative on illness experience, we must first understand the relationship between story and self, self and other, and narratives and our social worlds.

According to Frank, “selves are perpetually recreated in stories. Stories do not simply describe the self; they are the self’s medium of being,” (53). Stories then, are not merely vocalized or written experiences, they are phenomenological compositions. Phenomenology, according to Smith, is a branch of philosophy which is concerned with “structures of experience, or consciousness...the ways we experience things, thus the meanings things have in our experience.” Stories, then, are the way in which we construct and give voice to our very being; they constitute our existence, as Frank says: “The self is being formed in what is told,” (55). Frank, relying on the work of psychoanalyst Roy Schafer, goes on to claim that, while stories are self-constitutive, they are not entirely isolated or individuated. The self also needs others to hear the stories, for reaffirmation: “The self-story is told both to others and to one’s self; each telling is enfolded within the other. The act of telling is a dual reaffirmation. Relationships with others are reaffirmed, and the self is reaffirmed,” (56). The concept of self-story Frank

introduces here is important: the self-story is not *only* a story of the self. The self-story, and thus the creation of the self, is defined and made secure by a person's relationship to others. Susan Brison, in her discussion on recovery from trauma, also notes the significance of the relationship between self and other in the recreation of identity in the wake of serious bodily harm.<sup>55</sup> She claims that survivors need autonomy, but also need to be reconnected with humanity in order to navigate their worlds safely: she notes, for example, that following her sexual assault, she needed others to help her make arrangements that would make her feel she could function safely at the gym and at work (61). These arrangements encouraged her autonomy, but also helped her understand relationships to others as they relate to personal autonomy: "These ways of enhancing my autonomy...reinforced my view of autonomy as fundamentally dependent on others...the right sort of interactions with others can be seen as essential to autonomy...The autonomous self and the relational self are thus shown to be interdependent, even constitutive of one another," (61). The self-story is not an entirely individuated or autonomous construction; rather, the self-story is a symbiosis between the autonomous self and the self's relation to others (61). The self, according to Brison, is relational (61).

Rita Charon's work echoes the importance of sharing the self-story with others in her emphasis on the phenomenological concept of intersubjectivity. She claims that intersubjectivity gives meaning to the narrative exchange. According to Charon,

<sup>55</sup> See Brison, Susan J. *Aftermath: Violence and the Remaking of a Self*.

intersubjectivity includes “the cognitive acts of perception and interpretation...the personal transformations incurred by virtue of human relation,” (51).<sup>56</sup> Charon puts it a bit more simply, claiming that intersubjectivity “occurs when two subjects, or two authentic selves, meet. It is in meeting with the other selves that the self comes alive,” (51). This claim aligns with Frank’s claims above: stories comprise our being; in order to *be*, we need others to authentically engage with our stories. We need the subjectivity of others to open itself to engaging with our subjective experience. Havi Carel elaborates on the concept of intersubjectivity, noting that intersubjectivity must also include acknowledgement of the bodies of those involved in the exchange, their “shared corporeal foundation” (*Phenomenology of Illness* 53). This intersubjective perception of others’ bodies (which Carel calls “intercorporeality”) allows for understanding the social aspects of illness: “...the lived body encompasses not only one’s experience but also the social aspect of one’s experience of one’s own and others’ bodies, as well as how others’ experience of one’s own body might impact on their own experience of their body,” (*Phenomenology of Illness* 54). The acknowledgement of others’ corporeality returns us to Charon’s discussion of phenomenology, in which she notes that a critical aspect of phenomenology is the concept of being, existing, *with* one another: “...joint being-in-the-world grants fellowship to its cohabitants, in both their mutual regard for its objects and their becoming objects for one another’s regard and experience,” (51). In

<sup>56</sup> Charon’s claims are directly drawn from the phenomenological work of Heidegger and Husserl.

order to have our self-stories, our bodies, our beings, validated and made real, we need others and we also need to acknowledge the beings and bodies of others.

Intersubjectivity, including intercorporeality, is crucial. Charon tells us that it allows both the ill person and the audience, reader, or listener, to engage in a “powerful and transformative connection” (52). Carel notes that the “experience of empathy is crucial to this exchange,” (*Phenomenology of Illness*, 54). Self-story, then, is constructed by ourselves and by others. Moreover, it is ideally constructed intersubjectively with others, in such a way that acknowledges lived and corporeal experiences and “joint being-in-the-world.” Self-story, in this context, can have a terrific impact on the ill person’s attempt to successfully create and negotiate a new identity in illness.

Understanding stories through a phenomenological perspective helps us to understand that they are all the more critical when utilized in illness. Frank claims that the lives of the ill are “narrative wrecks”: “the conventional expectation of any narrative...is for a past that leads into a present that sets in place a foreseeable future. The illness story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable,” (55).<sup>57</sup> The ill person’s narrative of self, narrative of being, is blown apart, not only at the mere moment of diagnosis; the past is useless and fragmented because it did not lead to the present expected by the self; the present is traumatic; the future non-existent. The ill person’s story, and thus the ill person's

<sup>57</sup> Frank’s work draws heavily on the theories of the philosopher, Ronald Dworkin.

phenomenological experience, the *self*, is shattered. Frank claims that the way out of this narrative wreckage is to tell stories to others, to recreate the narrative structure of our lives. Brison concurs:

In order to reconstruct self-narratives we need not only the words with which to tell our stories, but also an audience able and willing to hear us and to understand our words as we intend them. this aspect of remaking a self in the aftermath of trauma highlights the dependency of the self on others and helps to explain why it is so difficult for survivors to recover when others are unwilling to listen to what they endured. (Brison 51)

The narrative self in illness needs others. It forms a network of intersubjective relationships and an understanding of one's body through a social lens which help the ill person redefine the self, as Brison notes: "On this view the self is both autonomous and socially dependent, vulnerable enough to be undone by violence and yet resilient enough to be reconstructed with the help of empathic others," (38). Similarly, Charon acknowledges the importance of narrative to our identity as a human community:

"...narrative knowledge and practice are what human beings use to communicate to each other....a major source of both identity and community...bearing witness to one another's ordeals, celebrating our common heritage as listeners around a campfire," (11).

Thus, narratives of self in illness (or, illness narratives) can be unique and autonomously created, but they are also always created through relationships to others, generating a

network of relationships which forms a larger community.

## 2. Impact of the Master Narrative

Many of our stories, including illness narratives, are generated from frameworks or stories which are already part of our world, as Frank says: “People tell their own unique stories, but they compose these by adapting and combining narrative types that culture makes available” (75). Thus, to create our new stories in illness, we often build from, recycle, or remodel, elements of stories that have been part of our cultural lives. Some of these elements may be taken from stories that Hilde Nelson calls, “master narratives.”<sup>58</sup> Nelson claims that master narratives “are often archetypal, consisting of stock plots and easily recognizable character types...[such as] Our culture’s foundation myths—the Passion of Christ...the best-known fairy tales...great literature, movie classics,” (7). In the same way we use these types of master narratives to negotiate things like spirituality, morals, romance, and other aspects of our lives, we may use others, specifically those that pertain to illness and are socio-culturally constructed. We know that illness narratives are created, to some extent, through a network of relationships with others and in the context of communities, as we have noted above. Because others and communities are involved in the creation of illness narratives, it follows that socio-cultural experiences would come to bear on understanding illness narratives. So, at this juncture, it’s important for us to examine the ways in which elements of master

<sup>58</sup> Here, we revisit and elaborate on the definition of master narratives which we first encountered in Chapter 1.

narratives influence personal illness experiences.

Master narratives, according to Nelson, are “the stories found lying about in our culture that serve as summaries of socially shared understandings. Master narratives are often archetypal...repositories of our common norms,” (6). While Nelson is quick to clarify that master narratives “need not be oppressive,” she notes that they can “contribute to the construction of an oppressive identity” (7). In the context of master narratives about medical professionals, Nelson gives the example of a master narrative about nurses, in which physicians perceived nurses as “touchy-feely” and in which the anecdotes they believed and repeated about nurses cast them as “subservient to men, as emotional rather than rational, as mothers, rather than scientists,” (4). These ideas are part of the detrimental and oversimplifying master narrative about nurses; in this particular case, the nurses sought to resist the master narrative. In his discussion of patients and illness narratives, Frank, too, notes that we must be careful of narrative elements which “risk creating yet another ‘general unifying view’ that subsumes the particularity of individual experience,” (76). In other words, we should avoid ascribing to patients identities which are reductive and obscure their personal experiences. So, while master narratives are a critical part of our culture and not, by definition, harmful, they have the potential to be when they overwhelmingly shape the perception of a person or group, and when they obscure individual experience. Carel notes this phenomenon in her description of living with lung cancer: “Instead of choosing what you disclose about yourself, you

become a passive vessel of information provided through your own betraying body, a body that cannot keep a secret. A stranger takes a glance at you and already knows so much...as a result the person may be reduced to her illness,” (*Illness: The Cry of the Flesh* “The Elephant in the Friendship”). Reducing a person to the features of her illness in this way is dehumanizing, and severely limits the ways in which we can intersubjectively interact with that person. Master narratives are ubiquitous aspects of our culture which we utilize perhaps without even realizing it; however, because they rely on archetypal simplifications and reductions, they can be problematic, and we should be aware of the ways in which master narratives about breast cancer may be oversimplified, reductionist, and dehumanizing to the people dealing with the illness.

It’s crucial to note that, by virtue the fact that master narratives are “repositories of common norms” we often subconsciously make use of them in constructing our personal stories. It is pertinent, here, to return to Foucault’s concept of the Panopticon which was introduced in Chapter 2. Foucault claimed that, while the tactics of the Panopticon may be utilized by specific institutions (medicine and education among them), they may also become disseminated throughout society via what he called the “discipline-mechanism”: “a functional mechanism that must improve the exercise of power by making it lighter, more rapid, more effective, a design of subtle coercion of society to come...the gradual extension of mechanisms...their spread throughout the whole social body, the formation of what might be called a disciplinary society,”

(*Discipline and Punish* 209). Master narratives are also “common norms,” gradually extended through the social body. If we combine Foucault’s theory of the discipline-mechanism with Nelson’s definition of master narratives as “repositories of common norms,” we see that oppressive master narratives may serve as a mechanism of discipline: they are socially disseminated norms which may contribute to an incorrect, reductionist, or otherwise problematic identity. The oppressive master narrative becomes the set of expectations given by the disciplinary society (such as the example of the nurses, above, in which the nurses are expected to be nurturing and emotional, rather than scientific and rational). We internalize these expectations and may perform according to them ourselves; because they are part of social norms, we may also use those expectations to police others and their behavior as well as our own.

Additionally, there is a secondary aspect of Nelson’s definition of master narratives. Drawing on several scholars,<sup>59</sup> she claims that master narratives have moral import: “we use them not only to make sense of our experience...but also to justify what we do...As the repositories of our common norms, master narratives exercise a certain authority over our moral imaginations and play a role in informing our moral intuitions,” (6). Oppressive aspects of master narratives may infiltrate the consciousness of the person or group to whom they are attributed (such as the nurses mentioned above)

<sup>59</sup> From Nisbett and Ross (1980) Nelson concludes that, “we use them to make sense of our experience”; from MacIntyre (1984) she draws that we use master narratives to “justify what we do,” (6).

causing a lowered self-perception of self-worth. Again, we should take Nelson's theory in the context of Foucault's theory of the discipline-mechanism. If oppressive master narratives are the expectations by which we surveil and police others, they also have the potential to lower the perception of self-worth of the people who are subject to them. Then by engaging in the surveillance and discipline elicited by the master narrative, we may also be engaging in the lowering of others' self-perception of worth. Further, because we use master narratives to "inform our moral intuitions," we may use them to form moral judgments of others who refuse to abide the expectations of the oppressive master narrative. Our moral intuition has been shaped by the master narrative in such a way that we believe that the expectations that are part of it, are morally right; and therefore, anyone who refuses to follow them is deemed morally wrong, or amoral. We use the oppressive master narrative as a mechanism by which to surveil, police, judge, and finally, marginalize those who don't abide it.

Foucault and Nelson both note that resistance to these oppressive elements of social life—the Panopticon and the master narrative—is possible. While Foucault's work on power and resistance is extensive, one particular aspect is worth highlighting here. Foucault claims that in a disciplinary society, mechanisms of power are diffused throughout, and that members of the society are imbricated in the structure of that society and those mechanisms of power: "...the circuits of communication are the supports of an accumulation and a centralization of knowledge...it is not that the beautiful totality of the

individual is amputated, repressed, altered by our social order, it is rather that the individual is carefully fabricated in it, according to a whole technique of forces and bodies,” (*Discipline and Punish* 217).

According to Foucault, because the elements of the disciplinary system are so diffuse, the resistance to that power must also be diffuse. He tells readers that resistance to power comes in the form of “spontaneous organizations, coalitions—anything which may establish *horizontal conjunctions*,” (italics mine) (*Discipline and Punish* 219). These horizontal relationships oppose the panoptic power structure, according to Pickett’s analysis of Foucault: “Power, by its very nature, must be hierarchical and egalitarian. In contrast, Foucault repeatedly links resistance with ‘horizontal conjunctions’ and equality,” (459). Equal, balanced relationships of power, as opposed to those in which the power is asymmetrical, may help to resist panoptic structure.

My suggestion here is that that illness narratives, by virtue of their intersubjectivity, may be one way in which to create and foster the types of “horizontal conjunctions” to which Foucault and Pickett refer. These horizontal conjunctions may resist the power system of the disciplinary society. Notably, with regard to equality and horizontal relationships of power, Nelson’s theories about resistance to master narratives appear to concur with Foucault’s theories about resistance of the disciplinary society.

Nelson claims that the way to resist master narratives is the telling of counterstories. By way of definition, she says that counterstories have two essential parts:

the revelation of the master narrative, and a re-telling of the story “about the person or group to which the person belongs in such a way as to make visible the morally relevant details that the master narrative suppressed,” (7). Nelson claims that this second part may allow a new respect for the person (or group) about whom the master narrative was initially generated: “If the retelling is successful, the group members will stand revealed as respectable moral agents,” (7). This revelation of the person or group members as “respectable moral agents” may create the type of “horizontal conjunction” to which Foucault refers: the relationship of power between the storyteller and the listener becomes more symmetrical. Additionally, Nelson tells us, resistance to master narratives through counterstories is a method by which the oppressed person may change self-perception, and thus increase feelings of personal moral worth (7). Resistance, according to both Foucault and Nelson, is possible, and may help to resolve some of the problems generated by the master narrative. So, we need illness narratives which are counterstories in order to resist and pluralize the master narrative of breast cancer. The notion of resisting disciplinary mechanisms and master narratives through counterstories, and how we restore worth, will become more important later in this work. After we have seen the ways in which the master narrative utilized by pinkwashing can be destructive, we will discuss the ways in which counterstories can be useful in resisting and pluralizing the master narrative. In the final chapter, we will discuss the importance of counterstories and their potential for resistance. We will also analyze some examples of counterstories which demonstrate the point. For now, all we need to bear in mind is the idea that master

narratives are often oversimplified and archetypal, have the potential to be oppressive and disciplinary, and shape our perception of our own moral worth and that of others.

In the first chapter, we saw the inherited problematic constructions of the female body which became embedded in the nascent breast cancer awareness movement in the early part of the 20th century. The second chapter demonstrated the ways in which the breast cancer body, throughout the last several decades, has occupied the abject subject position. These two trends of perception of the female body have intersected in the context of the contemporary breast cancer awareness movement to foster a master narrative about breast cancer which serves to discipline the abject breast cancer body, to keep it within systemic expectations for behavior, and to internalize self-policing. One specific and definitive aspect of the breast cancer awareness movement of recent decades has been the pink awareness campaign and the partnering of charities with for-profit corporations in order to ostensibly raise awareness and generate funds for research and treatment. Foucault notes that the tendency of charities to occupy positions which allow them to enact discipline is not a new one: “Religious groups and charity organization had long played this role of ‘disciplining’ the population. From the Counter-Reformation to the philanthropy of the July monarchy, initiatives of this type continued to increase...their aims were religious...economic...or political,” (*Discipline and Punish* 213). There is historical precedent for charities performing as controlling forces and creating behavioral expectations for the populations they represent and, as Foucault notes

in the passage above, it may have been in effort to raise money: "...discipline increases the skill of each individual...coordinates these skills...tends to increase aptitudes, speeds, outputs, and therefore profits; it exerts a moral influence over behavior...introduces bodies into a machinery, forces into an economy" (Foucault *Discipline and Punish* 210). In short, the discipline enacted in a society is meant to increase production, to create and support productive bodies which participate in, and promote, commerce. In the case of breast cancer awareness charities, we know that their aims are primarily financial: they seek to raise money. Through their use of disciplinary tactics and the master narrative of breast cancer, they seek to discipline bodies into being productive bodies, bodies that participate in breast cancer awareness commerce. Let's examine, for example, the social expectation that those with breast cancer should be enduring, stalwart, strong, and heroic. This was an expectation of feminine behavior in illness which we saw in Chapter 1 (and we will explore below, in detail, the role it plays in the master narrative of breast cancer). A person in this position might demonstrate this heroism, this strength, by leading a team in a charity walk, or attending or helping to plan a major fundraising event. Or, a person with breast cancer might simply demonstrate strength and endurance by disguising the effects of treatment using wigs and makeup, and going through daily treatment routines without complaint. All of these actions, though, mean that this person is a productive body, participating in the movement and in commerce in ways potentially resulting from the expectations created by the master narrative.

These pink campaigns, motivated primarily by fundraising, have made use of, and reified, the concepts of the master narrative of breast cancer through their ubiquitous marketing, but why? To what end? Frank acknowledges the beneficial potential in what he terms “general unifying views” (which overlap with Nelson’s definition of master narratives): “The advantage is to encourage closer attention to the stories ill persons tell. Listening is difficult because illness stories mix and weave different narrative threads. The rationale for proposing some general types of narratives is to sort out those threads,” (76). In the case of the breast cancer awareness movement, however, the opposite has happened: the master narrative has constructed or made use of easily recognized archetypes which make it simpler and more efficient for the campaign to reach the general public. Many stories of illness, including stories of breast cancer, create what Frank terms “chaos narratives,” (97). Chaos narratives are stories in which “the plot never imagines life getting any better,” (97). Chaos stories are hard to hear because they provoke anxiety: “...they are too threatening. The anxiety these stories provoke inhibits hearing,” (97-98). Chaos narratives are difficult and frightening for us to hear because they remind us “how easily any of us could be sucked under,” (97). These kinds of stories, which are existentially threatening and difficult to engage with, don’t make for good and efficient advertising. Instead, consumers want stories that are easily accessed and not existentially threatening. They crave stories in which illness is vanquished like an enemy, or in which it becomes something useful and productive, or results in life-altering wisdom.

Stories that genuinely confront us with our own own mortality don't sell. It's easier for consumers to access a series of generalized, archetypal notions of breast cancer which make illness a productive, non-threatening experience.

Pink awareness ads and products are unavoidable; advertisers bombard the public with their messages and non-threatening archetypes. Making the concerted effort to hear and confront alternative narratives is a difficult venture (particularly over the din of advertising), and not one which many of us have the existential and emotional endurance to do all of the time. Additionally, many people legitimately identify with aspects of the master narrative. But we should be mindful of the context and frequency with which we accept the master narrative. By accepting the master narrative and the social expectations comprised in it, we may expect that all people's experiences of breast cancer match the archetypal stories we see told through the breast cancer awareness movement. We may resist engaging with those who need us to acknowledge their stories. In doing so, we have internalized policing behavior. That behavior, as we shall see later, is demonstrably harmful to people with breast cancer.

The master narrative of breast cancer subjects those with breast cancer to regulated social and behavioral expectations, generating a number of compelling problems for people seeking to tell or enact their breast cancer illness narratives for the purposes of re-identifying themselves. In the context of this analysis, we will examine several major problems which arise from the master narrative of breast cancer: people

with breast cancer may internalize the lowered worth of themselves communicated through master narratives, and they may lack witnesses, leaving their illness narratives unacknowledged and unheard. Thus, they are subjected to injustice. They may be shamed or scapegoated for their illnesses or for their behavior in response to their illnesses. For the lack of having someone to bear witness to their narratives, some may pay a price of decreased mental, emotional, or physical health, or poorer outcomes of recovery.<sup>60</sup>

It should be noted, here, that one feature of the breast cancer awareness movement in the United States, and the master narrative it utilizes, is that it has been historically predominantly white. The discussion below and the implications of pinkwashing and the master narrative apply to all who experience breast cancer, including people of color. Of people of color, black women (in comparison with Latina, Asian, or Native American women) experience breast cancer most frequently, and a good part of the work examining women of color and their experiences with breast cancer is about black women, specifically. So, that population is what the current discussion will focus on in its address of issues of women of color and the master narrative of breast cancer.

The ways in which the influence of the pinkwashed breast cancer awareness movement manifests itself in the lives of black women, and their experiences of the

<sup>60</sup> In the opening section of the final chapter, we will examine several studies done on women and their emotional and physical outcomes during and following breast cancer and treatment.

illness, may differ from those of white people.<sup>61</sup> Black women are subject to the effects of a historically different relationship to the medical hegemony. They live in socio-economic and environmental conditions which may affect their risk of illness or their mortality.<sup>62</sup> The ways in which their communities address illness vary as well. A comprehensive examination of the ways in which the master narrative of breast cancer affects women of color would (and should) require much more historical context regarding the problematic constructions of black women's bodies, specifically, and the dark and complex history of the relationship between the medical hegemony and black women's bodies in the United States. It would also require a closer examination of the ways in which black women's bodies can be construed as abject. Laying out those histories and contexts individually and thoroughly would take much more than the current discussion can address; however, the experience of black women with breast cancer, particularly in the historical, socio-economic, and cultural contexts, merits further work by myself and others in the future. What I have done below, in explaining each of the main concepts of the overarching master narratives of breast cancer, is to note one or two significant examples of the ways in which each concept may manifest differently in the lives of black women. Through this method, readers can see the ways in which women of color are subject to some of the same oppressive features of the master narrative of breast cancer, but they can also see the ways in which black women's

<sup>61</sup> See Gattison, Annette D. Madlock. *Health Communication and Breast Cancer among Black Women Culture, Identity, Spirituality, and Strength*.

<sup>62</sup> See Eisenstein, Zillah. *Manmade Breast Cancers*.

experiences of those features are distinctive and worth examining independently.

### 3. Cause Marketing and Pinkwashing

Before we can begin to uncover and analyze the master narrative of breast cancer, we must see and understand the foundational principles upon which the breast cancer awareness movement operates. Then, we can begin to know the motivations of non-profit organizations driving the movement and the reasons they execute specific strategies that make use of the master narrative. These non-profits, organizations like Susan G. Komen for the Cure and the Avon Foundation for Women, partner with for-profit companies like Ford, BMW, Yoplait, or KFC (among many others) in a practice called cause-related marketing (or cause marketing). Cause marketing occurs when corporations partner with nonprofit fundraising organizations to raise some amount (however small) of money for the non-profit, while also generating good publicity for the corporation and encouraging sales. Cause marketing allows for the “integration of a corporation’s philanthropic activities with its drive for profit,” (King 9). According to Samantha King, corporations began taking advantage of cause-related marketing in the mid 1990s, as a way to “‘cut through the clutter’ of increased competition...to attract the attention and loyalty of the consumer who is understood to be increasingly adept at reading marketing messages,” (10). So, marketing is advantageous for corporations because it gets consumers’ attention. Additionally, cause marketing appeals to a shift of American consumer sensibility, according to Bill Laberis, editor of *Computerworld* magazine: “they want something they

can believe in...[It's] a kind of spirituality," (as cited in King 11). Cause marketing is helpful to corporations not only because it gets consumers' attention, but because it offers a belief system in which the viewer can invest. As we noted above, part of the appeal of master narratives is that they present methods to make sense of our experience, ways of negotiating our experience that also form our moral intuition. Understanding the ways in which cause marketing appeals to consumers' belief systems may be easier if we return briefly to Frank and note two other types of illness narratives: restitution narratives and quest narratives. According to Frank, restitution narratives share the same plot line: "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again," (77). In these stories, ill people expect to get better or do get better. Quest narratives are stories in which the ill person casts herself as the hero on an adventure, a journey, from which she will return improved, wiser, having gotten something from it.<sup>63</sup> These stories "accept illness and seek to *use* it," (italics Frank's) (115). Frank claims that people want to hear restitution stories (77) and that, "most published illness stories are quest stories" (115). These types of stories are familiar to the public and heard often. Both of these types of narratives (which are frequently used in advertising) offer consumers "something they can believe in" (to return to Laberis' claim). In the case of restitution narrative, they can believe in health, the power of medicine to heal, the ability of the human will to conquer illness. In the quest narrative, they can believe in a hero and the wisdom the hero garners

<sup>63</sup> Frank's theory of quest narrative is derived directly from Joseph Campbell's theory of the "journey of the hero" or "monomyth," from his well-known work, *The Hero with a Thousand Faces*.

from her journey; they can believe that illness is valuable, useful, or productive. By buying an item that uses stories like these for endorsement, consumers can feel as though they've supported the search for a cure, praised the endurance of the human spirit, or helped share the wisdom a person gained on the figurative journey. The Yoplait "Save lids to save lives" campaign is a powerful example. The slogan itself is a restitution story: purchase this and you can help people get well. The master narrative provides an easily digestible archetypal story about breast cancer, and also informs the consumers' moral belief systems. Consumers of the product get to literally buy-in to the belief that their purchase has helped save a life.

Some activism and awareness groups resist these depictions of breast cancer, noting the clear influence of capitalism in the booming breast cancer awareness industry (Lerner 262). According to Klawiter, Women's Cancer Research Center and Breast Cancer Action are two such groups (168-177).<sup>64</sup> In fact, BCA coined the term "pinkwashing." ("Think Before You Pink"). Pinkwashing is a phenomenon which has recently arisen as a result of cause marketing related specifically to breast cancer and the famous pink ribbon campaign. The term, according to Breast Cancer Action, originally meant, "a company or organization that claims to care about breast cancer by promoting a pink ribbon product, but at the same time produces, manufactures and/or sells products that are linked to the disease," ("Think Before You Pink"). But the definition has changed and broadened as

<sup>64</sup> For more information on early resistance against the pinkwashed breast cancer awareness movement, see the Klawiter's chapter, "Patient Empowerment and Feminist Activism."

global and popular culture has embraced it. In 2011, the Hindustan Times defined it as “adopting the color pink and pink ribbons to imply that they support breast cancer research,” (“Companies Adopting Pinkwashing for Profit...”). This definition includes all companies and institutions who may use the pink ribbon to generate corporate support, not just those who manufacture products linked to breast cancer, and it includes companies and institutions who give the pretense of “support” through promotion, but not necessarily financial commitment to the cause. Gena Asher, columnist for the Bloomington Herald-Times, breast cancer survivor, and facilitator of the website, *BreastCancerFYI.org*, defines pinkwashing as “using pink ribbons as a sales tool,” (“Pinkwashing Obscures Breast Cancer Message”). A news release from the U.S. Federal News Service contextualized the definition by noting the ubiquitousness of the color pink, pink ribbons, and breast cancer awareness materials during the month of October, and called pinkwashing “corporate exploitation of breast cancer,” (“Pinkwashing Depicts Ideal Patient in Breast Cancer Awareness”). This last definition, the broadest one, allows for the most comprehensive discussion of the ethos of breast cancer awareness marketing. Given the history of the pink ribbon, which will be articulated below, this definition is probably the most apt.

While the term, “pinkwashing” is relatively new, corporate exploitation of breast cancer began with the pink ribbons themselves.<sup>65</sup> Since the inception of the ribbon,

<sup>65</sup> Readers saw this phenomenon in chapter one, when Estee Lauder and Self magazine first began using the ribbon at events and cosmetic counters.

several companies have gotten in on the pink action. A quick Google search reveals multiple pink ribbon-themed merchandise sites where consumers can purchase party supplies, clothes, and jewelry, all purportedly in effort to promote breast cancer awareness. Consumers can purchase breast cancer awareness Yoplait yogurt with a pink lid, a pink eyelash curler from Sephora, or a perfume from the Susan G. Komen foundation called “Promise Me.” TV viewers can watch NFL players clad in pink cleats and wristbands, and parade-goers can see the shiny, pink stretch Humvee and the gloriously huge pink ribbon-shaped hot air balloon, all while they eat KFC chicken from a Komen-sponsored bucket. According to Anastasia Pantsios, even fracking company Baker Hughes in Texas has joined the fray, with its “Doing Our Bit for the Cure” campaign, in which it created a distributed 1,000 hot pink fracking drill bits for use worldwide, and donated \$100,000 to the Komen Foundation. That specific shade of pink is nearly everywhere, especially in October during Breast Cancer Awareness Month. Undeniably, pinkwashing is effective in its efforts to increase awareness and funding: Revlon's support of research led to the development of a powerful new treatment, and Vera Bradley's Foundation for Breast Cancer has raised \$12 million for research (“Pinkwashing—Breast Cancer Awareness Month Inspires...”). Fernandez notes that the Susan G. Komen Foundation has raised \$685 million for research since its inception in 1982. It would appear, from cursory assessment, that cause marketing for breast cancer has been a beneficial strategy.

Pinkwashing, though, creates serious ethical issues which merit attention.

According to Westervelt, studies have linked several pink ribbon-themed items directly to toxins which cause cancer, including Estee Lauder cosmetics, the Komen perfume (which Komen vowed to reformulate before reintroducing to the market) and Yoplait yogurt (which contained rGBH and has now been reformulated). Because of the association between fracking and the carcinogenic toxins it adds to our environment, the pink drill bits should also be named in this litany of pinkwashed products. According to Kinsman, KFC partnered with Komen in 2010 to launch its “Buckets for the Cure” campaign, telling consumers that fifty cents of each purchase of a bucket of chicken would go toward cancer research and awareness (though, at the bottom of its website, the “Buckets for the Cure” campaign acknowledged that contributions would not be determined by the number of individual consumer purchases, but by the number of buckets purchased by restaurant operators). KFC is widely known for its high-fat, high-calorie products, and being overweight or obese is linked to increased risk of breast cancer in postmenopausal women, according to the *American Cancer Society* website (“Lifestyle Related Cancer Risk Factors”). The irony of this venture and others like it was not lost on Elizabeth Kucinich, wife of then-congressman Dennis Kucinich, who wrote Nancy Brinker (founder of Susan G. Komen) to request an end to the campaign: “Selling chicken in pink buckets to benefit breast cancer research is like selling pink cigarettes to benefit lung cancer research or selling bottles of pink liquor to support Alcoholics Anonymous.” The use of cause-marketing to peddle products which have actually been linked to breast cancer, while claiming to help people with breast cancer, is so ironic it’s nearly laughable.

Or at least, it would be, but for the fact it's actually quite tragic: while the Komen foundation sold "Buckets for the Cure," over 40,000 women in the U.S. died from breast cancer in 2015 ("Cancer of the Breast {female}: Cancer Stat Facts"). Exposing and resolving this unethical practice of pinkwashing is paramount in the efforts to direct fundraising to expanded treatment and research on prevention. Several articles and books, including *Pink Ribbons, Inc.*, by Samantha King (and the eponymous 2012 documentary) have been written and produced on these issues. The watchdog group, Breast Cancer Action, continues to monitor and call out pinkwashing practices. This is significant work which must be supported and should continue. However, there is another problem at hand with pinkwashing: the master narrative, which is utilized by these non-profits and corporations through pinkwashing, is detrimental to the reconstruction of identity in illness and supports other unethical practices. The purpose of the current project is to analyze these occurrences.

The corporate narrative (which makes use of the master narrative) of the breast cancer experience has now become entwined with public discourse about breast cancer. Thanks to the ubiquity of corporate advertising, the master narrative of breast cancer is nearly all the general public is exposed to. Because the master narrative is a method by which people are surveilled and disciplined about their unique breast cancer experiences, it threatens to overwhelm and obscure individualized or alternative stories. If the master narrative of breast cancer can potentially cause internalized lowered moral self-worth of those with breast cancer, and difficulty reconstructing narratives of self in illness, then

pinkwashing, in its support and reification of the master narrative, is causing a great deal of emotional and moral harm (to say nothing of the association between “pink” products and carcinogens) to those with breast cancer.

#### 4. The Master Narrative of Pinkwashing and the Breast Cancer Awareness Movement

Pinkwashing threatens to delegitimize the lives and identities of the people whose breast cancer experiences do not fit into the mold of the master narrative. In order to fully comprehend the ways in which it does so, we must define and examine the master narrative of breast cancer and examples of that master narrative at work. In the context of the present discussion, we will delimit four major concepts of the overarching master narrative (though, this list is certainly not meant to be exhaustive). The first is the massive oversimplification that early detection inevitably means that a person’s breast cancer will be cured. The second concept is the myth of the omnipotence of medicine and the idea that the knowledge of the patient about their own experience should be subjugated to that of medical professionals. The third is the expectation that people will maintain heteronormativity in their bodies and behaviors during and after their breast cancer diagnosis and treatment. The fourth and final problematic concept of the master narrative is the notion of the “ideal” breast cancer patient, who is heroic, strong, enduring, and full of hope. As we shall see below, those who don’t fall into this category are scapegoated or subject to victim-blaming for their behavior. Each of these concepts is related to the nature of breast cancer bodies as abject. Each of them have, embedded in them, methods by which to police behaviors of the abject breast cancer body. If we take

together the criticisms of the master narrative of breast cancer with examples of pinkwashing, and juxtapose those against the stories of those speaking from outside the master narrative, we can see the ways in which pinkwashing polices and regulates the behavior of people with breast cancer, minimizing the importance of their alternative stories in the socio-cultural context.

#### 5. Early Detection Means a Cure

In the previous chapter, we saw that the abject breast cancer body is a body out of control, a body which is considered deviant. Foucault notes that one of the features of disciplinary systems is that they can be (and are) utilized by institutions such as medicine, and we have established, via Ussher, that the monstrous feminine body is subject to medical management of its excess. In the context of the breast cancer awareness movement, the “early detection means a cure” message is the way in which the abject female body is subject to policing and discipline through medical management of illness. We already examined strong evidence of such in the previous chapter’s exploration of mammograms: they are recommended often and fairly frequently, even though they are not as accurate as the public seems to believe, and there is a significant occurrence of misdiagnosis and overtreatment resulting from mammograms. Mammograms are an excellent metaphor, here: they are a figurative and literal example of the way in which the abject breast cancer body is surveilled and then subject to medical management and discipline.

Maren Klawiter notes pinkwashing’s support for the “early detection means a cure”

message in her observation of the Komen “Race for the Cure,” an event that (along with corporate partners) raises money for breast cancer treatment and research: “In the discourse of the race, survival is a matter of individual choice as responsibility. Regular mammograms never fail to diagnose breast cancer early and women diagnosed with breast cancer never die...breast cancer may constitute a momentary setback, but it is not a debilitating, recurring, or chronic disease,” (“Racing for the Cure...” 145). Even the race itself, by virtue of the fact that it is a physically competitive event which requires the strength and endurance of a relatively healthy person, implies that a person can somehow control disease and is capable of willing oneself to achieve physical goals. So, one of the earliest key features of breast cancer’s popular narrative is the message that, essentially, if a person sees the doctor in a regular and responsible way, that person simply will not die from breast cancer. This message is an old one, in the history of the breast cancer awareness movement, used from the inception of the movement to urge the pathologized woman to subject her body to medical management to control its deviance.

Features of the master narrative of breast cancer appear as early as the campaign against breast cancer begun by the American Society for the Control of cancer (ASCC) in 1913, (Knopf-Newman 16) of which the main message was, essentially, that early detection equals cure (Gardner 1). The ASCC (later known as the American Cancer Society), endorsed by several allopathic medical groups, operated as a clearinghouse for information and promoted the cause (Gardner 2). Traditional medicine at the time followed the simple belief that early treatment offered the best opportunity for a cure, so

that idea became the foundation for the ASCC's early campaign, as we saw in Chapter 1. But this message fostered two mistaken beliefs that contributed to the popular discourse of breast cancer: that physicians had the power to actually cure the disease (which they didn't, at the time), and that a woman ignored symptoms at her own peril (Gardner 3). According to Gardner, "The message was repetitive, didactic, simple, and in hindsight, profoundly naïve," (3). At that time, many women died from breast cancer, regardless of detection and treatment. As of 2006, about 25% of women diagnosed still died from the disease (Herndl 236). That percentage appears to solidly controvert the master narrative's message that, "early detection equals a cure." We should take a moment to discuss and examine survival rates for breast cancer; the impact of these numbers can't be underestimated. Reported survival rates often seem relatively high, for example the National Cancer Institute (NCI) statistic that the relative survival rate for breast cancer is 89.7% ("Cancer of the Breast (female): Cancer Stat Facts."). But these numbers can be misleading: according to Soerjomatarm et al., a "long term survivor" is a person who has lived five years after diagnosis. Survival rates are often reported in terms of five-year survivors (as is the NCI relative survival rate above). In their 2008 study, Soerjomatarm et al. showed that the five-year relative survival rate for breast cancer was 88%, but the ten-year relative survival rate for breast cancer was 77%, meaning that ten years post-diagnosis, 23% of women in the study had died from breast cancer. The National Cancer Institute estimates that in 2016, more than 40,000 women died from breast cancer ("Cancer of the Breast {female}: Cancer Stat Facts."). The deluded and oversimplified

idea that curing women of breast cancer was not only possible, but nearly guaranteed, as long as they empowered themselves to visit the doctor is one that, like most features of the master narrative of breast cancer, we still see today. The presence of these oversimplified notions is noted by a user who goes by Abbeyfighter in the *BreastCancer.org* forum: "...everything I read says that my survival can be prolonged but I will probably die from breast cancer and within the next 10 years. I supposedly have good prognostic factors...but honestly does not seem to matter. I don't want 5 or 10 years. I want to live to old age and see my beautiful family grow up. I feel I have been robbed. I am angry and disillusioned. Why have they not found a way to prevent this coming back?" ("Topic: Is There Any Hope for Long Term Survival?"). As we can see from Abbeyfighter's comments, the term "survival" often connotes something very different from the five-year range that statistical experts use. This woman's remarks demonstrate that, while treatment and prognosis have improved since the middle of the 20th century, the reductive message that, "early detection equals a cure" may be detrimental, and it may be diverting focus from preventing breast cancer.

Pinkwashing, in the form of the "Race for the Cure" and all the race's accoutrements, supports the idea that if a person sees their doctor in a regular and responsible way, that person simply will not die from breast cancer. This message disregards voices like those of Marilyn Hacker, those who seek to understand and acknowledge mortality, rather than ignore it (as we shall see below). Failure (or perhaps refusal) on behalf of the mainstream breast cancer awareness movement to engage in

dialogue about the mortality associated with breast cancer amounts to dismissal and delegitimization of this aspect of the breast cancer illness narrative. The discourse generated by the master narrative, and utilized by the breast cancer awareness movement ostensibly supports breast cancer awareness, but it fails to help breast cancer patients cope with their own mortality. This neglect of terminal breast cancer patients is exploitative and unethical, and it demonstrates the extremity of the fear that our society harbors of the deviant, abject female body.

Marilyn Hacker's poem "August Journal," a contemporary breast cancer illness narrative, calls attention to the fact that breast cancer does, in fact, come with a very real risk of death: "If I'm one of the victims, who survives?/If I'm—reach for it—a survivor, who/are the victims? The heroic dead,/the ones who died in despair, the ones who died in terror and despair/and having to be brave...It is exceptional to die in bed/ at ninety-eight..." (Hacker 24).<sup>66</sup> Here, Hacker seeks acknowledgement of the dead, and acknowledgement of the frightening mortality rate of breast cancer. This desire for openness about mortality clashes with the message sent through pinkwashing.

Pinkwashing does not include room for acknowledgement of death. There are no pink breast cancer awareness funereal bouquets, no pink caskets. The front page of the *Susan G. Komen* website serves as a stellar example of pinkwashing's relationship (or lack thereof) to death (*Susan G. Komen*). The page includes several tabs and other pages

<sup>66</sup> Original use and analysis of this poem comes from Bahar, Saba. "If I'm One of the Victims, Who Survives?": Marilyn Hacker's Breast Cancer Texts." *Signs*.

full of resources: three main tabs on the front are labeled as though mimicking voices: “I have breast cancer,” “I had breast cancer,” “Someone I care about has breast cancer.” (*Susan G. Komen*). Visitors to the site are meant to categorize themselves under one of those three choices and click on the page which applies to them. Notably, there is no tab labeled “Someone I care about died from breast cancer” or “End of life planning.” Under another tab labeled, “The Breast Cancer Journey,” searchers find a timeline labeled with landmarks along the “journey,” but true to pinkwashing form, the timeline stops at the mark which reads “Living with Stage IV.” The pinkwashing message is one that focuses, sometimes unrealistically so, on the will to survive, which Nuland cautions against: “the prevailing temperament of our times [is that]...death is regarded as the final and perhaps the ultimate challenge of any person's life—a pitched battle that must be won...But the fact is, death is not a confrontation. It is simply an event in the sequence of nature's ongoing rhythms...the confrontation with disease should be approached with the realization that many of the sicknesses of our species are simply conveyances for the inexorable journey [to]...nonexistence,” (10). In reality, death is another stage of life, and illness is one way by which we arrive at that stage. The reason for this strategic avoidance of death, and the overwhelming support of the “early detection equals a cure” message, is that death doesn’t sell. Non-profits like the Komen Foundation, as well as the corporations that partner with them to sell their products, seek to make money. The general public isn’t interested in buying products with dying people associated with them; further, dead people can’t buy products. The pinkwashed movement has no interest in,

and no need, to appeal to people who might be dying or seek to acknowledge death. The movement and its various involved constituents need to appeal to consumers, and consumers are much more comfortable with a hopeful message that breast cancer can be cured because biomedicine has everything well in hand.

While the prognosis for breast cancer recovery now can often be fairly positive, and optimism mustn't be dismissed in favor of overly gloomy prognostications, this unrealistic emphasis on survival on behalf of the pinkwashing movement, precludes legitimate emotional (and practical) preparation for death and fosters a culture of death denial. It also dismisses the necessary and psychologically healthy grieving process for two categories of people: those who are faced with their mortality as a result of breast cancer, and those who grieve for loved ones lost to breast cancer. While it appears hopeful, the "early detection means a cure" message is perhaps the darkest and most insidious of all the master narratives of breast cancer, because it chooses to ignore those who are dying, who need us to acknowledge their mortality (as Hacker does above), in favor of selling products.

The message appears even more insidious when racial disparities are analyzed. The situation is even more dire for black women: according to Parker-Pope, in 2015, the incidence of breast cancer among black women in the U.S., which had historically been significantly lower than that of white women, became roughly equal to the incidence rate of white women. However, Parker-Pope notes, the rate of black women dying from breast cancer, which has historically been higher than than of white women, remained

significantly higher than that of white women. That means that, while the pinkwashed movement is out selling perfume and Ford Mustangs, more and more black women are dying of breast cancer. And the movement doesn't adequately acknowledge or respond to either the problem of death generally or the inequity of the mortality statistics. On a practical level, death denial precludes the dying and their families from making the necessary plans—financial, funerary, spiritual—which could ease the transition for the dying person and the family, and spare the family significant turmoil and trauma. From a philosophical perspective, death denial holds much more significant implications than mere logistical planning. Here, we must return to phenomenological precepts.

Phenomenology, as I stated in the beginning of this chapter, is concerned with the meanings of our subjective experiences. Jenkinson essentially argues that dying is a valuable phenomenological experience.<sup>67</sup> Like Nuland, he claims it should not be viewed as a pitched battle or a moment to be resisted and avoided. Resisting the notion of dying, even as our metabolic systems shut down, means that we, our *selves*, are not engaging in the phenomenological experience of dying: “But this is our body doing what it knows how to do when it cannot continue as it once did. This is our body being itself at the end of its days, but we are doing none of it,” (80). Further, he claims that the inability to engage with dying deprives us of the ability to make meaning of our lives and our deaths: “Your dying changes your eye, it changes what you see, and in that way your dying

<sup>67</sup> For an analysis of death denial in American culture which includes a phenomenological perspective, see Jenkinson, Stephen. *Die Wise: A Manifesto for Sanity and Soul*.

begins first in your seeing. *Your dying changes what your life means,*” (italics Jenkinson’s) (91). Dying can add meaning to life, and it can also be a meaningful experience in itself. It can be part of the narrative of self. If the pinkwashed breast cancer awareness movement excludes discussion of death, it may preclude people from engaging with, and making meaning from, their own dying and the dying of others. That the movement would do so in effort to sell products, is unethical. Further, the movement continues to under-emphasize the significantly higher rate of death of black women. As a culture, their human value is erased; as individual people, their ability for themselves and their families to prepare for their deaths is inhibited. Finally, and most significantly, they may be deprived the opportunity for meaning-making in their own lives and deaths.

Additionally, while this master narrative and the agencies in the movement who make use of it don’t actually threaten people with death, the threat is implied nonetheless: if you visit your doctor promptly for visits, you will not die of breast cancer; if you don’t visit your doctor for visits, who knows what may happen to you. This maneuver reifies the idea that death is something to be feared and resisted, and thus perpetuates the cycle of death avoidance in the contemporary breast cancer awareness movement.

## 6. The Knowledge and Authority of Biomedicine and the Subjugation of Women’s Knowledge

The idea that the knowledgeable physicians could cure the disease, combined with the concept of early detection which puts people in a position to be held accountable for their illness, contributed to two other elements of the breast cancer master narrative: the

authority of biomedicine, and the idea that patients assumed some responsibility for the outcome of their diagnosis. Gardner calls this a “myopic metanarrative focused on a linear cancer experience that included primarily early detection...” and cites a 1944 Parke-Davis pharmaceutical ad as a perfect example (4). The ad contrasts two women: one, a healthy white woman with her two children who has, ostensibly, recovered from her breast cancer because she ‘decided to take no chances,’; the other woman, a lonely white woman sick in bed, reads a telegram which says that her cancer has progressed beyond the point of treatability. This ad reinforces two messages: the blame for incurable cancer rests at her feet; with early diagnosis, a woman will inevitably be cured by her doctor. Thus, women should follow the instructions of their medical professionals without fail and without question. The power of medicine is demonstrated through pinkwashing’s emphasis on detection, treatment, and cure through annual visits to physicians and frequent mammograms. One example is the NFL’s “A Crucial Catch” campaign, as Karuna Jaggar observes, in which the NFL players wear pink cleats and wristbands for breast cancer awareness. The subtitle of the campaign slogan is “early detection saves lives,” a statement reminiscent of the vastly oversimplified ASCC campaign which began over a hundred years ago. With the “Crucial Catch” campaign, we have a form of pinkwashing which implies that salvation from breast cancer lies entirely and easily in the domain of medical examination and treatment, particularly through mammography screening. Further, according to Cork Gaines, only 8% of the money made from pink merchandise from the “Crucial Catch” campaign actually goes to cancer

research and programs (and even then, it goes to general cancer research and programs, not specifically to breast cancer). Gaines notes that almost 88% goes to the retailers and manufacturers of the products. That means that these companies make millions at the expense of clear and accurate messaging about breast cancer treatment. Notably, the concept of professional football, arguably the most masculine of professional sports and certainly male-dominated, enacting this campaign, subtly mimics the power of paternalist allopathic medicine: just as the strong football player will catch the ball if the right play is made; so will the powerful physician assuredly catch and cure breast cancer if the proper precautions are taken. Even the imagery of the player making the “crucial catch” of the football essentially mimics the squeezing and massaging motions of a manual breast exam. While the message may not be deliberate but rather the result of the master narrative, it is still pretty clear: put your life in the hands of biomedical protocol and you'll be saved. It should be noted that this oversimplification creates a disadvantage not only for patients, but for physicians as well: if patients come in believing that preventing or curing breast cancer is as simple as getting a mammogram, they may hold their doctors fully accountable for their physical well-being, blaming them when prognosis and treatment are not as simple as the commercial media has led them to believe it should be. The point here is not to vilify physicians and healthcare professionals who are culturally perceived as powerful and knowledgeable; rather, the goal is to point out that our culture has inherited a systemic imbalance of power between patients and physicians, and that the message of pinkwashing reifies that imbalance. That reification perpetuate situations

in which patients and doctors are potentially alienated from one another, and in which patients are perceived as having less authority or power.

Today, we can see that imbalance of power in Blackstone's exploration of the culture of Komen volunteers: "Pamela...told me about an experience that led her to question the priorities of the medical community and its respect for issues, such as breast cancer, that primarily affect women...she tells her doctor at every appointment that she is convinced that there is something about the environment ...causing increasing numbers of [women] to become inflicted with breast cancer. Her doctor...tells her the women she knows have simply had bad luck...Pamela told me 'He just brushes me aside. It's like he thinks I'm paranoid or something,' (359). Here, Pamela clearly needs her physician to hear her concerns about the ways in which cancer is impacting herself and her friends, but he dismisses her, causing her to struggle further to deal with her fears. While, certainly, many doctors are caring, attentive people who conduct exams in a reciprocal way, this example demonstrates that an asymmetrical power structure can sometimes present itself between physicians or surgeons and their patients. Bahar notes that, "...the glorification of the surgeon's struggles, along with cultural norms of modesty and discretion as appropriately 'feminine' contributed to silencing any expression of suffering, discomfort, and pain" (1027-28). In cases like Pamela's, or those of women who've had the Halsted mastectomy, the surgeon or physician wields an extraordinary amount of power to either overtly construct her surgical and treatment experience, or to engage with (or dismiss) her illness narrative and thus her new identity. In the interest of

fairness and full disclosure, it should be noted that work in the healthcare industry is increasingly difficult, given the demands for efficiency handed down by managed care organizations. According to Rabin, doctors are often expected to complete patient consultations within fifteen minutes. Their resources are limited by strictures which are often beyond their control. However, it's important to acknowledge that, while healthcare providers are educated authorities on the science of medicine, patients may bring to the table an acute awareness of their own bodies and their own embodiment, and also a human need for compassion, to have their doctor assist them in the construction of their illness narratives, and thus their *selves*. Both of those points of view must come to bear in a relationship to create effective treatment and recreation of identity in illness, which allows for patient empowerment and healing.

The subjugation of female knowledge is another phenomenon of western medicine which gives power to the master narrative of breast cancer. According to feminist scholar, Jennifer Fosket, medical knowledge has been legitimized: "Medical knowledge has been seen as the benevolent application of the objective knowledge derived through scientific methods...the traditional conflation of biomedical knowledge with truth and objectivity means that the profoundly social and constructed nature of such knowledge is overlooked, ignored or denied," (18). Drawing on Foucault, Fosket claims that the legitimization of medical knowledge means the subjugation of other types of knowledge, such as women's knowledge of their bodies, because of their lack of grounding in scientific knowledge (24). In her analysis of epistemic knowledge and pregnant women,

Freeman identifies this type of problem as “epistemic injustice”<sup>68</sup>:

Being recognized as a knower whose claims have legitimacy and are taken seriously and having the ability to exercise agency are basic human values that are necessary in order to navigate social, public, and private domains. When one’s claims are not taken seriously and when one is rendered powerless as a result, this constitutes an epistemic injustice. (45)

Carel concurs, noting that, “epistemic injustice is caused by biases and negative stereotypes about illness that can lead interlocutors to treat ill persons’ reports with unwarranted disbelief or dismissiveness,” (*Phenomenology of Illness* 180). Note that neither scholar argues that the patient’s knowledge should be elevated above the doctor’s, or seen as superior to the doctor’s; rather, both scholars claim that problem is when the patient’s knowledge is dismissed as having little or no value in the clinical experience.

In the context of breast cancer, examples of epistemic injustice are not hard to find. For example, in her field study of Komen volunteers, Blackstone recounts the story of a woman named Lora who, despite identifying herself as a woman with “lots of confidence,” made several visits to her doctors regarding a lump which concerned her, and was not able to convince them the lump was worth investigating. As a result, she began to worry she was “crazy and maybe overreacting or paranoid,” (360). Here, Lora’s intuition about her own body is dismissed in favor of medical knowledge, on the basis

<sup>68</sup> Freeman’s use of the term “epistemic injustice,” and her work in the article to which I refer, are both drawn directly from Miranda Fricker’s seminal work, *Epistemic Injustice: Power and the Ethics of Knowing*.

that medical knowledge is, ostensibly, more scientific and therefore more credible. She is discredited as a knower, and therefore subject to epistemic injustice, and her doctor may have what Freeman would call “inflated epistemic authority,” (53). The doctor believes (without warrant) that his knowledge is superior to hers, that it trumps her knowledge. While this epistemic injustice could be detrimental to her relationship to her doctors and to her narrative sense of self, it also could be physically harmful to Lora if her doctors are negligent in detecting a recurrence in her cancer.

We saw a similar dismissal in the previous chapter recounted by the writer Maxine Kumin, when her diagnostician calls to tell her that she has noninvasive intraductal carcinoma. She asks him what that means, and he responds in a way that essentially excludes her from being a knower in the conversation: “It means you have three choices. You can do nothing. You can take tamoxifen. Or you can have a mastectomy. You’ll have to come in and let me explain this to you,” (Kumin 19). Carel calls this type of dismissal, epistemic exclusion, and defines it as a situation which someone is “[denied] the role of contributing epistemic agent,” (182). In Kumin’s case, her knowledge is not viewed as inferior; it is not even acknowledged. Additionally, when they do meet, he is dismissive of Dr. Susan Love, whose book about breast health Kumin has been reading. The doctor doubly subjugates women’s knowledge: he dismisses Kumin’s ability to interpret the records of her own body and he also dismisses the knowledge possessed by Dr. Love, surgeon and widely acknowledged breast cancer advocate.

The subjugation of black women's knowledge by medicine, and the ways in which

that subjugation is tangled up in relationship between black women and medical hegemony, is very complex and in itself could be the subject of many articles. For the current discussion, it might be most useful to note a subjugation of black women's collective knowledge relative to public health and breast cancer. The higher mortality rates for black women have long been attributed to socioeconomic factors and the ways in which they overlap with class: "Racial disparities in socio-economic position suggest a link between one's class and one's survival...working-class women are more likely than affluent women to be already suffering from other adverse health conditions...the meaning of race itself becomes multi-factorial," (Eisenstein 97). However, this may be an oversimplification of the case. We may perhaps have been focusing for too long on statistics generated by public health researchers, and not on something that black women may have known for some time, as Gatison points out: "It has only been in recent years that some attention has been paid to other environmental and psychosocial stress factors that affect Black women's health. Black women have always known these stress factors exist," ("The Cost of Strength"). Gatison goes on to discuss studies which posit possible links between racial discrimination, stress, and breast cancer, some which concluded that there is a link between stress and breast cancer ("The Cost of Strength"). She seems to be implying what interviewee Ngina Lythcott says more straightforwardly: "Discrimination is toxic for us all...living as 'other' creates chronic tension and forces you to live protecting yourself from the next psychic wound," (Eisenstien 99). In other words, black women have long had the innate knowledge that simply existing as a black woman in the

United States is physically and emotionally difficult, that it takes its toll on the body one way or another. The epistemic authority lies with public health entities and biomedical scientists, but those with epistemic authority are only just now catching up.

As we discuss epistemic authority, it is pertinent to return to the previous chapter's mention of the concept of documentation as the ultimate power. In Chapter 2, readers were asked to note the relationship between written documentation and surveillance in Foucault's theory of disciplinary systems. Documentation is the epitome, the physical embodiment, of the power of the one who is performing the surveillance in the Panoptic structure. Documentation of the body's surveillance is one of the strongest and most powerful ways in which the agents of the disciplinary system can exert control over the behaviors of those imprisoned inside it. In the example above with Maxine Kumin, the power dynamics of the holder of documented knowledge (her doctor) and the person inside the disciplinary system (Kumin) are brought to life. The doctor uses control of her medical documents in order to set behavioral expectations for her: he expects her to come into his office and acknowledge his power and knowledge as the physician. When she refuses to abide the expectation, he uses his epistemic authority to enact discipline through refusal to cooperate. Then, he commits epistemic exclusion by dismissing her knowledge of her illness. Because they have epistemic authority, the power of documentation stays in the hands of medical professionals, for the most part. This type of documentation may support the master narrative concept of the omniscient doctor, and is the epitome of the power of the Panopticon at work. For example, a patient who stops

taking her Tamoxifen because the side effects are overwhelming may be labeled “noncompliant.”<sup>69</sup> This label may cause further problems in patient-doctor relationships, and may be difficult to shake off, as Danielle Offri (herself a medical doctor), notes: “As soon as a patient is described as noncompliant, it’s as though a black mark is branded on the chart, ‘This one’s trouble,’ flashes into most doctors’ minds, even ones who don’t want to think that way about their patients.” This particular type of documentation, then, exerts power over patients, sometimes even in cases in which doctors attempt not to oversimplify their patients’ experiences. In contemporary western culture, when it comes to illness, the preferred, legitimized type of knowledge is that of biomedical science, and that knowledge is what primarily constructs the documentation about the patient. The person who constructs the patient’s documentation becomes the more powerful entity, resulting in an imbalance of power in the patient-doctor relationship. Also, the narrative of self in illness is not only constructed autonomously, but through others and with others. So, a relationship between a healthcare provider and a patient in which the patient is narratively disempowered, or in which the patient is subject to epistemic injustice may change, impede, or even harm the construction of the patient’s narrative of self. The subjugation of women’s knowledge reifies and gives power to the master narrative of the authority of biomedicine in our disciplinary system, and may lead to epistemic injustice or epistemic exclusion, as well as other potential detrimental effects.

<sup>69</sup> According to Offri, “‘noncompliant’ is doctor-shorthand for patients who don’t take their medications or follow medical recommendations.”

Notably, this imbalance of narrative power may be disadvantageous for doctors' too: if they perceive themselves as having significant power and control over the narrative of another, they may consequently blame themselves when treatment does not go to plan, as Charon notes in her discussion of how doctors handle death: "Doctors may look at death with the worry that they have caused it—purposefully, passively, through negligence or error," (25). Similarly, Nuland notes feeling like a failure when one of his patients dies from a sudden, massive heart attack: "I was crying, in great shaking sobs. I realized, too, that I had been shouting at McCarty, demanding that he live...and weeping all the time with the frustration and sorrow of my failure, and his," (7). Nuland goes on to discuss how he came to the understanding, later in his career—McCarty is his very first patient to die—that death is not a failure on the part of either the patient or the physician. Interestingly, he notes that a reciprocal relationship to his patients helped him come to a more complex understanding of his role in his patients' stories: "It is the cardiologist's skill as a physician that enables him to befriend his patient and to know him—it is inherent in the art of medicine to appreciate that the testing and the medications are of limited usefulness without the talking," (36). Freeman claims that people in relationships like Nuland describes above, in which both the patient and the doctor can make valid epistemic claims which are then equally respected by one another, are epistemic peers.<sup>70</sup>

<sup>70</sup> See Freeman, Lauren. "Confronting Diminished Epistemic Privilege and Epistemic Injustice in Pregnancy by Challenging a 'Panoptics of the Womb.'" For further discussion of the ways in which doctors can facilitate reciprocity during examinations, including co-authoring of the patient's illness narrative, see Charon, Rita. *Narrative Medicine: Honoring the Stories of Illness*.

It is the epistemic equality and reciprocal narrative constructed between doctors and patients which facilitates a balance of power. As Foucault notes, one way in which to resist the power of the Panopticon and the disciplinary society is to establish “horizontal conjunctions” and illness narratives have the power to do just that.

It is possible for patients to exercise agency and empower themselves in the construction of their self-stories by creating their own documentation of their illness through counterstories. These counterstories exist in disruption of, or discordance with, the master narrative, as Nelson notes: “The proper target of a counterstory is a master narrative that has been generated by an abusive power system to impose on a particular group an identity the system requires,” (155). The purpose of a counterstory is to resist the master narrative and assist in the creation of an identity which does not match the expectations set by the master narrative. Counterstories have the power to create intersubjective relationships between the teller and the audience/listener/reader. These intersubjective relationships, these “horizontal conjunctions,” foster empathy and pluralize our notions of breast cancer experiences for those who read them. In order to facilitate this process, we must be willing listeners or readers, ready to acknowledge the significance of the epistemic authority of the teller; we must be open to experiences outside the discipline-mechanism of the master narrative, and willing to engage in the storyteller’s construction of self.

## 7. Heteronormativity

As we noted in the previous chapter during our discussion of Foucault’s figurative

Panopticon and its application to society, systems of discipline are generally incompatible with non-binary labels. Disciplinary systems force things (or people) to be labeled according to dichotomies: "...all authorities exercising individual control function according to a double mode; that of binary division and branding (mad/sane; dangerous/harmless; normal/abnormal)," (*Discipline and Punish* 199). In the case of breast cancer, the master narrative concept of heteronormativity seeks to delimit the female body safely within the confines of the male/female gender binary. As we discussed in Chapter One, heteronormativity generally means a mode of thinking in which heterosexual relationships are considered the norm, and gender roles within heterosexual relationships are considered the definitive roles. In heteronormative thinking, women are identified as wives and mothers in nuclear families, and they perform traditional gender norms of femininity; in heteronormative thinking, members of the LGBTQ community are considered abnormal and marginalized from general discourse.

In the early stages of the breast cancer awareness movement, non-heteronormative people were overtly policed and disciplined by medicine, as we saw in Chapter One, in Knopf-Newman's observation of a 1935 medical report (which initially appeared in the work of Leslie Reagan) which called breast cancer "the penalty women pay for failing to bear and...nurse children," (18). The ad implied that the punishment for refusal to conform to maternal, nurturing gender roles was breast cancer. This reportage, according to Knopf-Newman, "suggested that women had to succumb to their biological destinies

as wives and mothers,” (18). As a result of this kind of early messaging, women felt social pressure to look, behave, feel, and act, “normal,” in the wake of their diagnosis and treatment, as we see in mid-century movements (such as Therese Lasser’s “Reach for Recovery” campaign, discussed in Chapter One). While not as overt as the 1935 medical study which directly attributed breast cancer to a woman's choice to defy gender norms by not having children or not breast feeding children, pinkwashing supports and utilizes concepts of heteronormativity in its campaigns.

Breast cancer threatens heteronormative concepts of what it means to be traditionally “feminine”; through losing a breast (or both breasts) or hair via chemo, people in breast cancer treatment cannot maintain a “normal” heteronormative appearance. Often, people feel they must return to “normal” and will go to great lengths to do so. Following treatment, patients endure many physical modifications which make them feel or appear “normal,” such as uncomfortable clothing, wigs, and prosthetics. Terese Lasser’s Reach for Recovery organization encouraged breast cancer survivors to wear a prosthetic to disguise the fact that they’d had a mastectomy, which intensified the secrecy and shame surrounding mastectomies (Gardner 339). Her manual for recovery, which includes illustrations of recovery exercises depicting a white woman wearing heels and coiffed hair, and a “Letter to Husbands,” to address their reactions to their wives’ mastectomies, concludes with her reminder for women: “Remember that you are the same person today that you were before—IN EVERY WAY,” (339). Though she meant well, Lasser supported the emphasis on returning to pre-cancer heteronormative

normalcy, ignoring the voices and feelings of those who legitimately looked and felt different in many ways, after their breast cancer treatments (339). Narratives of those who refuse to perform traditional gender appearances are marginalized from the discourse. This kind of exclusion and threatening of non-heteronormative people is still present in the current movement.

Many breast cancer organizations are guilty of focusing their efforts almost exclusively on the heteronormative concept of femininity. The Susan G. Komen Foundation, for example, utilizes a fashion show (Blackstone 358). The foundation charges admittance and solicits funding from corporate sponsors (358). Then, survivors receive complimentary wigs and makeovers before the fashion show, in which they display themselves by strutting down a runway like models (358). Komen also “displays” survivors at “Race for the Cure” events, a choice which is meant to honor them, but which also supports the idea that they are “suitable for display” (358). In both cases, the women are meant to exemplify breast cancer patients who can still perform heteronormative concepts of femininity, getting makeovers and having long hair, and being typically “pretty” enough to display. These displays send the message that, during and after their breast cancer diagnosis, the social expectation is that they will do their utmost to maintain an appearance of outward heteronormative femininity.

Even the choice of color of the ribbon itself emphasizes the fact that people should focus on heteronormativity. As we have already recounted from Fernandez in Chapter 1, Amy Langer, (Executive Director of the National Alliance for Breast Cancer

Organizations) offered a revealing response when she was asked about the color choice for the original ribbon: “It’s about body image, it’s about nurturing, it’s about femininity...” (as cited in Fernandez). This concept, of course, implies a vast oversimplification of the term “feminine.” It includes only those who have “feminine”-looking bodies (those who have, or appear to have, breasts) and those who are “nurturing” (those who value motherhood). Additionally, this attitude around the color choice equates health and femininity. If “healthy” and “pink” are equated, the implication is that those who don’t identify with pink are somehow unhealthy, or will be excluded from the concept of “healthy.” Langer’s attitude essentially sends the message that the pink campaign represents women who define femininity using the same definition that the campaign does. That language, when internalized, results in people with breast cancer policing themselves, feeling pressured to look and act heteronormatively feminine, particularly if they’d like to be able to identify as part of the breast cancer awareness movement (which is so closely tied to pink and pinkwashing). This pressure to look heteronormatively feminine in order to be part of the breast cancer awareness movement creates a division: heteronormative women in the movement, and non-heteronormative people distanced from the movement. Foucault notes that division is critical to maintenance of power and control: he claims that “constant division between the normal and the abnormal” brings about “a whole set of techniques and institutions for measuring, supervising, and correcting the abnormal,” (Foucault *Discipline and Punish* 199). Those who are not heteronormative are labeled “abnormal” in the context of the

pinkwashed movement (because, as we noted in Chapter 2, disciplinary societies need to ascribe to binary divisions; if they are not “normal” they must be “abnormal”). This labeling happens in other contexts as well, but is especially acute in the context of pinkwashing, since such an emphasis is placed on girliness and femininity. If these people do not conform to what is “normal,” their bodies will be subject to control and discipline that ranges from marginalization to potentially decreased health outcomes. Through this aspect of the master narrative of breast cancer, we ensure that the abject breast cancer body fits suitably into a safe binary divide through which we can label and control it.

This emphasis on heteronormativity in the contemporary breast cancer awareness movement and the pinkwashing strategies it utilizes, means that members of the LGBTQ (lesbian, gay, bisexual, trans\*, and queer) community are often marginalized from the mainstream movement. While Lorde's *The Cancer Journals* and *A Burst of Light* are seen as seminal texts in discourse around breast cancer, and are often cited and circulated, they stand out as one of the few texts written by a black woman and one of very few written by a member of the LGBTQ community.<sup>71</sup> In 1990, Susan Hester founded the Mary-Helen Mautner Project for Lesbians with Breast Cancer, named for her partner who died of breast cancer at the age of forty. The organization did and still does tremendous work in advocating for and supporting lesbians with breast cancer, but it is still far less

<sup>71</sup> Other texts from members of the LGBTQ community, such as Brownworth's *Coming Out of Cancer*, will be examined as counterstories in Chapter 4.

well-known than organizations like Susan G. Komen. While Lorde's text is widely praised, and there are now several groups like the Mautner Project, the master narrative of breast cancer still reifies the concept of breast cancer as a mostly hetero issue, as we shall see.

One significant struggle for those who identify as LGBTQ is the expectation that they perform heteronormative femininity. The breast cancer awareness movement straightforwardly aligns itself with the belief that breast cancer is a women's disease; further, it uses pink and pink products to support the idea that it is a disease and a movement associated with girly femininity. Girly femininity may not be an identity with which all people with breast cancer are comfortable, including those in the LGBTQ community who identify with varied manifestations of gender and gender performance, such as lesbians who identify as butch, or those who identify as non-binary. But the breast cancer awareness movement's association with heteronormative femininity backs members of the LGBTQ community into a painful existential corner, as S. Lachlann Jain notes: "...at least one aspect of shame of breast cancer for those who inhabit non-normative genders lies in the seeming destiny of biological gender. Breast cancer demands a surrender to femininity and to the mortality doled out by the feminine body," (504). Breast cancer cites a body as female, and the movement supports the idea that the female body must perform heteronormative femininity. Tig Notaro, an openly lesbian comic, notes this phenomenon in her interview with Grigoriadis about her breast cancer. On the day she is diagnosed, a person on the street mistakes her for a man, but she is

acutely aware of her femaleness: “Usually I have a sense of humor about that...I just got diagnosed with breast cancer in both breasts; that’s how much I’m not a man ... not today, not a man.” Jain notes, in concurrence with the argument presented above, that gender norms in the breast cancer awareness movement are a way of monitoring and correcting gender behavior: “...the relentless hyper- and heterosexualization of the disease results in something of a recursive process through which gender is produced and policed,” (505). This production and policing of gender marginalizes people who are non-normative, as Catherine Lord notes in her breast cancer narrative: “I do not want to be a woman who is her breast cancer. I do not want to wear a pink ribbon and go on walks in crowds,” (12). Lord, a lesbian, seeks to break out of the pattern in which breast cancer identifies her as a woman, and also the expectation that her identity as a woman means she must wear pink and go on breast cancer walks. But choices like hers are not represented in the master narrative of breast cancer.

Jain claims that the movement and its pinkwashing strategies promote heteronormative femininity so zealously that they result in a “redoubling of femininity that fissures through the entire biomedical complex of cancer treatments,” (503). A primary example of the way in which this redoubling of femininity is evident in the biomedical complex is the mastectomy procedure--the emphasis on femininity is present in how choices around reconstructive surgery are handled by family, friends, medical professionals, and communities. According to Jain, “mastectomy necessarily cites gender, mastectomy queers a woman in a homophobic world,” (521). Because we identify a

woman so acutely with breasts, says Jain, if we remove breasts, the woman no longer bears the social signifiers of her gender. Robin Warshaw's interview with Vonn Jensen includes similar observations. Jensen, a gender non-binary person who founded the “Flattopper Pride” movement for those who choose not to have reconstructive surgery, agrees that mastectomy raises some conflict about our social norms about gender and gender performance: “If you take a woman who has breast cancer and she loses her breasts...which is how we define a woman, she might still feel very much like a woman. So what does that mean about our concepts of female bodies and socialized gender norms?” Because mastectomy causes a person to lose the body part which signifies her as a woman, society expects that people who undergo mastectomy will also undergo reconstructive surgery to fix the ostensible problem. Jerilyn Goodman noted this phenomenon in her discussion with her doctor: “I met with the plastic surgeon who, when I said 'I'm not sure I want reconstructive surgery,' replied incredulously, 'Why not?!” (141). This example supports Jain's claim that notions of heteronormative femininity supported by the master narrative of breast cancer are present in biomedical treatments. This point is further strengthened by the *JAMA: Surgery* study by Morrow et al. which showed that, as of 2014, roughly 58% of women who have a mastectomy choose not to undergo reconstruction at all. Though the biggest percentage of women do not choose reconstruction, some members of the medical community still ascribe to the sociocultural notion that a woman would be expected to have breasts, and the wider social community still expects women to have breasts as well. Christine Middlebrook most profoundly

notes the expectation that women have breasts (or, at least, appear to have breasts) in a story she tells about dropping her prosthesis on the floor of her gym's locker room: “Embarrassment floods me like a hot flash. The prosthesis, out in the open, is far more embarrassing than the Amazonian scar across my chest. The prosthesis is proof that I am trying to pass!” (176). The use of the word “pass” here is important, because it is often applied to non-white people attempting to pass as white, or non-heterosexual people trying to pass as straight. While she is a straight woman, Middlebrook is cognizant of the notion that a women are identified by their breasts. In a world of two-breasted women, and a movement that very much supports femininity associated with breasts, she feels that her breast loss detracts from her identity as feminine, and she feels compelled to abide social norms. Our culture's emphasis on breasts as signifiers of femininity is so strong that she needs a prosthesis to “pass” as something she already is. Issues around mastectomy and reconstruction are more pronounced for members of the LGBTQ community, as is noted by Melanie Barker's interviewee, Susan DiPronio, who identifies as lesbian and genderqueer: “Straight people don't get it. You fight all your life for your identity, and then something like breast cancer happens to you, and that's a huge part of your identity is your body...sexuality is so tied with physicality and the physicality of who you are starts to change.” While one could argue that certainly straight or cisgender women's bodies are also a huge part of their identity and sexuality, it's important to remember that their identities as heteronormative are socio-culturally accepted, while LGBTQ people have had to negotiate living non-normatively in a predominantly

heteronormative world. When they are diagnosed with breast cancer, they are then confronted with a movement, a cultural narrative, and a huge consumerist trend (pinkwashing) that all work together to remind them of the ways in which their narratives of self are non-normative, rather than create cultural space for those narratives.

Identity is not the only major concern for members of the LGBTQ community with breast cancer: lack of access to treatment as a result of that non-normative identity is also a problem. Misunderstanding, lack of information, discomfort, and bias about non-normative identities can be an impediment to healthcare, as we see from Jensen's commentary during Jensen's interview with Warshaw:

If you're a person who's queer or gender non-binary, the medical community is a scarier place than it is for somebody who is normative. When you're worried about cancer, the last thing you should be worried about when you go to the doctor is if they're going to be prejudiced against you and say hurtful, harmful things.

Parvin concurs that bias is a problem: “The biggest issues seem to be problems with the healthcare industry...homophobia is the biggest risk for lesbians,” (91). This is a significant issue because, as the *Susan G. Komen* website notes, “Lesbian, gay, and bisexual women have a greater risk of breast cancer than other women,” (“Facts for Life”). If lesbians are at higher risk, shouldn't the breast cancer awareness movement be reaching out to them specifically, and with greater effort? Shouldn't it seek to aid healthcare providers in dispelling myths, providing information, and overcoming bias? It

doesn't. It utilizes the master narrative, and the master narrative of breast cancer reifies concepts of heteronormative femininity. That emphasis on heteronormative femininity may foster problematic concepts about lesbians and breast cancer, as we see from further text on the *Komen* website: "...these women may be more likely to never have children or have them later in life. Lesbians also tend to have higher rates of obesity and alcohol use. All of these factors increase breast cancer risk," ("Facts for Life"). While these comments may be statistically correct, the presentation of them is vastly oversimplified. They ignore the historical socio-cultural dismissal of families with LGBTQ parents as violating American values, a factor which may impact a couple's decision or ability to have children either biologically or through adoption. These statements also vastly oversimplify possible causes of obesity and smoking and drinking habits, some of which may relate to public health concerns, cultural environments, or other factors. As they stand, these statements read as victim-blaming. Though the page is careful to articulate that breast cancer in lesbians is "not because of their sexual orientation," it follows that claim immediately with the language above, the subtext of which is "Lesbians may be more likely to engage in behaviors that may cause breast cancer ("Facts for Life")." It's worth noting, as well, that of the massive resources available on the *Susan G. Komen* website, this is the one page that deals exclusively with LGBTQ concerns, and it amounts to roughly two pages of printed information, including graphics. This page is another example of the ways in which gender and gender performance is policed and disciplined by the breast cancer awareness movements and its pinkwashing affiliates: people who

display non-normative gender characteristics or behaviors are victim-blamed and subsequently marginalized. Jensen, during the interview with Warshaw, notes feeling marginalized by the resource material she initially found after diagnosis: "...any information I was looking for was designed for straight people and didn't speak to me."

A similar example of information which does not speak to the LGBTQ community is found on the *Komen* site, under a small section about trans\* people and breast cancer, which states that "at this time, data on the risk of breast cancer among transgender people is limited," ("Facts for Life"). This, too, is correct, but subsequent content on the site may be alienating and inadvertently hurtful. The site offers a few recommendations which are meant to help trans\* people. The most revealing is that the person should find a health provider with whom they feel comfortable and then "once you find a provider you like, see *him/her* on a regular basis," (*italics mine*) ("Facts for Life"). This language is remarkably presumptive. First, it supposes that it's easy or affordable for anyone, much less a trans\* person, to find a provider with whom they feel comfortable. It ignores the huge difficulty of this task for trans\* people. Second, in direct address to the trans\* community, in which gender identity is complex and not always binary, it presumes gender binaries as standard. This linguistic choice directly indicates the organization's support of gender binaries and heteronormativity, policing trans\* identities and marginalizing LGBTQ people.

Heteronormativity is the standard approach to gender and gender identity in the breast cancer awareness movement and pinkwashers. Use of the master narrative

(through pink, girly products, for example) heteronormativity as the standard. Therefore, most of the information, materials, products, and resources are heteronormative.

The discussion of gender identity, sexuality, and breast cancer is complex and nuanced. Breast cancer, and its subsequent treatment (mastectomy) brings to light many questions about social norms regarding gender in our country, as Jain articulates: "...the absence of the breast introduces a new set of interpretive problems for the odd mix of gender and illness, internal and external health and appearance, that cancer and its cultures presents," (515). The analysis and conversation should be ongoing and these concerns should be examined further and with more depth than this particular work can allow. What is clear, though, is that the mainstream breast cancer awareness movement and its affiliated pinkwashing strategies are heteronormative. As such, it polices non-normative gender identities and does not support narratives of self that are not heteronormative, and this practice marginalizes and has the potential to silence people who do not identify as heteronormative. This marginalization and silencing happens at the expense of the narrative constructions of self of a significant segment of the population.

#### 8. The Ideal Breast Cancer Patient

If heteronormativity is the master narrative which assures that the female body (in appearance) abides the proper binary divide, then the expectation of the "ideal" breast cancer patient assures that the female character and mannerisms also fit the proper binary mode. The expectation of people to perform heteronormative femininity during and after

breast cancer and treatment means that they are expected to be demure, strong, and enduring. It requires that people engage in commodified notions of “hope,” as characterized by the movement. Those who refuse to engage in these behaviors become scapegoats and are victim-blamed. Expectations for heteronormative female behavior create a dichotomous attitude toward the breast cancer patient's responsibility for illness: the patient becomes either the hero or the scapegoat. The hero is the “ideal” breast cancer patient, who is also known as either the warrior or a fighter. The scapegoat, the victim who is also at fault, becomes the cautionary tale, the example of what can happen if a person refuses to engage in correct heteronormatively feminine emotionality and behavior.

The hero is characterized by ability to have doubtless faith in doctors and remain positive and enduring throughout treatment. The hero is, quite literally, the embodiment of mind over matter, because the hero overcomes cancer through sheer force of will. Knopf-Newman cites former First Lady, Betty Ford, as a primary example. Just before her biopsy, the *New York Times* ran an article in which they described her emotional state: “Although she knew that she might have to undergo a breast removal, Mrs. Ford was described by aides as in ‘really good spirits,’” (Hunter 22).<sup>72</sup> Throughout her ordeal, Ford was pictured smiling, well-dressed, and composed. Photos published in national news outlets one week after her surgery showed her sitting up in bed next to her husband, with

<sup>72</sup> For further analysis of First Lady Betty Ford's media image during breast cancer, see Knopf-Newman pp. 58-85

perfect makeup, coiffed hair, and a frilly housedress, holding open a large leather portfolio filled with ‘Get Well’ messages from congresspeople (Knopf-Newman 74). As we noted in Chapter 1, shortly after her Halsted procedure, Ford was pictured cheerfully throwing a football to her husband, a physical movement which would have been difficult (if not nearly impossible) and painful for a woman having just undergone such a procedure (Knopf-Newman 75). According to the depiction of the ideal, a breast cancer patient should remain strong, stalwart, cheerful, and endlessly optimistic. The ideal patient also finds purpose and meaning in her cancer, as Tamara Joe Stevens demonstrates: “To have the ability to encourage others to remain positive and live life to its fullest despite their prognosis, I believe, is my God-given purpose now,” (Herndl 224). Ehrenreich, too, notes the frequency and zeal with which this “relentless bright siding” is spread: “...in our implacably optimistic breast cancer culture, the disease offers more than the intangible benefits of spiritual upward mobility. You can defy the inevitable disfigurements and come out...prettier, sexier, more femme...for those willing to get with the prevailing program, opportunities for self-improvement abound,” (49). The ideal breast cancer patient is one who always looks for the silver lining, never appearing angry or pessimistic, seeking to make illness a journey from which something may be gained.

The best example of pinkwashing enforcing the concept of breast cancer patient as hero, is the *Susan G. Komen* website homepage, which features pictures and stories of survivors. The survivor story of Maura Bivens, a woman with dark hair with bright red streaks, pictured in her karate gi and her black belt, uses the “fighter” metaphor:

“Although a trained fighter, Maura Bivens never expected to cross swords with breast cancer...But not once did she surrender to the disease. This is the story of a tenacious woman who survived despite the odds,” (“Maura Bivens”). This language implies the possibility, and even probability, for reversal of the worst of breast cancer prognoses, as long as the patient maintains the positive, heroic attitude.

The notion of the strong, heroic warrior takes on a more pronounced role in the lives of black women with breast cancer, according to Gatison. She claims that in illness, black women are expected to shoulder the “strong black woman” mantle:

Any sign of vulnerability or weakness is tantamount to failing oneself, family, and community. The strong Black woman ideology does not allow space for Black women to express their feelings related to traumatic experiences (much like the ways in which Black women swallowed sexual violence on their bodies during slavery and today as victims of intimate partner violence). The strong Black woman trope has become a barometer of how Black women’s behavior should be evaluated in adverse situations. (“Historical Context”)

This manifestation of a problematic concept of the master narrative of breast cancer is much more complex for women of color, as we see in this passage. The “strong black woman” mantle carries with it a cultural legacy which involves black women's ability to take back the traumatic history of their bodies and their health in this country. To some extent, they are culturally expected to accept the title: not to do so may imply denying the power of the cultural reclamation of black women's agency; to do so means that her

illness experience is oversimplified and she can't be honest with her community about the difficulty, sadness, and trauma involved in the diagnosis and treatment of breast cancer.

The message that people with breast cancer should be heroic warriors oversimplifies and skews the reality of the experience, as Raz notes: "Conventional wisdom says that suffering ennobles...cancer patients aren't by definition strong. Nor are we heroes...None of us needed advice. We needed new models of experience. We needed new metaphors. No sinking ships. No heroic victims," (xvii). Couser notes the same problem, claiming that the tendency to valorize the cancer patient by using heroic metaphors is dangerous: "[this type of narrative]...sometimes resorts to a rather facile formula for recovery; in doing so it makes implicit (and finally irresponsible) claims for the power of mind over malignancy," (Couser 49). Thus, any moments of perceived difficulty or weakness brought about by breast cancer, up to and including death, are implicitly the fault of the patient. These claims are not only irresponsible, they are unethical: they create a cultural situation in which those who refuse to behave ideally or heroically are marginalized. The master narrative creates expectations and, because the master narrative is a "repository of common norms" as Nelson tells us, we are uncomfortable when those expectations are not met. But marginalizing a person who does not feel emotionally compelled to take on the "hero" mantle means we are not open to intersubjectively engaging in the construction of that person's new narrative of self, the creation of a new identity. That person, by virtue of exclusion, is disciplined by society for refusal to perform the expected social role. Black women who refuse to perform

heroically, with constant strength, risk being marginalized not only by the breast cancer awareness movement, but also by their cultural communities.

If we use language which implies that those who survive cancer are “heroes” or “fighters,” whose willpower allowed them to “survive despite the odds,” we legitimize and support the dangerous problem to which Couser refers: if the mind has power over malignancy, then people are responsible for their own malignancy and illness, and those who die from breast cancer simply didn't try hard enough. That we would claim, through engaging in pinkwashing, to be supportive of people with breast cancer, and then simultaneously employ language which blames them for health conditions which are clearly beyond their control, is the epitome of hypocrisy: we are engaging in a practice that appears supportive, but actually marginalizes and excludes those whose narrative of self is not constructed around the hero archetype. Further, by virtue of the implication that those who die are failures or not fighters, we engage in victim-blaming. These occurrences demonstrate the frightening extent to which we police people's behaviors, particularly around illness, in our society. Nelson notes that this kind of victim-blaming often takes place in the presence of master narratives (160). She claims when a person tells a narrative which opposes the master narrative and cannot easily be accommodated within the master narrative or explained away, our society tends to undermine the cognitive authority of the person: “One morally dubious way to undermine cognitive authority is to blame the victim. A strategy for doing this is to deny the victim's complaints of being harmed and to accuse the victim of imagining things or being

oversensitive,” (161). We see many examples of this type of victim-blaming in breast cancer, as Herndl observes, “to present the disease as an issue of will and of one’s recovery as a matter of attitude is to indirectly claim that those who die from the disease just had the wrong attitude,” (236). Bahar, too, notes this in her observation of the discourse of the Susan G. Komen “Race for the Cure”: “...it casts patients as 'heroines of their own lives,' placing the burden of individual choice and responsibility squarely on their shoulders,” (1030).

As we have already noted above, the narrative self of illness is not an individual construction, nor is it entirely autonomous; it involves others. If we use language that individualizes and places responsibility on the shoulders of those with illness, we engage in morally dubious victim-blaming and exclude ourselves from those people’s construction of their narrative selves. We distance ourselves from them when we should be engaging with them.<sup>73</sup> This refusal to engage with those who are non-normative may have serious implications for these people.

Some might argue that this analysis makes too much of language that is ostensibly intended to support and empower women. Yet if we analogize this type of victim-blaming with another--that which takes place as a response to rape--we see that the situation is dire indeed. When young women are sexually assaulted, they are often blamed for wearing promiscuous clothing, drinking too much, or putting themselves in bad

<sup>73</sup> In the beginning of the fourth chapter of this text, I will demonstrate the potential impacts this refusal to engage with non-normative women may have, therefore justifying why we should engage with their narratives of self.

situations. All of these accusations place gendered social expectations on these young women for their behavior, and these expectations for behavior imply that the young women are responsible for the bad things which may happen to them if they transgress those expectations. That is the way in which we undermine the victim's authority and deny the harm, as Nelson mentions above. Similarly, those with breast cancer are expected to behave in certain gendered ways (such as performing the role of ideal breast cancer patient) and if they transgress those expectations, they are held accountable for their illness or its impacts. In both cases, we have generated a cultural message to women which is, essentially, 'Bad things happen to you because you refuse to behave according to the gender norms constructed for you. If you had just acted like a nice, well-behaved lady, you'd be safe now.' Thus, much of the language of pinkwashing is invested in perpetuating gender norms we know are antiquated and destructive, not empowering or, as some would like to believe, progressive. The language, and engagement in it, is another form of internalized self-policing for gender roles and heteronormative behavior.

For the archetypal ideal breast cancer patient, the concept of "hope" also plays a vital role: the idealized breast cancer patient is expected to be full of hope. DeShazer has identified this same phenomenon—an overwhelming focus on being positive, hopeful, and upbeat—in what she calls "survivor discourse," (95). Barbara Ehrenreich calls this phenomenon "the tyranny of cheerfulness," "In the mainstream of breast cancer culture, one finds very little anger...The stance toward existing treatments is occasionally critical ...but more commonly grateful; the overall tone, almost universally upbeat," (48). We

need only take a cursory survey of the *Susan G. Komen* website to see her observation played out in this “survivor story” by Loraine Hutchinson: “I want to encourage, inspire and motivate...I want to inspire women who hear my story and are fighting breast cancer to know that there is hope and to fight on,” (“Loraine Hutchinson”). We find similar sentiments of inspiration, motivation, and hope, on clothing, hats jewelry, angel pins, scarves, candles, coffee mugs, pillows, license plates, and even customized checks (Ehrenreich 46). It's everywhere and inescapable, and those who've been diagnosed often receive these items as well-intentioned gifts. The version of hope which is part of breast cancer culture's rhetoric becomes an expectation of those diagnosed with breast cancer.

To emphasize the moral problem of having the expectation for hopefulness and optimism, we must return to the latter part of Nelson's definition of master narrative, that they “inform our moral intuition.” Further, Nelson claims, they “exercise a certain authority over our moral imaginations,” (6). She cites the Passion of the Christ and well-known fairy tales as examples of master narratives which shape and inform our moral imagination (6-7). These are narratives which may help to shape our moral judgments. For example, in reading the fairy tale, “Beauty and the Beast,” we may acquire the moral sense that physical beauty is not as valuable as inner beauty. We may subsequently apply that moral sensibility to the lives of ourselves and others, believing that it's morally good to behave in such a way that exhibits value for inner beauty over outer beauty. The master narrative of breast cancer includes the expectation that those with breast cancer be hopeful and cheerful; so, that message may have shaped, to some

extent, our moral judgment. We may believe that, in breast cancer, we, and others, should be hopeful and cheerful, and that that is a good thing to do. If the master narrative of breast cancer has shaped our moral intuition in such a way, we are subject to making the moral judgement that those who refuse to engage in cheerfulness and hopefulness are somehow wrong or immoral. That judgment is how we categorize people with breast cancer into dichotomous groups of either “hero” or scapegoat.” Women who are hopeful, cheerful, and enduring, are heroes; those who are not have transgressed against the master narrative, so we perceive that we may justifiably scapegoat them, at least to some extent, for their illness experience. As Ehrenreich notes: “...in the seamless world of breast cancer culture...cheerfulness is more or less mandatory, dissent a kind of treason,” (50). “Hope,” as it’s defined by the breast cancer awareness movement, becomes the measuring stick by which all breast cancer patients are judged “ideal” or “scapegoat.”

Ehrenreich observes that those who refuse to execute the movement’s notion of hope are marginalized and policed, made into scapegoats: as part of an experiment, she posts an angry comment about her breast cancer treatment on the *Susan G. Komen* website (50). While some sympathize (even if they don’t, precisely, relate), most are critical. One woman tells her she has a “bad attitude,” and another suggests that she “run, not walk, to some counseling,” (50). This woman’s response to Ehrenreich demonstrates the problem with the “tyranny of cheerfulness”: it results in the social expectation that other emotions (those not part of the master narrative, such as anger) are behaviors that should be modified, treated, or regulated. King, too, notes this problem: “the dominant

discourse of breast cancer survivorship...leaves little room for alternative, less positive understandings of the disease experience and its long-term effects,” (102). The rhetoric of hope is used to police and control the voices of those who refuse to perform the role of ideal breast cancer patient: if they don’t want to engage in the master narrative’s definition of hope, they are simply shamed out of the discourse.

Gatison notes that this problem of the pressure to be hopeful may be particularly acute for black women, who are culturally expected to engage in what she calls “faithtalk” about their illnesses. Faithtalk, according to Gatison, is a religious or spiritual mode of discussing illness in which the speaker “makes harmony out of disharmony” (“Spoken Word”). When engaging in faithtalk, members of black communities are expected to demonstrate their faith in god, but acknowledging the difficulty of diagnosis, illness, or treatment, may result in judgment from the community:

Some see talking about your illness and the resulting side effects from the treatment as a faithless act— speaking about the negative brings about the negative. In this situation, words must be carefully framed around the acknowledgment that God is in control and that His will be done. (“Spoken Word”)

The expectation for faithtalk to be positive is one example of the ways in which the expectation for hopefulness has intersected with cultural norms for women of color, to create an experience of breast cancer unique to black women: black women are also policed for lack of optimism, but the policing comes through a faith mode which is

intertwined with community.

Another problem Ehrenreich notes, when it comes to the tyranny of cheerfulness, is the way in which it infantilizes women (46). A cursory internet search proves her point: dozens and dozens of websites (one, notably titled, “www.choosehope.org”) sell pinkwashed items which seem made for children or young adults, including stylized charm bracelets, pink Converse all-star tennis shoes, mini-backpacks, pink gloves with giant pink and white pom-poms on each fingertip (what adult could execute any daily activities wearing these?) and, the example which Ehrenreich identifies in her article, teddy bears. DeShazer notes this phenomenon, too, in her discussion of Miriam Engelberg’s satirical comic pamphlet, *Something Unpleasant and You* (105-108). Engelberg observes that medical pamphlets often distributed to breast cancer patients to educate them about the effects of chemo are condescending and oversimplified, and often include images of women, ostensibly in recovery, smiling, laughing and feeling great; in response, she designs her own comic pamphlet in which some of the women are bald, but still smiling, saying things like “I loved having surgery!” and “Plus, we get all these great prescriptions!” (as cited in DeShazer, 106). The best example, by far, of the way in which the “tyranny of cheerfulness” infantilizes women, however, is one Ehrenreich finds in a tote bag distributed by the Libby Ross foundation: crayons and a journal in which women can “express themselves.” She speculates that this treatment of women may reflect some gender ideology in which women are assumed to be in a state of arrested development, but also notes that this a phenomenon specific to breast cancer: “Certainly men diagnosed

with prostate cancer do not receive gifts of Matchbox cars,” (46-47). This infantilization of women contributes to their cultural construction as simple, motherly, emotive, nurturing creatures. These women fit neatly into the heteronormative concept of femininity. Hope, and its infantilization of women, reifies the master narrative of the ideal breast cancer patient who is submissive, heroic, and an optimistic fighter.

Ultimately, the expectation of optimism and cheerfulness from breast cancer patients has a depoliticizing effect, according to Ehrenreich, “transform[ing] breast cancer into a rite of passage—not an injustice or tragedy to rail against, but a normal marker in the life cycle,” (49). The rhetoric of hope reduces the significance of breast cancer, to individual people and to our culture and our public health. It attempts to negate and silence the anger and frustration which often motivates political action, which leaves us vulnerable, as Audre Lorde notes: “...silence about any area of our lives is a tool for separation and powerlessness” (7). This offensive and ironic use of the word “hope,” is actually the method by which our disciplinary society keeps people quiet and controlled within the system: people internalize the master narrative’s concept of hope, then they begin self-policing and policing others, diminishing narratives which may include anger, and keeping them regulated.

Above, Lorde notes that silence is a tool for separation and powerlessness. That separation is evident in Blackstone’s field study of Komen volunteers. She notes that the women with whom she interacts prefer not to identify themselves as either activists or feminists. They choose to distance themselves from women whose stories of the

experience include anger because, as one member said, “I don’t burn the flag or my bra or anything,” (361). The women in Blackstone’s study are distinctly not interested in actions which might be construed as political. She notes that this sentiment is common among the volunteers: “Carla and other women at Komen are reluctant to adopt identities that might make them appear to be too contentious,” (361). Blackstone puts this problem succinctly when she notes, “The Komen women’s insistence on being perceived as positive is directly linked to the idea that women, especially feminine women, are not supposed to be political or divisive,” (362).<sup>74</sup> Komen’s rhetoric of hope and optimism is in direct conflict with political activism for breast cancer, as Brenner notes in the documentary, *Pink Ribbons, Inc.* in the context of criticizing pinkwashing: “People say, anger is not helpful. Actually anger is helpful, depending on what you do with it. And I think if people actually knew what was happening, they would be really pissed off. They should be,” (Pool, Dir.). Anger, as Brenner notes, can often motivate people to action. But the rhetoric of hope and optimism often does not leave room for anger and thus may not spur waves of revolutionary changes as readily as language that does encourage what Brenner might label “helpful” anger. The notion of hope and positivity gives these women a way to believe they are working for a cause without having to “rock the boat,”

<sup>74</sup> It's worth noting that, with the current political climate in the United States, this notion may be shifting: women who identify as traditionally feminine, like the one quoted in Blackstone's piece, may be becoming more political and/or divisive. That phenomenon is, and should be, subject to further examination and discussion. In the context of the Komen organization specifically, however, this particular participant feels that the Komen organization is not the place in which to enact major political behaviors.

but, because of its powerful role in the master narrative, it works in direct opposition to frustration-fueled political action.

The master narrative's notion of hope is what Audre Lord might have called "superficial farce" and, to paraphrase Lorde, it obscures realities which, when considered, might prove threatening to the status quo (76). It polices and disciplines reactions to breast cancer which fall outside the culture of cheerfulness and optimism. It attempts to frustrate political anger and activism which might be necessary in order for our cultural understanding of breast cancer to evolve. It is the pinkwashed notion of hope that actually undermines and obscures the important healing role of realistic hope, joy, and happiness, and Lorde warns us against such phenomena: "I believe it is this love of my life and myself...which has been largely responsible for my strong and healthy recovery from the effects of my mastectomy. But a clear distinction must be made between this affirmation of self and the superficial farce of 'looking on the bright side of things,'" (76). Hope, uncorrupted by cause-based marketing and the master narrative of the breast cancer awareness movement, is a powerful force for healing; however, it is also a philosophical, poetical notion, one of life's great intangibles. It is, as Emily Dickinson once wrote, "the thing with feathers.../[that never] asked a crumb - of me."<sup>75</sup> Perhaps, hope, in breast cancer awareness movement, should not demand so much of those who wish to engage in it. Hope which demands so much of people with breast cancer, and shames them for not

<sup>75</sup> See Dickinson, Emily. "Hope is the Thing With Feathers." Published online by the Poetry Foundation.

measuring up, is not hope at all, but masked discipline meant to keep people in line. This false hope distracts them from witnessing all the compelling alternative narratives of breast cancer which may have the potential to change the status quo (and thus threaten the social order on which the breast cancer awareness movement has come to depend, for its loyal consumers). But realistic and informed hope, hope that has not been made into a commodified falsehood, lies in the pursuit of diverse and subversive narratives of breast cancer which may help restore a person's moral self-worth and allow them to feel comprehensive healing. Hope lies in pluralizing the master narrative to accommodate people whose experiences do not fit neatly within it; it lies in the inclusion of the black and LGBTQ communities, as well as other women who choose not to engage in the master narrative, in our cultural understanding of breast cancer. In the next, final, chapter, we will turn to those narratives.

In this chapter, we've established the ways in which our the contemporary breast cancer awareness movement takes advantage of the master narratives of breast cancer, and supports and perpetuates a disciplinary system which policies and controls those with breast cancer. We now know the master narrative of breast cancer and its main components: the claim that detection equals cure, the imbalance of the authority of medicine and the subjugation of the patient's knowledge, the emphasis on heteronormativity, and the notion of the "ideal" breast cancer patient. We know the aspects of the abject female breast cancer body each of those concepts is meant to control. We also know the urgent compelling need to hear and include counterstories of

breast cancer: that those stories may affect people's moral self-worth and contribute to the reconstruction of their identity in illness. In the final chapter, we'll examine some compelling research that supports the idea that engaging with and helping to construct illness narratives is important for health outcomes. Finally, we'll analyze some examples of counterstories and learn the ways in which they pluralize our understanding of the breast cancer experience, benefit those who write them, and improve our socio-cultural understanding of illness.

## CHAPTER FOUR: COUNTERSTORIES

Now, we have seen the ways in which the master narrative of breast cancer supports a Foucauldian disciplinary system that polices and potentially silences those with breast cancer who do not behave according to the expectation of the master narrative. Pinkwashing, as a major strategy of the breast cancer awareness movement, supports and reifies the oversimplified messages of the master narrative. Because of its powerful and ubiquitous presence in contemporary U.S. culture, the master narrative's use of pinkwashing may therefore result in epistemic injustice and silencing of a number of people. But what are the compelling reasons for significant portions of the population to engage in stories which resist the master narrative of breast cancer? And how do counterstories help us do that? In this chapter, I will address those questions. First, we will examine some significant psychological research which demonstrates that women whose experiences are witnessed<sup>76</sup> by others may have improved outcomes for quality of life and long-term prognosis. I posit that when these women have their experiences witnessed, they are acknowledged as epistemic peers.<sup>77</sup> That recognition may create an

<sup>76</sup> I will be ascribing mainly to Rita Charon's definition of "witnessing," which I will discuss and augment below.

<sup>77</sup> As we noted from Freeman's work in chapter three, a relationship in which a people are epistemic peers means that their claims can be acknowledged by one another as valid; essentially, it is a relationship in which both people are recognized as knowers.

intersubjective relationship in which the ill person is supported in efforts to restore a damaged identity, and in which that person's moral worth is reconstituted and moral agency enacted. Next, I will analyze a series of counterstories—stories which resist the master narrative—in order to substantiate the ways in which counterstories can be useful for many of those diagnosed with breast cancer. These stories may aid in the efforts of those people to have their experiences witnessed and their reconstruction of identity acknowledged.

As I have noted a number of times, we need to pluralize the master narrative in order to acknowledge and engage with these people, but what exactly do we intend when we say that it needs to be pluralized? In order to elaborate on and clarify this notion of pluralization, we should return to Nelson's discussion of the purpose of counterstories. According to Nelson, "counterstories...don't merely *reflect* a shift in understanding. They set out to *cause* a shift," (italics hers) (156). Further, she notes that a counterstory seeks to replace problematic aspects of the master narrative (153); in fact, according to Nelson, "a counterstory could itself be a master narrative, though it never oppresses the individual it identifies. Indeed, optimally successful counterstories must be master narratives, since success consists precisely in the counterstory's becoming...socially shared," (157). So, when I claim that we need to pluralize the master narrative, what I mean is that we need counterstories which can then contribute to a new master narrative which is socially shared, causes a shift in thinking, and is not oppressive. In this chapter, I will use the key points above to endeavor to prove that pluralizing stories of breast cancer beyond the

current master narrative is vital to our culture's improvement of the ways we understand and treat those with breast cancer.

1. What is Witness?

Before we can discuss the compelling need for counterstories for pluralization of the master narrative, we must understand what exactly is comprised by the act of witnessing a story of illness. As is noted above, I have chosen to ascribe to Charon's concepts of witness, but I will also augment her framework with concepts from Fricker<sup>78</sup> and Carel.<sup>79</sup> First, in addressing witness, Charon notes that sickness opens doors. She claims that "we find our kin through our bodies--not among blood relatives but among those who share our corporeal dispositions," (178). This concept is echoed by Carel's emphasis on intercorporeality: "...the lived body encompasses not only one's experience but also the social aspect of one's experience of one's own and others' bodies, as well as how others' experience of the body might impact on their own experience of the body," (*Phenomenology of Illness* 54). So, witnessing first involves attentiveness to how our experiences of our bodies and the bodies of others relate to one another. Carel claims that this intercorporeality leads to empathy and intersubjectivity (53). Charon's discussion of witness includes an excerpt from an online discussion group with several healthcare professionals about the fact that sickness opens doors. In his discussion of one patient's experience, one physician noted a response which speaks to the creation of

<sup>78</sup> See Fricker, Miranda. *Epistemic Injustice: Power and the Ethics of Knowing*.

<sup>79</sup> See Carel, Havi. *Phenomenology of Illness*.

intersubjectivity and empathy: "While I displayed empathy (therapeutic validation) little was based on compassion...I was simply...to listen professionally...compassion emerged from the interaction, not caused it," (179). Witnessing also involves engagement in intersubjective relationships,<sup>80</sup> which Charon calls the meeting of two authentic selves (51); witnessing means openness to empathy and compassion. Sharing a narrative offers people the opportunity to engage their own subjectivity with another's subjective experience. Finally, Fricker claims that "to be wronged in one's capacity as a knower is to be wronged in a capacity essential to human value...they are degraded *qua* knower, and they are symbolically degraded *qua* human," (italics hers) (20). If we take that to be true, then an important part of bearing witness is the acknowledgement of a person's capacity as a knower, which is an acknowledgement of that person's essential humanness, as one physician notes in Charon's online discussion: "It is true that many people...who are facing death find the need to "narrate" their experiences as a part of the search for meaning that in some ways characterizes the human condition." Because witness means acknowledging a person as a knower, bearing witness to someone's illness story means that a relationship will be created in which the people involved are epistemic peers: the people involved in the relationship are both acknowledged as knowers.<sup>81</sup>

Now, let's examine the concept of witness in the context of the master narrative of breast cancer. The master narrative, as we know, can potentially silence or exclude certain

<sup>80</sup> For a more thorough discussion of intersubjectivity, see Chapter 3, pg. 112

<sup>81</sup> See Freeman, Lauren. "Confronting Diminished Epistemic Privilege and Epistemic Injustice in Pregnancy by Challenging a 'Panoptics of the Womb.'" "

people's experiences, implying that their knowledge of their illness experience is somehow inferior. This occurrence qualifies as what Fricker calls a "testimonial injustice": a kind of injustice in which someone is wronged *specifically in her capacity as a knower*," (20). The master narrative of breast cancer, and the exclusion it causes, has the oppressive power to wrong someone in her capacity as a knower. The master narrative of breast cancer is an oppressive one, but counterstories, as Nelson notes, "aim to alter...an oppressed person's perception of *herself*," (italics hers) (7). Counterstories, according to Nelson, set out to repair the damage inflicted by the oppressive master narrative, but also to restore moral agency (154-155). Here, we come back to witness. Because the self is not autonomous but rather creates itself in the context of, and in relationship to, other selves, we need others to acknowledge and engage in the reconstruction of identity in illness. That is what witnessing does. Further, witnessing counterstories supports the teller's endeavor to restore moral agency, as Nelson noted above. Charon appears to concur: "Our narrative efforts toward...intersubjectivity enable us...to commit acts of particularized and efficacious recognition that lead beyond empathy to the chance to restore power or control to those who have suffered," (181). In order to ensure that we pluralize the current master narrative of breast cancer to create a new, socially shared understanding of the illness and the identities of those who have it, we must bear witness in the way laid out above. Then, we will be supporting the reconstruction of identity and the restoration of moral agency. This restoration of moral agency may help to catalyze a shift, as Nelson tells us, that good counterstories should

do. This is not to say that we, as a culture, are obligated to create the shift in thinking; rather, if we support the restoration of moral agency to those whose moral agency may be somewhat diminished, their increased agency may organically contribute to a shift in cultural thinking about breast cancer.

## 2. Witness, Community, and Breast Cancer Stories

A survey of published breast cancer narratives reveals that, anecdotally, many find relief through sharing their stories with their communities (whether those stories are in print essays, poetry, or visual art). For example, Ellen Goldsmith writes in her poem “Chemotherapy,” “Tired from the inside out/I need new words for tired” (88). In her commentary, she claims that, “taking on the topic of breast cancer in my poetry allowed me to be with and look at my illness. Bringing poems to my poetry group, getting reactions...was healing,” (88). Similarly, Betsy Bryant felt compelled to write about her distress, as she exhibits in poems like “Breast Exam”:

I am breathing, breathing deeply,  
trying to detect alarm in your fingers.  
Your faint voice calls me back, 'Fine, everything feels fine.'  
Fine as the quicksand I am still sinking in... (97)

Bryant, in her commentary, notes that during her treatment, she wrote almost daily: “Writing has been a refuge for me as long as I can remember. The process gave silent witness to my pain, bewilderment, and joyous victories. I expressed myself with ruthless honesty and felt more liberated and whole as a result,” (97). While Bryant does claim that

her writing bore “*silent witness*,” (italics mine) readers should note that she did place the poem in a widely published anthology of art and writing on breast cancer, so she did seek to share her story with her community as part of her writing experience.

Some find healing in sharing and are able to share and publish their stories readily. Moreover, stories which resist the master narrative of breast cancer (counterstories)<sup>82</sup> are readily accessible in published versions as well. Those who experience stories which don’t readily comply with the master narrative can find the stories of others, through published material and support groups, as well as a variety of online media. Those texts might make them feel as though their experiences are not isolated, and as though they are safe to share their own experiences with others like them. Why is it so important for us, as a culture, to pluralize the master narrative of breast cancer when those living counterstories already have those resources? The answer is twofold: first, we already know from several examples given in Chapter 3<sup>83</sup> that there are a significant number of people reporting that the material they find, the texts they read, don’t adequately speak to their experiences, such as Vonn Jenson, who claims that most of the material found doesn’t address Vonn’s position as a queer person. Similarly, Marilyn Hacker and Christine Middlebrook, find it necessary to confront the hard questions about breast cancer mortality that the pinkwashed breast cancer awareness movement ignores. We

<sup>82</sup> Below, I will elaborate on Nelson’s theory of counterstories, what defines them, and how they work.

<sup>83</sup> See the sections “Early Detection Means a Cure,” “The Authority of Medicine and the Subjugation of Female Knowledge,” “Heteronormativity,” and “The Ideal Breast Cancer Patient.”

know that these people need more from their culture and the breast cancer awareness movement. The second part of my response to that question is that the ill need the acknowledgement of their social world, as Frank notes. People living with breast cancer who clearly feel that their social and cultural communities are not acknowledging and validating their experiences are not getting what they need. Pluralizing the master narrative and pressing American culture to shift to a new mentality about breast cancer may prompt a new awareness of the situations of those living with breast cancer as a chronic condition. Charon notes that concepts of narrative medicine can be drawn from culturally experienced tragedies, such as the Holocaust because "...we can recognize in catastrophic and public suffering that which is always present and needful of attention in local and private suffering," (181). If we can make public the suffering of people living counterstories, instead of enacting the master narrative, we can help those people recover from the damage done by the master narrative and restore their moral agency. Thus, counterstories for the pluralization of the master narrative need to be part of the larger cultural discourse of breast cancer, not just specialized niche experiences.

Herndl, in her analysis of the purposes and effects of mammographies, notes that intersubjectivity generates the critical healing element of illness narratives, and she implies below that that intersubjectivity can occur when the ill person's story is shared, particularly in breast cancer stories:

...we assume the responsibility of telling, but we understand the other as one who can, will, and should respond to us...this constructs a relationship between self

and other that is built on connection and reciprocity rather than subordination.

When breast cancer autobiographers construct a sense of self, I think they are doing so implicitly with this notion of “response-ability” in mind; their sense of “living out loud” is in part to reconstruct a sense of self, but that relation of self and body becomes a model for a relation between self and other. (225)

The use of the word “reciprocity” by Herndl is interesting here, as well, because it recalls Foucault’s notion of the need for “horizontal conjunctions” in order to resist disciplinary mechanisms such as the one we have identified in the master narrative of the breast cancer movement. Additionally, the term "reciprocity" reminds us that intersubjectivity is an experience in which both parties engage with the subjectivity of the other, experiencing the way in which the other lives in the world. The story told by the person with breast cancer is one by which the woman or trans person reconstructs a narrative of self, but also one which calls for response, because it creates the new understanding of how the person will relate to others. In his discussion of the nature of suffering in illness, in which he enumerates the conditions of suffering, Frank appears to concur: “The fifth condition of suffering is its social nature...people tell uniquely personal stories but they neither make up these stories by themselves, nor do they tell them only to themselves. Bodies and selves are...culturally elaborated (171). Stories of breast cancer need cultural engagement and response, in order for those with the illness to reconstruct narratives of self, create new relationships to others, and to create the horizontal relationships which resist the the master narrative. If we don’t engage in the stories of those who need us, we

risk epistemic injustice,<sup>84</sup> but we may also deprive them of opportunities for healing which may impact their health outcomes and even their long-term survival (as we shall discuss further below). Christine Middlebrook notes the need for witness in her autobiographical account of her experience of dying from aggressive breast cancer: “Who I am could not endure the torture of that room. Without the periodic witness of James or Jonathan, who knew who I was, I could not know myself. Not to know oneself is to die,” (italics Middlebrook’s) (62). While Middlebrook was figuratively “dying” during the course of her brutal treatment, her husband and children somehow held and guarded her identity, her sense of self. The sense of self is intersubjective and symbiotic, based on connections to others. Through their connections to her, they knew her deeply, so that during a time so terrible and painful that she could not even get a sense of herself, her family could provide her with one. Middlebrook’s family and friends were a community which bore witness to her experience so that she could reconstruct herself. Charon’s work best encapsulates the relationships between witness and community: “Bearing witness creates community. Bearing witness to the suffering of individuals creates community...it is in these communities that a return to wholeness or health happens,” (196).

### 3. Breast Cancer as a Chronic Condition: The Compelling Need for Breast Cancer Stories

Across the U.S., more and more women live in the wake of breast cancer

<sup>84</sup> See Chapter 3. Epistemic injustice occurs when we “[downgrade] certain person’s testimonies and interpretations,” (Phenomenology of Illness 184).

diagnosis and treatment. According to Bodai and Tuso, an estimated 3.5 million women were living in the aftermath of breast cancer as of 2015.<sup>85</sup> The word “aftermath” here is key: even after a patient has survived cancer, much more of the ordeal is left to be endured. It’s worth noting, however, that many of these issues begin, not in the aftermath of remission or cure, but in the aftermath of diagnosis. While many women suffer from a variety of problems surrounding their breast cancer diagnosis and treatment, a significant number of them specifically suffer from depression, anxiety, or (at the least) clinically significant levels of symptoms for depression and anxiety which, according to the research presented here, can have a detrimental effect on other aspects of their health and treatment. These detrimental effects, as we shall see below, can appear and endure years after treatment is completed, even after remission. In fact, according to Bodai and Tuso, breast cancer is now considered a “chronic condition.” As the number of women living in the aftermath of breast cancer increases, it’s reasonable to extrapolate that the diversity of these people, of their lives, lifestyles, and cultural experiences of illness, will also expand. More people will experience breast cancer in ways not represented by the master narrative. Therefore, it becomes more pressing for us to turn our attention not only to the lasting effects of diagnosis and treatment on patients and their well-being, but also to the experiences of a variety of people during their breast cancer and treatment. Some

<sup>85</sup> See Bodai, Balazs, and Phillip Tuso. “Breast Cancer Survivorship: A Comprehensive Review of Long-Term Medical Issues and Lifestyle Recommendations.”

research, as we shall see below,<sup>86</sup> may indicate that those who feel their experiences are witnessed may be more likely to have more positive outcomes. This phenomenon is one reason why we, as a culture, need to be prepared to hear and acknowledge stories which resist the master narrative: there is a growing population of people whose experiences aren't that of the master narrative, and they need to be acknowledged in order to reconstruct their narratives of self, be supported in the restoration of their moral agency, and possibly acquire improved outcomes related to adherence, mental stress, and long-term survival.

Concerns and insecurities about self-identity often arise in the wake of common treatments for breast cancer, mastectomy and chemotherapy; these treatments often have lasting effects which may lead to distress. People who have had mastectomies (in the literature, these are called, "mastectomies,") often struggle with reconstructing their self-images and reshaping their identities in the wake of their surgical procedures: "Mastectomy causes many changes in women's self perceptions and social interactions. These complex factors require women to reevaluate their self-concept and self-image...Mastectomies are particularly disturbing to women. The body mutilation affects several aspects of female identity, including lifestyle. Ways of thinking and female attitudes in general are affected after the mastectomy," (Hoga et al. 318-319).

In addition to extraordinary physical impacts such as scars, disfigurement, problems with

<sup>86</sup> Studies which support this claim will be discussed in depth in later sections of this chapter.

fertility or their ability to have children, women who have breast cancer treatment may deal with other significant challenges as well, including sensitive skin, ongoing pain, cognitive impairment, short-term memory problems, emotional difficulties, and overall struggles with their identity (Bahar 1026). Abel and Subramanian note that the vast collection of mammographies share a major theme, the search for a new identity: “Who am I now that I am a person with breast cancer? To some extent, that question derives from the trauma of diagnosis and treatment as well as from the aftereffects...Lingering issues that have received less attention may make identity issues even more urgent,” (37). As we know from Chapter 3, when we attempt to recreate the self in illness, we are not autonomous; we look to others. But often, the person's new identity is not simply and easily encapsulated by the master narrative, and friends and family are focused on physical wellness or survival, and overlook struggles with identity. These issues are also frequently overlooked in long-term care for breast cancer patients. Bodai and Tuso observe:

Survivorship care programs provide an important component of the patient treatment pathway but fail in the elaboration and communication to the patient regarding many issues relevant to long-term survival. Most long-term care plans inadequately address the most important medical issues involving the long-term consequences of survivorship.

Here, they refer to a variety of concerns related to ongoing physical wellness, but also include a multitude of other problems, including relationships and communication

between patients, physicians, and families, which may play a role in non-adherence or non-compliance.

Right now, many healthcare strategies focus on simply eradicating the cancer.<sup>87</sup> For example, Pat Garland, after her treatment, discussed with her physician the fact that she was experiencing debilitating cognitive problems and extreme hot flashes, but her doctor seemed focused on her prognosis, whereas Pat was interested in maintaining a quality of life: “The doctors kept saying ‘You’re going to get better. They said breast cancer was not debilitating. They said it had a good prognosis as far as living was concerned,” (42). While Pat was glad to be alive, living in the wake of breast cancer treatment was not simple or easy. Abel and Subramanian note that, “there are many parallels between the experiences of breast cancer survivors and people reporting chronic fatigue syndrome, Gulf War syndrome...like the sufferers of those invisible and often ‘contested’ diseases, these women...faced widespread skepticism...and watched their social and work lives narrow,” (4). Behaviors resulting from struggles with identity may lead to the diminishment of social and work lives, but may also pose significant risks for health outcomes, according to Bower: “Behavioral symptoms cause significant disruption in patients’ quality of life and may also have implications for treatment adherence, morbidity, and mortality,” (768). As we have seen above, struggles with identity can be

<sup>87</sup> To avoid digression, I have admittedly simplified this notion a bit. Cancer treatment and survival is complex and multifactorial. However, Bodai and Tusso concur that healthcare practitioners need to place more emphasis than they currently do on long-term survivorship problems and concerns.

side effects of the chronic condition of breast cancer (Hoga et al. 318-319; Abel and Subramanian 37), and relationships to others are critical to re-establishing that identity. We need others to bear witness. If that is the case, is it possible that those who struggle to have their stories witnessed may suffer from poorer prognosis and treatment outcomes? Below, I will analyze cancer-related depression as one facet of the struggle with identity; my analysis will endeavor to demonstrate that witness which creates empathy may alleviate, to some extent, the struggle with identity and therefore, depression. Breast cancer and treatment, while complex and multifactorial, can involve a variety of problems, only one of which is the struggle with identity: that struggle may impact a person's long-term quality of life and prognosis. Thus, we should attend to that problem, as a culture.

One of the most common (and therefore most widely studied) side effects associated with breast cancer is depression or depressive symptoms (Kyranou et al. 79-80; Bower 774). Additionally, several studies have noted that depression is associated with higher mortality rates (Suppli et al. 3831; Bjørnklett et al.198; Kyranou et al. 79-80).

<sup>88</sup> There is some debate about the amount of women who experience depressive symptoms of breast cancer, and the extent to which those women experience symptoms (Bower 774; Kyranou et al. 79-80) but it's reasonable to conclude from the research examined here that anywhere from 18-30% of women with breast cancer may have some expression of depression or depressive symptoms, while also acknowledging that women

<sup>88</sup> These studies will be discussed further below.

who have been diagnosed with breast cancer have a higher likelihood of experiencing symptoms of depression. Additionally, clinical depression or depressive symptoms may be even more common than statistics demonstrate, as a few studies noted (Kyranou et al. 97). Other women, by virtue of the fact that cancer and its treatments often bear some of the same symptoms of depression, may not be diagnosed (Suppli et al. 3837). While current studies indicate that levels of depression or depressive symptoms in women dealing with breast cancer are already significant, further work may demonstrate that the numbers of women suffering from cancer-related depression are even higher than we currently estimate. In any case, a significant number of women deal with depression or depressive symptoms during or after breast cancer treatment.

While women who have breast cancer are much more likely to demonstrate depressive symptoms than women who do not, the risk for depressive symptoms is not necessarily reduced as time passes after the experience. While one study claimed that “depressive symptoms are most pronounced during the first year after diagnosis,” (Bjorneklett et al. 198), another study showed that cancer-related depression could appear in significant amounts of breast cancer survivors for years afterwards: “...the prevalence of clinical depression is reported to be between 10% and 30% within the first five years after diagnosis,” (Suppli et al. 3831). By examining the rate at which breast cancer patients and survivors received antidepressants and noting their hospital interactions with staff, Suppli et al. found that women still had a significantly increased risk of depression diagnosis up to eight years after treatment (3834). All of these women are, therefore, also

at risk for poorer survival rates and poorer health outcomes. Depression also impacts compliance, recurrence, and recovery (Bjorneklett et al. 198). Kyranou et al. concurred, also finding that depression was related to poorer quality of life and, additionally, longer hospital stays (79-80). Finally, depression has been associated with higher mortality rates (Suppli et al. 3831; Bjornklett et al.198; Kyranou et al. 79-80). Cancer-related depression has potentially grave impacts on the patient's long-term prognosis.

#### 4. Communication, Support, and Improved Outcomes

It may be tempting for some to assume that the simple prescription of an antidepressant or anti-anxiety medication is in order; however, for a variety of reasons, medication may not be the best option. In fact, in some cases, certain types of antidepressants cannot be used because they may be contraindicated with cancer treatment medications. Medical scholars are still debating whether certain selective serotonin re-uptake inhibitors can inhibit the conversion of Tamoxifen (a drug used almost universally, which inhibits the recurrence of cancer) to its active metabolite, thereby negating some (or all) of the Tamoxifen's usefulness (Suppli et al. 3837). Additionally, a study performed by Vega et al. notes that pharmacological intervention coupled with other forms of intervention may have more impact than any one intervention alone. Additionally, medicinal routes may simply not appeal to all patients, or may not be feasible options for a number of other reasons. In any case, the purpose of the current discussion is to explore the possibility that witness may be a way to potentially address issues of identity; in this case, I am particularly examining depression

as a side-effect of breast cancer which affects identity. We now know that counterstories are a way in which women can attempt to repair the identity damaged by the master narrative and regain moral agency; bearing witness to those counterstories supports the attempt to regain identity and moral agency. Can witness potentially improve treatment outcomes as well? I posit that, because witness has the power to repair the damage of an oppressive identity of the master narrative and restore moral worth, it can potentially improve some of the problems which result from the struggle with identity (such as depression). Many of the studies below examine open communication and support as a method for improved outcomes; I contend that, while these studies don't specifically use the term "witness," as I have defined it above, this communication and support from physicians and family may qualify as a form of witness or, at the very least, the beginnings of witness. While more work needs to be done to specifically study the impact of witness on people with breast cancer, what we see below is enough to indicate that my theory is potentially valid and worth pursuing.

Many studies examine possible interventions—support groups, narrative therapy, relaxation techniques—to treat emotional distress resulting from breast cancer. Of those, many collectively emphasize the need for cancer patients to have open communication and support, as Bower notes: “interventions that emphasize support and emotional expression may be more useful for women with advanced stage disease,” (775). Further, emotional support and open communication may offer improved outcomes. Mallinger et al. note: “In studies with cancer patients and cancer survivors, increased emotional

support and more open communication have been associated with better psychological outcomes,” (359). Finally, Mallinger et al. concluded that, “efforts to enhance productive communication between patients and their family members may help women cope with and overcome the challenges of breast cancer survivorship,” (355). We already know from the information presented in studies above that women who feel psychological distress such as depression and anxiety have overall poorer health outcomes, including a potentially higher risk or mortality. If that is the case, and it is also the case that people who have open communication and support have better psychological outcomes, it stands to reason that, at least for some, communicating openly and feeling supported may indirectly lead to improved general health outcomes, perhaps even improved mortality rates.

Mallinger et al. note that the desire to cope with any stressful life experience through discussion is common and healthy:

Sharing and talking about one’s experiences, thoughts, ideas, and emotions is a positive adjustment behavior, and discussion of traumatic life events has been identified as a key component of successful coping. Talking about a traumatic event may help the individual make sense of the experience, find meaning, and achieve emotional resolution. (55)

Open communication and support such as this may be helpful in alleviating psychological problems because it is in this way that patients are encouraged to engage in intersubjective relationships to others. Through these intersubjective relationships in

which they tell the stories of their experiences, they reconstruct their narratives of self.

The hypothesis that open communication and support allows a patient to reconstruct a narrative of self through intersubjectivity is supported by a Spanish study which examined the effects of mindfulness-based narrative therapy (MBNT) (paired with pharmacological intervention) on cancer-related depression. Narrative therapy, according to Vega et al., is defined as “a psychosocial form of therapeutic intervention [based on the premise that] reality is constructed through language and narrative description in the intersubjective field between human beings.” The word “intersubjective” is key to our discussion. The practice of MBNT is focused on, to some extent, recreating reality, but that venture can only be undertaken when the patient has a willing other to engage with. Vega et al. explain that, in this type of therapy, “...the therapist serves as a witness to the client's storytelling and a coeditor of the unfolding narrative.” The therapist becomes the patient's necessary witness to the reconstruction of the narrative self, and the researchers found that strategy to be somewhat effective. Vega et al. found that medication along with MBNT resulted in “greater compliance and improvement in functional dimensions of QOL [quality of life].” This study would seem to support the idea that, not only does intersubjectively shared narrative have the power to alleviate depression, it does so in a way which also resolves physical health risks (lowered adherence to treatment, lower quality of life). Additionally, Vega et al. demonstrates that the effective application of narrative techniques to depression must involve an intersubjective relationship to others: reality cannot be reconstructed by the patient without the manipulation of the

intersubjective field “between human beings.” The research noted here, as well as that above, would seem to collectively indicate that witness, in the form of open communication and support, may allow for the creation of the intersubjective relationship which is necessary to reconstruct the patient’s narrative of self, and the subsequent relief of some aspects of psychological distress such as depression.

## 5. Counterstories

Now that we have established the importance of witness and its potential impacts on breast cancer patients, their reconstructions of self, their moral agency, and some aspects of their long-term outcomes, we turn to counterstories. In order to engage in witness for many of the people who need us, we must understand counterstories and their purpose in resisting the master narrative.

Nelson claims that counterstories are the method by which a person resists degrading representation and restores worth and agency (150). Counterstories have the specific mission of undermining the master narrative: “They ordinarily proceed by filling in details that the master narrative has ignored or underplayed...they are...narrative acts of insubordination,” (8). Those who tell counterstories seek to repair the damage done to their identities by the master narrative (154), and to regain moral agency that has been constricted by the master narrative (155). It should be noted, here, that moral agency, according to Williams, is generally defined as the human capability to be held

accountable for actions based on reasoned knowledge, to some extent.<sup>89</sup> Master narratives which are oppressive, then, can be understood as depriving those whom they oppress of the ability to act on, or be accountable for, decisions related to their reasoned knowledge of a given situation. Counterstories, by resisting and replacing the oppressive aspect of the master narrative, change the depiction of the subject of the master narrative from one who has diminished ability to act on reasoned knowledge, to one who has increased or complete ability to do so.

Counterstories, Nelson claims, are constructed in two key steps: the first is that the oppressive aspects of the master narrative are identified and noted as misrepresentations; the second is that the counterstory alters “the oppressed person’s version of herself,” (7). Nelson claims that these steps help to repair the narrative self (150). She also notes that there are several things a counterstory must do in order to be successful. These aspects of the counterstories’ potential success cast some light on our discussion of the need for cultural acknowledgement and integration of counterstories. First, Nelson claims that counterstories cannot merely exist: they must be embraced by the wider culture (in much the same way the master narrative is) (151). Counterstories must also be acknowledged and embraced not only by those who write them, but by those who have benefitted from the oppressive master narrative as well (151). Nelson tells us that those who have benefitted from the master narrative must be moved by

<sup>89</sup> The concept of moral agency, and its definition, is debated by philosophical scholars. For a more comprehensive overview, see Williams, Garreth. “Responsibility.”

counterstories to understand that the master narrative is "morally degrading" to those who are oppressed by it, and give up their position of privilege (151). In the context of the definition of moral agency established above, we can understand Nelson's notion of moral degradation to mean that one who is subject to being morally degraded means that they have reduced moral agency; their capacity as moral agent is less respected, in this case, than those who have the privilege of working within the master narrative. Finally, Nelson notes that, in order for counterstories to be effective, those who write them must come to accept them as constitutive of their identity (151). From Nelson's description of effective counterstories, we can see that the resistance of the master narrative is imperative; moreover, it is work that must be done not just by those writing counterstories. It is work that must be done by our culture as well.

From Nelson's framework, I will proceed below to give examples of counterstories which resist the master narrative and seek to provide altered versions of selves; specifically, altered versions of selves which resist and re-write a given aspect of the master narrative. Because, in Chapter 3, I systematically proceeded through the problematic concepts of the master narrative—that early detection means a cure, that biomedicine is the authority and treatment guarantees survival, that having breast cancer means performing heteronormativity, and that people are expected to be ideal breast cancer patients—I will proceed in the same manner below. For each concept, readers will see examples of counterstories which fit Nelson's description, demonstrating the compelling nature of counterstories and the powerful need for the pluralization of the

master narrative. The texts used below are narratives from diverse people, including black women and those who identify as members of the LGBTQ community. I have deliberately avoided older, more well-known counterstories, such as that of the beloved Audre Lorde. Lorde and her ilk, our predecessors in breast cancer narratives, have left a tremendous and powerful legacy. However, works like those of Lorde and Carson have been examined and discussed at length, in deeper contexts, and by a multitude of established scholars; here, I think it's especially important to explore counterstories which can offer the freshest expressions of what it feels like to live with breast cancer in a pinkwashed world.

#### 6. Early Detection Still Means You Have Cancer

In previous chapters, we saw that the abject breast cancer body is a body perceived to be out of control and subject to medical management of its excess. In the context of the breast cancer awareness movement, the “early detection leads to a cure” message is the way in which the abject female body is subject to policing and discipline through medical management of illness. Promotion of regular mammograms, for example, is one way in which this message is spread. Ehrenreich notes the presentation of the message in breast cancer walks: “Beaming survivors, proudly displaying their athletic prowess, are the best possible advertisement for routine screening mammograms, early detection, and the ensuing round of treatments,” (51). The idea that, “early detection means a cure,” (particularly if a person gets regular mammograms) is an oversimplified notion that the writers of some counterstories seek to dispel. Christine Middlebrook is

one of those women. In her story, she documents her aggressive pre-menopausal breast cancer, even as she is dying from it. Her story resists the oversimplification of the early detection message, and replaces it with the idea that breast cancer can be fatal, even when we've had our mammograms: "I didn't know, as I believe the world does not know, about the virulence of premenopausal breast cancer. I didn't understand the intentional vagaries of the words *early detection*, which imply that finding a potentially lethal disease early is the same as discovering its cause and curing it," (2). In this passage, Middlebrook fulfills the first condition for a counterstory by correcting the notion that early detection is a near-guarantee for those with breast cancer to be cured. As we discussed in the previous chapter, the notion that people should get regular mammograms, and that those who don't are somehow accountable for their illness, creates a situation in which people are victim-blamed for their breast cancer, and that is the oppressive aspect of the master narrative. Middlebrook fulfills the second condition for counterstory by pointing out the "intentional vagaries" of the message. By noting that it's the message which is problematic, not the patient's behavior or choices, she reverses the notion of victim-blaming implicit in this master narrative concept. Winnow reclaims the same notion on behalf of lesbians: "When they talk about prevention, they are talking about early detection...and then they pass it off as prevention...We don't control our environment. We know that as lesbians we don't control the society," (24). Here, Winnow also corrects the oversimplified idea that "early detection means a cure." Further, by claiming that lesbians have a stronger sense of the things beyond their control, she

removes the capacity for victim-blaming: one cannot accept or feel blame for something one already knows and acknowledges is beyond control.

Winnow is not alone in acknowledging that breast cancer may be beyond the control of early detection, that it might even be fatal. Comic Tig Notaro gave a historic performance at The Largo in 2012, in which she revealed her recent diagnosis of potentially fatal bilateral breast cancer to the audience (Notaro). Early in the show, she hears a woman sympathetically exclaiming, “Awwww,” as Notaro recounts aspects of her diagnosis (Notaro). After a few off-the-cuff cracks to the audience, Notaro chuckles, looking at the woman but speaking to the broader audience: “It’s Ok. It’s OK. It’s OK,” (Notaro). The audience laughs at the irony of the role reversal: the woman with cancer is comforting the ostensibly healthy woman. Then Notaro goes deadpan: “It *might not* be OK. I’m just sayin,” (Notaro). The audience laughs again then goes silent, save for a few nervous chuckles, confronted with the reality of Notaro's admission (Notaro). The counterstory to the oversimplified message that, “early detection equals a cure” is that even when it’s detected, it’s still cancer, and that might not “be OK.” The major subtext, of course, implied by the idea that it might not be OK, is that the possibility exists that you might die. In just these two sentences, Notaro tells a counterstory: she resists the idea that early detection always means a cure, and she replaces it with the idea that even, with early detection, breast cancer is potentially life-threatening. Notably, just a few moments later, Notaro suggests to the audience that she transition away from the dark material and tell more lighthearted jokes. A man from the audience yells, “No! This is fucking

amazing." (Goolsby and York, Dirs.). Notaro, chuckles and pauses. The audience cheers uproariously, so loudly that, for a moment, she can't go on with the set. In a subsequent documentary about the groundbreaking set, Notaro comments on this moment by noting that when the audience member yelled that comment, that was when she knew she'd done the right thing in making her diagnosis part of her set (Goolsby and York, Dirs.). Crude as his comment is, it (along with the audience's subsequent response) indicates that Notaro and the audience entered an intersubjective space which resulted in her feeling like her counterstory was witnessed.

The notion that people die of breast cancer, that it can't always be controlled by early detection via mammograms, is not one that's included in the "early detection means a cure" concept, which is problematic because it excludes from the movement the people who in fact, do die of breast cancer. The exclusion of acknowledgement of death from the popular breast cancer awareness movement creates a silence in which many find it hard to break, for fear that they may somehow "jinx" their outcome, as Middlebrook observes in her daughter's reticence to discuss her poor prognosis: "Talking about my dying, Maggie...is not going to kill me. Not talking about it will not save my life," (31). Here again, Middlebrook's counterstory corrects the master narrative by noting that she may die. The oppressive aspect of this part of the master narrative is that it potentially silences dying patients; Middlebrook resists that notion by talking about her illness, and refusing to let others be silent about her illness. She replaces that aspect of the master narrative by reclaiming the silence which has affected her life and the life of her daughter, not only in

their conversation, but by documenting her dying and publishing her story. She also reclaims the silence around death by acknowledging its inevitability, controverting our culture's death denial: "But what is a cure, I ask myself? If we have drummed away cancer, what then? Will I live forever? Of course not," (51). When faced with her own death by a rare and aggressive breast cancer, Ruthann Robson finds that her oncologist predicts she will not survive, and that her editor does not find her story "good copy," (53). She vows to tell her story anyway. Robson aligns her rebelliousness in confronting death with her rebelliousness in becoming a writer, and in coming out: "I remind myself that my Sunday school teacher told me I couldn't be a dyke and my high school English teacher told me I couldn't be a writer...I grew up to be a dyke writer...I will live to tell the tale...If only for today, this bald dyke lives," (53). Robson seeks not to resist physical death but rather to resist the figurative death caused by the silencing of her voice, of her narrative of self. The message that, "early detection means a cure" creates a silence around death, a silence in which some people may be excluded. Notably, they both indicate that narrative is the method by which they intend to go on living: silence destroys the narrative of self, which is its own figurative death. By complicating the idea that "early detection means a cure," Middlebrook and Robson tell counterstories: they break down this problematic concept of the master narrative, and replace it with the idea that breast cancer still means a confrontation with one's own mortality.

#### 7. Biomedicine as Fallible and the Epistemic Authority of the Patient

The idea that breast cancer is easily curable, combined with the concept of early

detection which put people in a position to be held accountable for their illness, contributed to two other elements of the breast cancer master narrative: the imbalance of knowledge and power between physicians and patients, and the idea that people with breast cancer assumed some responsibility for the outcome of their diagnosis. These problematic concepts of the master narrative allowed the abject breast cancer body to be policed and disciplined, as Ehrenreich observes: "...I can tell you from a few hours of investigation that the career of a breast cancer patient has been pretty well mapped out in advance for me: You may get to negotiate the choice between mastectomy and lumpectomy but...you're doomed to chemotherapy, meaning baldness, nausea, mouth sores, immunosuppression, and possible anemia," (44). Her use of language around the relatively limited options for breast cancer treatment, and her feeling of being "doomed" to chemotherapy, indicates the authority with which medicine has constructed the breast cancer "career." Robson indicates the way in which the medical authority, like that noted by Ehrenreich, puts responsibility for outcomes of treatment onto the patient. She notes this in an observation her doctor, who she finds comforting by the way in which she confronts the grim reality of Robson's illness: "She certainly isn't like the doctors who write those popular healing books...These doctors are always positive... "Personal responsibility" is their mantra. Which is pretty close to blame if you ask me," (48). In this case, Robson appreciates the fact that her doctor simply acknowledges the possibility of death that comes from Robson's illness, and does not presume an authority which deflects the blame for the outcome back onto Robson. She and Robson both know that she is

likely to die. Therefore, the doctor does not exclude Robson from being a knower in this situation. She does not subjugate Robson's knowledge of what is happening to Robson's own body. The authority of medicine in illness sometimes does result in the subjugation of knowledge of the ill person, as Carel notes: "It seems to us that it is frequently the ill person's ability to offer relevant assertions that is being questioned, rather than their ability to make assertions at all. The patient in such cases is 'recognized as unable to participate in activities whose content is intrinsically epistemic'," (*Phenomenology of Illness* 199). As noted in Chapter 3, women are particularly subject to having their knowledge subjugated to biomedical science.<sup>90</sup> In the case of breast cancer narratives, this subjugation may result in epistemic injustice. Further, it supports cultural norms by which people with breast cancer are somehow viewed as responsible for their diagnosis or poor outcomes if they do not subject themselves to the authority of biomedicine.

In her memoir, *Seeing the Crab*, Christina Middlebrook also constructs a counterstory against the power of medicine and the inevitability of a cure. In reflecting on her worst moments of treatment, in the wake of high-dose chemotherapy, Middlebrook mediates the power of medical language by equating the experience to the physical death of her body (rather than using the word "treatment"). In the opening line of the chapter, "Witness," she tells the reader, "It is difficult to remember being killed," (57) and then later in the chapter she elaborates: "They had thought all of me, body *and* soul, was going to die. But I had known that if my body was going to die, *I* was not going to accompany

<sup>90</sup> See chapter three, page 36.

it,” (61). By acknowledging the physical difficulty of her treatment, and calling it a physical death (though, not a death of the soul), Middlebrook focuses on how the experience feels to her. The irony here is that the treatment, while aggressive and painful, is meant to keep her alive. Middlebrook, though, seeks to complicate our socio-cultural notions of the experience. She wants readers to understand that, while the therapy may actually keep her physical being alive for the time being, her body as she has previously known it will never be the same—it will die.

Furthermore, Middlebrook shirks the oppressive identity of herself as one who does not have epistemic power by indicating that she knew how to preserve her narrative of self, even in the face of the “death” of aggressive treatment. Many have felt the social pressure to endure chemo with stoicism and bravery, or to keep secret the brutal and often disturbing details of what actually happens to the body. The message of these counterstories is that the authority of medicine is fallible; treatment is often a difficult and painful series of efforts which does not always cure breast cancer (and can even feel like it's killing the patient, rather than helping her survive). Moreover, and more importantly, they demonstrate that those with breast cancer should be encouraged to use their epistemic power as knowers, and that medical professionals should engage in relationships to their patients as epistemic peers. They will also empower patients in the construction of their narratives of self, and form Foucault’s “horizontal conjunctions,” and resist the disciplinary mechanism at work in the master narrative.

#### 8. Breast Cancer Beyond Heteronormativity

As we noted in the previous chapter, one concept of the master narrative of breast cancer is that it expects people with breast cancer to perform heteronormative femininity. It seeks to delimit the female body safely within the confines of the male/female gender binary. The master narrative enforced by pinkwashing and all its overtly traditionally effeminate accoutrements, allows for policing and discipline of those who do not fit comfortably within the realm of heteronormative femininity. Counterstories of this section note the need to acknowledge people whose notions of femininity do not necessarily match the master narrative and its expectation for the heteronormatively feminine. Instead, these stories acknowledge the voices of those who struggle with the idea of reconstructive surgery or the wearing of a prosthesis as normalized and expected, as something people do so as to make others more comfortable. Middlebrook notes the phenomenon: “A friend says that, because of a prosthesis, no one ever thinks about her mother-in-law’s mastectomy. (‘Except your mother-in-law,’ I think to myself, picturing my own empty chest in the mirror. ‘What do you think your mother-in-law thinks when she gets dressed each morning?’) (7-8). These are the counterstories of those who seek to complicate or alter concepts of the female breast as a cultural signifier of the feminine, and people who complicate traditional notions of femininity altogether.

Counterstory tellers attempt to loosen the ties between breasts and concepts of female beauty, such as Carol Bonicelli does in her painting, *Venus Revisited* (143). In this painting, the artist has capitalized on the traditional vision of Venus, icon of feminine beauty, but the painting has been altered to incorporate the counterstory. First, it is

painted with rather flat dimensions and simplified colors, with fewer detailed brushstrokes than the original, which indicates its contemporaneity. This choice is important because viewers must understand that the woman pictured is a contemporary woman in order to get the point. Second, the view of our modern Venus is much closer up, from just below her navel to just above her head, which forces the reader to focus directly on her torso and very little else. Third, and most critically, Venus is surrounded by a frame of very delicate, feminine, vines, one of which has crept across the left side of her chest, forming a tendril-like scar where her left breast should be. Her right hand, as in the original painting, rests on her chest, but in this case it rests just above the vine/scar, her pinkie finger serving as a pointer to draw the viewer's attention directly to the scar. By using the image of Venus, but redefining her as a contemporary woman with a mastectomy scar, Bonicelli seeks to redefine how we consider contemporary feminine beauty; this is the aspect of the painting which resists the master narrative. Bonicelli replaces the master narrative's concept of heteronormative femininity by focusing the viewer's attention on the notion that the loss of a breast does not make her less whole, or less beautiful or even less feminine; simply a different version of femininity from the original. This painting is a counterstory in that it deconstructs the master narrative's accusation that mastectomy scars are ugly or unfeminine; it alters the self-perception of the oppressed by using one of the world's most famous icons of beauty to demonstrate the way in which mastectomy scars can be reclaimed within the realm of beauty.

Other counterstories of breast cancer by members of the LGBTQ community complicate our cultural concepts of the feminine. Two writers of breast cancer narratives liken the experience of reconstructing their identities in the wake of breast cancer to the process of coming out. Lord says that, “It’s like coming out of the closet. You don’t do it just once, and once you’ve done it you can never stop...cancer...is an identity I must state, or choose not to state, at every encounter,” (18). This observation notes the way in which these women are doubly marginalized by the experience of cancer. Even before her illness, cultural heteronormativity put Lord in a position in which she had to constantly acknowledge her sexual identity as a lesbian. She came out, but she often needed to remind others around her, those who assumed heteronormativity, that she did not fit that mode. Further she had to do it again and again. Now that she has cancer, she is doubly non-normative. This counterstory resists the master narrative's association of breast cancer with heteronormative femininity; it replaces the master narrative's emphasis on heteronormativity by instead aligning breast cancer with homosexuality.

Robson, too, tells a counterstory in which she resists notions of traditional heteronormativity, and instead aligns her experience of breast cancer with homosexuality: “I guess I somehow believe that I can write my way out of this mess. The way I’ve written myself out of other messes, like heterosexuality for instance,” (50). Here, Robson indicates that the same narrative inclinations which helped her construct her sexual identity will be extended to reconstruct her identity during cancer. This identity, of course, is also bound up with her sexual identity, as she observes when she discusses her

love of hair, and her sadness at losing hers: "I loved hair, including my own. Especially my own...At night, I fanned it across my lovers' fantasy breasts," (50). Long hair, of course, is culturally signified as feminine, and having it splayed across one's body is a common male fantasy. She will not miss her hair because it makes her feel feminine, which is the common heteronormative connotation of hair loss during breast cancer and treatment. Robson uses her counterstory to replace this aspect of the master narrative's concept of heteronormativity: she will miss her hair but because it has connotations of connection with other women to whom she is attracted. This, coupled with her initial comment above about feeling the need to constantly "come out," demonstrates the ways in which her subject position as a lesbian and her subject position as a person with cancer overlap: both require the personal and sexual reconstruction of her identity through counterstory. Like Lord, she is marginalized by what Jain calls the "redoubled" femininity of the breast cancer awareness movement. She has to reconstruct her narrative of self and body, but she also may have to reconstruct her sexuality (after having already done so) in the context of a heteronormative world. Just like normative women, Lord will have to create a new narrative of self in which she understands her body and how it relates to other bodies. Because the master narrative operates on the assumption that all people rewrite their narratives of self in a heteronormative way, Lord creates a counterstory by resisting that idea, and replacing it with the concept that she will have to re-write her narrative of self as a lesbian. She seems to indicate for her readers that the experience of breast cancer, because it requires "coming out," may be more closely

aligned with the experience of homosexuality rather than heteronormativity, which echoes Jain's comment from the previous chapter that breast cancer "queers" a woman. (Notably, in order to tell her counterstory, Lord queers the breast cancer experience as well.) This phenomenon is one of the many compelling reasons why the master narrative should be pluralized in order to acknowledge non-normative people: if we do not do so, we doubly marginalize them, twice subjecting them to the inability to have their narratives of self heard and acknowledged. We are doubly depriving them of the cultural and community witness of their counterstories, putting them at risk.

#### 9. The Less-Than-Ideal Breast Cancer Patient

As we noted in the previous chapter, the expectation of the "ideal" breast cancer patient assures that the female character and mannerisms also fit the proper binary mode. The expectation of women and trans\* people to perform heteronormative femininity during and after breast cancer and treatment means that they are expected to be demure, strong, and enduring. The heroic idealized patient is characterized by the ability to submit to the authoritative knowledge of allopathic medicine and remain positive throughout treatment. She is, quite literally, the embodiment of mind over matter, because she overcomes cancer through sheer force of will. This aspect of the master narrative requires that people engage in commodified notions of "hope," and endless optimism as characterized by the movement, as Barbara Ehrenreich observes: "...a collection of brief narratives with a foreword by Nancy Brinker and a share of the royalties going to the Komen Foundation, is filled with such testimonies to the redemptive powers of

disease...What does not destroy you...to paraphrase Nietzsche, makes you a spunkier, more evolved, sort of person,” (49). The mention of Nietzsche here offers us the opportunity to return to some of the pathologized notions of the female body which we have inherited from previous centuries. The female body was (and in many ways, still is) considered a deformed version of a male body; male bodies are the ideal or the standard. The body with breast cancer, already deformed, becomes abject and marginalized from the ideal even further. Ironically, it can never be ideal. The spunky, evolved hero is the “ideal” breast cancer patient, but can never be the ideal body. The archetype of the ideal breast cancer patient is merely a way of socio-culturally managing the abject body, which is why, if a person with breast cancer does not behave as the ideal breast cancer patient, that person risks being scapegoated or marginalized. Ehrenreich’s sarcasm in the above passage is evident. Here, she expresses a brief but compelling counterstory in which she deconstructs the idea of the ideal breast cancer patient, and replaces it with a breast cancer patient more like herself: cynical, snarky, and annoyed.

Additionally, the pinkwashed role of the ideal breast cancer patient is one which strongly affects the experiences of women of color, and in specific ways, as Gatison notes:

Being stoic and never complaining means simply being that infamous strong Black woman who lives through some of the “what if” scenarios that come to pass and just deals with them. By falling in line with the march of the pink ribbon as a (s) hero, a warrior, a breast cancer survivor, and a strong Black woman of faith,

one is in a way, being forced into a type of silence. (“Cancer Journals of Inspiration and Courage”)

Black women’s experiences are also silenced by the idea that the ideal breast cancer patient of the master narrative should be strong, heroic, and warrior-like. However, black women must also operate within the inherited cultural legacy of the strong black woman of faith, as we noted in Chapter 3, and therefore their potential for marginalization is increased exponentially: if they refuse to perform as ideal breast cancer patients, they may be scapegoated; if they refuse to perform the role of the strong Black woman of faith, they may be distancing themselves from their cultural community and their cultural legacy. Interestingly, Gatison’s remarks only partially fulfill the requirements for a counterstory. By pointing out the potential for silencing, she has deconstructed the oppressive aspect of the master narrative. However, she doesn’t offer an alternative to it. Perhaps that was simply not her intention for that text. Or perhaps it is more difficult for her to do given her position as a black woman who is subject to the master narrative of breast cancer and its specific reverberations within her cultural community. This is why the pluralization of the master narrative of breast cancer may be especially important to women of color: if we can create and socially share a counterstory in which women are not expected to be idealized, enduring, warrior-heroes, we may create more support for the moral agency of women of color, and their ability to re-create an identity without feeling marginalized by their communities or our culture.

King notes the problematic expectation that those with breast cancer act cheerful

and demure, and not show their anger about the illness:

She was mad, real mad,  
but she had been taught  
to be good  
and couldn't show it. (33)

Here, King claims that the woman to whom she refers in the poem “could not show” her anger, because she had been taught that it was unacceptable to do so. This statement implies that this woman is subject to the concept of the master narrative that ideal breast cancer patients are relentlessly positive and do not show negative emotions such as sadness or anger; otherwise, they risk being scapegoated. Again, King calls out the problem with this concept and also alters the notion of the ideal breast cancer patient simply by publicly decrying that this woman could to be free to express her experience, to expect others to engage with her reconstruction of self.

Middlebrook highlights the fact that the ideal breast cancer patient is expected to be enduring and positive: “I think dying is difficult enough without having to achieve a pleasant attitude about it,” (198). Middlebrook resists the pinkwashed idea that breast cancer patients constantly be full of hope and cheer. Furthermore, she replaces that aspect of the master narrative by refusing to “achieve” a pleasant attitude. The word “achieving” is significant here: in the world of ideal breast cancer patient-hood, having a pleasant attitude is an accomplishment, something one is publicly lauded for, considered a hero for, and given figurative gold stars. Refusing to do so, on the other hand, risks getting

identified as a scapegoat. Here, Middlebrook tells a counterstory in which she deconstructs the master narrative's concept that women dying from breast cancer should be stalwart and enduring, replacing it with the idea that she, like Ehrenreich, is allowed to be unpleasant.

Potentially being subject to blame is one fate which often backs women and trans people with breast cancer into the position of feeling like they have to be demure about their illness, that they should not speak too openly about the struggles, pain, and reality of it (like Betty Ford tossing her husband the football, fooling all of America into believing that a Halsted mastectomy is nothing at all). DeShazer notes that blunt comedy is one strategy by which people disengage from roles that define them as sweet and demure. She claims that, "Humorous breast cancer [memoirists]...prefer a postmodern sense of contingency that deflects rather than embraces sentimental discourses. Middlebrook's darkly crude but humorous story of her cancer support group illustrates the point: "Elimination, that's another secret the nasty creature keeps. In the support group, Jay asks, 'Can we talk shit here?' Yes. We can. Cancer support groups are the only place where we can talk shit, for real. Black, bloody stools, we agree, are not good," (184). Sweet, strong, demure breast cancer patients are most definitely not supposed to talk about shit, and yet, Middlebrook does. In this passage, she uses dark but forthright humor to expose the nastiness of cancer for what it is, rather than try to hide it for the sake of presenting herself as a hero. Instead, she reclaims the identity of the breast cancer patient by showing that breast patients talk about shit, and that they do so with other cancer

patients, and that it's OK, even necessary, for them to do.

Similarly, Notaro refuses to abide the pat, sweet, sentimentalities which breast cancer patients are often told to abide, to turn to for hope, in the discourse of the illness. The one platitude Notaro chooses to deconstruct is the well-known phrase, "God doesn't give us more than we can handle." For her stand-up audience, she breaks down the ridiculousness of this expression from her perspective as a woman who has nearly died from C-diff, then lost her mother to sudden accidental death, then been diagnosed with breast cancer, all in a few months: "You can always rest assured that God never gives you more than you can handle. And you just picture God going, 'I think she can take a little more.' And the angels are just standing back like, 'God, *what are you doing?!'*" (italics mine) (Notaro). Again, Notaro uses ironic humor to demonstrate the ways in which such an expression seems totally unable to encompass the tragedy of what she's experienced. She resists the master narrative by refusing to have her story defined by generic concepts of hope. She seeks to replace the image of the enduring hero with the dark humorist, as she notes when she says, "The good Lord giveth and the good Lord taketh away. But sometimes the good Lord taketh and just keep taking--it-eth. It's kind of like tit for tat. That's kind of what's going on right now," (Notaro). She does not try to perpetuate sentimental notions of the hero; she counters the master narrative of the enduring, ideal breast cancer patient, and replaces that image with dark but humorous truth about breast cancer.

Counterstories like these create a new concept of what it means to have breast

cancer, but the mere fact that they exist is not enough. As a culture, we must be willing to bear witness to these counterstories, which means acknowledging the imbalance of power and the privilege which comes with the current master narrative perpetuated by the contemporary breast cancer awareness movement and pinkwashing. Only when we are willing to embrace these counterstories, bearing witness to them as a cultural community, can we remedy the injustice created by the current master narrative, engage in the recreation of identity for many more women and trans people, and encourage their moral agency in their experience of illness. Moreover, in witnessing counterstories, we may be offering chances for improved outcomes and prognosis for some people struggling with identity. Therefore, counterstories are not just one aspect of the breast cancer experience that apply to some women and trans people; they are a cultural imperative, telling us the ways in which the current movement must change if we truly want to do better for all people with breast cancer, and not just those whose stories make fundraising easy or convenient.

## CONCLUSION

In this text, we have seen the ways in which antiquated, problematic constructions of the female body have historically caused it to be construed as pathologized, and the ways in which those constructions of the female body were integrated into the early breast cancer awareness movement. The movement, along with public discourse around breast cancer in the 20th century, took up these notions and used them to its advantage in order to discipline, police, and regulate abject breast cancer bodies. In the latter part of the 20th century, breast cancer awareness organizations which utilized the practice of pinkwashing, codified these concepts into a master narrative of the breast cancer experience which we still see today. This master narrative expresses distinct messages which are exclusive of the unique experiences of many women and trans\* people diagnosed with breast cancer. Those experiencing breast cancer are struggling to recreate their own identities in the wake of illness and treatment; this recreation of self necessarily calls for relationships between the self and other, and between self and community. Thus, the exclusion caused by the master narrative can be detrimental to the recreation of identity which is vital to the person with breast cancer. Further, we know that having some community to bear witness to a breast cancer experience can potentially lead to improved prognosis and long-term outcomes. The fact that our cultural community may

not be fully bearing witness to the experiences of a variety of women and trans\* people with breast cancer, may mean that those people are subject to poorer health outcomes than those whose experiences are easily and readily witnessed through the master narrative. Because of this compelling need to bear witness to stories more diverse than the master narrative currently allows, we must engage in, and embrace counterstories of breast cancer. We must make these counterstories a more integrated part of cultural discourse around breast cancer in order to do justice to the people experiencing the illness, and attempt to create new master narratives which are not oppressive to those with breast cancer. If we do not, we risk subjecting many people diagnosed with, or dying from, breast cancer to further exclusion and/or injustice.

Willingness to hear and acknowledge narratives of self about the experience of breast cancer can impact the identity and health outcomes of a person diagnosed with breast cancer. Because of its implications regarding identity, epistemic injustice, and long-term health outcomes, this research is compelling for both lay-caregivers and clinicians. Not all women and trans\* people diagnosed with breast cancer fit the story told by the pinkwashed master narrative. In order to facilitate the construction of a more genuine (less profit-oriented) understanding of the experience of breast cancer, and fully support those who are diagnosed, we must be willing to first resist the master narrative perpetuated by pinkwashing. Second, we must support and engage with counterstories which may replace our current, oversimplified master narrative.

In order for us to continue this work, much is left to be done. First, there is a

compelling need to understand the cultural experience of women of color when diagnosed with breast cancer. In order to do so, we need to fully examine the history of black women's bodies in the context of medical history in the United States, and analyze how that relationship might affect perceptions of, and adherence to, medical treatment for breast cancer. This analysis is extremely complex and requires the incorporation of many factors related to racial disparities in healthcare, generally. Additionally, we need to analyze the ways in which the contemporary breast cancer awareness movement has excluded or silenced the experiences of women of color in the U.S., and make a further effort to create a breast cancer awareness movement which operates from the premise of intersectional feminism, embracing women of color and the LGBTQ community.

Very little is known about the experiences of lesbian and bisexual women with breast cancer and, as of this writing, the narratives of those women are not widely included as part of our cultural understanding of the breast cancer experience. We need to begin to understand the legacy Audre Lorde left, not only for women with breast cancer, but for people who are not heteronormative who have breast cancer. There is an extraordinary dearth of knowledge about the experiences of trans\* people with breast cancer, even though their exposure to hormones may make them more susceptible to the illness. At the time of this writing, publicly accessible narratives of trans\* and queer people with breast cancer are still very rare. Perhaps it is necessary for a cultural shift away from our current master narrative in order for members of the trans\* and queer community to share their experiences in a more public venue, or to have them made more

available to the public; all the more reason for us to open ourselves to understandings of the breast cancer experience beyond the master narrative.

How do we proceed from this new understanding of breast cancer in our culture? Clinicians and caregivers alike must bear in mind that the pinkwashed master narrative to which we are constantly exposed is not, by far, the experience of all people with breast cancer. But they must also bear in mind the reality that many people do identify with the master narrative, and their lives are enriched by the activities of organizations like the Susan G. Komen Foundation. Breast cancer is an extraordinarily complex illness which brings to light not only questions of mortality, but questions of gender identity and sexuality, as well as questions of social, political, cultural, and epistemic power. Additionally, breast cancer research has not advanced to the extent that it is an illness that we might label as "curable." In fact, as we know from the final chapter of this work, it is now considered a "chronic illness." If that is the case, while we continue the efforts to find a cure (as we do with many types of cancer), we must also take into account, and bear witness to, the lived experiences of those diagnosed with breast cancer, in order to offer them the highest possible level of support.

## REFERENCES

### Works Cited

- After the Cure: The Untold Stories of Breast Cancer Survivors*. New York UP, 2008.
- “American Cancer Society Guidelines for the Early Detection of Cancer.” *American Cancer Society*. 26 July 2016. <https://www.cancer.org/healthy/find-cancer-early/cancer-screening-guidelines/american-cancer-society-guidelines-for-the-early-detection-of-cancer.html>. Accessed Mar. 2017.
- Aronowitz, Robert A. *Unnatural History: Breast Cancer and American Society*. Cambridge University Press, 2007.
- Art, Rage, Us: Art and Writing by Women with Breast Cancer*. Edited by Jaqueline A. Tasch. Chronicle, 1998.
- Asher, Gena. “Pinkwashing Obscures Breast Cancer Message.” *The Herald-Times*. [Bloomington, IN]. 25 Oct. 2011. *Proquest*. Proquest document ID: 900332967. Accessed Dec. 2014.
- Bahar, Saba. “‘If I Am One of the Victims Who Survives’: Marilyn Hacker’s Breast Cancer Texts.” *Signs: Journal of Women in Culture and Society*, vol. 28, no. 4, 2003, pp. 1025–1052., doi:10.1086/368327. Accessed 7 Mar. 2017.

- Barker, Melanie. "Living Beyond Breast Cancer As LGBT." *Curve Magazine*, 7 Oct. 2015, [www.curvemag.com/Lifestyle/Living-Beyond-Breast-Cancer-As-LGBT-666/](http://www.curvemag.com/Lifestyle/Living-Beyond-Breast-Cancer-As-LGBT-666/). Accessed 7 Mar. 2017.
- Bjorneklett, Helena, et al. "A Randomised Controlled Trial of Support Group Intervention After Breast Cancer Treatment: Results on Anxiety and Depression." *Acta Ontologica*, vol. 51, 2012, pp. 198–207., [www.ncbi.nlm.nih.gov/pubmed/21923569](http://www.ncbi.nlm.nih.gov/pubmed/21923569). Accessed 7 Mar. 2017.
- Blackstone, Amy. "It's Just About Being Fair: Activism and the Politics of Volunteering In the Breast Cancer Movement." *Gender and Society*. vol.18, no.3, 2004, pp. 350-368. *JSTOR*.  
<http://journals.sagepub.com.libproxy.bellarmino.edu/doi/abs/10.1177/0891243204264092?journalCode=gasa&volume=18&year=2004&issue=3>. Accessed Dec. 2014
- Bodai, Balazs, and Phillip Tusso. "Breast Cancer Survivorship: A Comprehensive Review of Long-Term Medical Issues and Lifestyle Recommendations." *The Permanente Journal*, vol. 19, no. 2, 2015, doi:10.7812/tpp/14-241. Accessed 7 Mar. 2017.
- Bonicelli, Carol. "Venus Revisited." *Tasch*, 143.
- Bordo, Susan. "The Body and the Reproduction of Femininity: A Feminist Appropriation of Foucault." *Gender/body/knowledge: Feminist Reconstructions of Being and Knowing*. Edited by Allison Jaggar and Susan Bordo. Rutgers UP, 1989. 13-33.
- Bower, Julianne. "Behavioral Symptoms in Breast Cancer Patients and Survivors."

*Journal of Clinical Oncology*. vol., 26, no. 5, 2008, pp. 768-777.

doi:10.1200/JCO.2007.14.324. Accessed Apr. 2015.

Brison, Susan J. *Aftermath: Violence and the Remaking of a Self*. Princeton University Press, 2002.

Brooks, James L., et al. *Terms of Endearment*. Paramount Pictures, 1983.

Brownworth, Victoria, editor. *Coming Out of Cancer: Writings from the Lesbian Cancer Epidemic*. Seal Press, 200.

Bryant, Betsey. "Breast Exam." *Tasch*, p. 97.

Burney, Frances. Manuscript letter in the Henry W. and Albert A. Berg Collection, New York Public Library.

<http://newjacksonianblog.blogspot.com/2010/12/breast-cancer-in-1811-fanny-burneys.html>. Accessed April 2016.

"Cancer of the Breast (female): Cancer Stat Facts." National Cancer Institute, 2016, <https://seer.cancer.gov/statfacts/html/breast.html>. Accessed 6 Mar. 2017.

Carel, Havi. *Illness The Cry of the Flesh*. Taylor and Francis, 2008.

---*Phenomenology of Illness*. New York, Oxford University Press, 2016.

Cerankowski, Karli Jane. "The Trouble with Surviving Cancer Against All Odds." *The Clayman Institute for Gender Research, Stanford University*. 3 Jun. 2013.

<http://gender.stanford.edu/news/2013/trouble-surviving-cancer-against-all-odds>. Accessed Dec. 2016

Charon, Rita. *Narrative Medicine: Honoring the Stories of Illness*. Oxford UP, 2006.

Chesler, Phyllis. *Women and Madness*. Doubleday, 1972.

"Companies Adopting 'Pinkwashing' for Profit Commit Social Injustice to Women."

*Asian News International*. 8 Jul. 2011.

<http://www.sify.com/news/companies-adopting-pinkwashing-for-profit-commit-social-injustice-to-women-news-international-lhiq4hefjgfsi.html>. Accessed 6 Mar. 2017.

Committee on Breast Cancer and the Environment: The Scientific Evidence, Research Methodology, and Future Directions; Institute of Medicine. *Breast Cancer and the Environment: A Life Course Approach*. Washington, D.C.: National Academies Press, 2012.

Couser, G. Thomas. *Recovering Bodies: Illness, Disability, and Life-writing*. University of Wisconsin, 1997.

DeShazer, Mary K. *Mammographies: the Cultural Discourses of Breast Cancer Narratives*. The University of Michigan Press, 2015.

Dickinson, Emily. "'Hope' Is the Thing with Feathers (314)." Manuscript in the Houghton Library, Harvard University. Republished by *Poetry Foundation*, [www.poetryfoundation.org/poems-and-poets/poems/detail/42889](http://www.poetryfoundation.org/poems-and-poets/poems/detail/42889). Accessed 7 Mar. 2017.

Ehrenreich, Barbara. "Welcome to Cancerland." *Harper's Magazine*, 1 Nov. 2001. pp. 43-53. <http://archive.bcaction.org/uploads/PDF/Harpers.pdf>. Accessed Dec. 2014.

- Eisenstein, Zillah. *Manmade Breast Cancers*. Cornell University Press, 2001.
- “Facts for Life.” *Susan G. Komen*. <http://ww5.komen.org/BreastCancer/Statistics.html>.  
Access 7 Mar. 2017.
- Fernandez, Sandy M. “The History of the Pink Ribbon.” *Think Before You Pink*. Breast Cancer Action. Reprinted from *MAMM*. June/July 1998.  
<http://thinkbeforeyoupink.org/resources/history-of-the-pink-ribbon/>. Accessed spring 2015.
- “Final Recommendation Statement: Breast Cancer Screening.” United States Preventative Services Task Force. Nov. 2016.  
<https://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/breast-cancer-screening1>. Accessed Dec. 2016
- Fosket, Jennifer. “Problematizing Biomedicine: Women's Constructions of Breast Cancer Knowledge.” *Ideologies of Breast Cancer: Feminist Perspectives*, edited by Laura Potts. St. Martin's Press, 2000, pp. 15-36.
- Foucault, Michel. *Discipline and Punish*. Vintage Books, 1979.
- “Je suis un artificier.” *Michel Foucault, entretiens*. Translated by Clare O'Farrell.  
Edited by Roger-Pol Droit. Paris: Odile Jacob, 1975.
- The Birth of the Clinic; an Archaeology of Medical Perception*. Pantheon, 1973.
- The History of Sexuality: The Will to Knowledge*. Translated by Robert Hurley.  
Penguin Books, 1974.
- Frank, Arthur W. *The Wounded Storyteller: Body, Illness, and Ethics*. University of

Chicago, 1995.

Freeman, Lauren. "Confronting Diminished Epistemic Privilege and Epistemic Injustice in Pregnancy by Challenging a 'Panoptics of the Womb.'" *Journal of Medicine and Philosophy*, vol. 40, no. 1, 12 Dec. 2014, pp. 44–68.,  
doi:[https://doi.org/10.1093/jmp/jhu\\_046](https://doi.org/10.1093/jmp/jhu_046).

Fricker, Miranda. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford University Press, 2011.

Frith, Susan. "Searching for Sarah Baartman." *Johns Hopkins Magazine*. June 2009.  
<http://pages.jh.edu/jhumag/0609web/sara.html>. Accessed Fall 2016.

Gale, Zona. "Does It Eat, Too?" Lifshitz, p. 35

Gardner, Kirsten E. "Disruption and Cancer Narratives: From Awareness to Advocacy." *Literature and Medicine*. vol. 28. no. 2, 2009, pp. 333-350. Proquest. <http://muse.jhu.edu.libproxy.bellarmino.edu/article/402252>

Gattison, Annette D. Madlock. *Health Communication and Breast Cancer among Black Women Culture, Identity, Spirituality, and Strength*. Kindle ed. Lexington Books, 2016.

Gehres, Sylvia Colette. "Reflection." 1995. Pastel. Taschen, p. 54.

Gramsci, Antonio. *Selections from the Prison Notebooks*. Edited and translated by Quintin Hoare and Geoffrey Nowell Smith. International Publishers, 1971.

Grigoriadis, Vanessa. "Survival of the Funniest." *Vanity Fair*, 18 Dec. 2012,  
[www.vanityfair.com/culture/2013/01/tig-notaro-breast-cancer-dont-connect-with-](http://www.vanityfair.com/culture/2013/01/tig-notaro-breast-cancer-dont-connect-with-)

- jokes. Accessed 6 Mar. 2017.
- Goedicke, Patricia. "100,000 Upon 100,000." Lifshitz, p. 61.
- Goldsmith, Ellen. "Chemotherapy." Tasch, p. 88.
- Goodman, Jerilyn. "A Scar I Did Not Want to Hide." Brownworth, pp.138-141.
- Goolsby, Kristina and Ashley York, directors. *Tig*. Netflix, 2015.
- Hacker, Marilyn. "August Journal." *Prairie Schooner*, vol. 68, no. 1, 1994, pp. 24–28,  
<http://www.jstor.org/stable/40633511>, 10.2307/40633511. Accessed 6 Mar. 2017.
- Halpern, Joan. "Diagnosis." Lifshitz, p. 7
- Herndl, Diane Price. "Our Breasts, Our Selves: Identity, Community, and Ethics in  
Cancer Autobiographies." *Signs: Journal of Women in Culture and Society*, vol.  
32, no. 1, 2006, pp. 221–245. *JSTOR*, doi:10.1086/505542. Accessed Dec. 2014.
- Hjelmstad, Lois Tshetter. "Bio." Tasch, p. 55  
—"Double Amputee." Tasch, p. 55
- Hoga, Luiza Akiko Komura, et al. "Psychosocial Perspectives of the Partners of Breast  
Cancer Patients Treated With a Mastectomy." *Cancer Nursing*, vol. 31, no. 4,  
2008, pp. 318–325., doi:10.1097/01.ncc.0000305748.43367.1b. Accessed 13 Mar.  
2017.
- Hunter, M. "Ford's Wife Undergoes Breast Cancer Surgery." *New York Times*. 29 Sept.  
1974, pp.1 and 22.
- Hurst, Elizabeth. "For the Time Being." Tasch, p. 80
- Imber, Gerald. *Genius on the Edge: The Bizarre Double Life of Dr. William Stewart*

*Halsted*. Kaplan Pub, 2010.

Irwin, Marian S. "Post-mastectomy, Week One." Lifshitz, p. 23.

Jackson, S. "Interchanges: Gender, Sexuality and Heterosexuality: The Complexity (and Limits) of Heteronormativity." *Feminist Theory*, vol. 7, no. 1, Jan. 2006, pp. 105–121., doi:10.1177/1464700106061462. Accessed Nov. 2016.

Jaggar, Karuna. "The NFL's Breast Cancer Scam Sells Bunk Science to Profit Off Pink Clothes." *The Guardian*, 28 Feb. 2017, <https://www.theguardian.com/commentisfree/2014/oct/05/nfl-breast-cancer-pink-women>. Accessed 7 Mar. 2017.

Jenkinson, Stephen. *Die Wise: A Manifesto for Sanity and Soul*. North Atlantic, 2015.

Kennedy, Terry. "Mammogram." Lifshitz, p. 4.

King, Samantha. *Pink Ribbons, Inc.: Breast Cancer and the Politics of Philanthropy*. University of Minnesota Press, 2006. Print.

Kinsman, Kat. "Activists Call Foul on KFC Bucket Campaign." *CNN*, 28 Apr. 2010, <http://www.cnn.com/2010/LIVING/homestyle/04/28/kfc.pink.bucket.campaign/>. Accessed 6 Mar. 2017.

Klawiter, Maren. "Racing for the Cure, Walking Women, and Toxic Touring: Mapping Cultures of Action within the Bay Area Terrain of Breast Cancer." *Social Problems*, vol. 46, no. 1, 1999, pp. 104–126., doi:10.1525/sp.1999.46.1.03x0244j. Accessed 7 Mar. 2017.

---*The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism*.

- University of Minnesota Press, 2008.
- Kleinman, Arthur. *The Illness Narratives: Suffering, Healing, and the Human Condition*. Basic, 1988.
- Klemesrud, Judy. "After Breast Cancer Operations, A Difficult Emotional Adjustment." *New York Times*. 1 Oct. 1974. 46.  
<https://mobile.nytimes.com/1974/10/01/archives/after-breast-cancer-operations-a-difficult-emotional-adjustment.html>. Accessed Dec. 2016.
- Knopf-Newman, Marcy Jane. *Beyond Slash, Burn, and Poison: Transforming Breast Cancer Stories into Action*. Rutgers UP, 2004.
- Kristeva, Julia. *Powers of Horror: An Essay on Abjection*. Translated by Leon S. Roudiez. Columbia University Press, 1982.
- Kucinich, Elizabeth. "Letter to Ambassador Nancy G. Brinker." 15 Apr. 2010. *Media Cleveland*. <http://media.cleveland.com/healthy-eating/other/kucinich.pdf>. Accessed on 6 Mar. 2017.
- Kukla, Rebecca. *Mass Hysteria: Medicine, Culture, and Mothers' Bodies*. Rowman & Littlefield Publishers, Inc. 2005.
- Kumin, Maxine. "Off." *Raz*, p. 18
- Kushner, Rose. *Breast Cancer: A Personal History and an Investigative Report*. Harcourt Brace Jovanovich, 1977.
- Kyranou, Marianna, et al. "Trajectories of Depressive Symptoms in Women Prior to and for 6 Months After Breast Cancer Surgery." *Journal of Applied Biobehavioral*

*Research*, vol. 19, no. 2, 2014, pp. 79–105., doi:10.1111/jabr.12017.

Leopold, Ellen. *A Darker Ribbon: Breast Cancer, Women, and Their Doctors in the Twentieth Century*. Beacon Press. 1999.

Leopold, Ellen. *My Soul Is Among Lions: Pages from the Breast Cancer Archives*. Valley Green Press, 2014.

Lerner, B. H. “No Shrinking Violet: Rose Kushner and the Rise of American Breast Cancer Activism.” *Western Journal of Medicine*, vol. 174, no. 5, Jan. 2001, pp. 362–365., doi:10.1136/ewjm.174.5.362.

---*The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth Century America*. Oxford UP, 2001.

Libbon, Stephanie E. “Pathologizing the Female Body: Phallogentrism in Western Science.” *Journal of International Women's Studies*, vol. 8, no. 4, 2007 pp.79-92. <http://vc.bridgew.edu/cgi/viewcontent.cgi?article=1401&context=jiws>. Accessed Sept. 2016.

Lifshitz, Leatrice H. *Her Soul Beneath the Bone: Women's Poetry on Breast Cancer*. U of Illinois, 1988.

“Lifestyle-Related Breast Cancer Risk Factors.” American Cancer Society., 2017, <https://www.cancer.org/cancer/breast-cancer/risk-and-prevention/lifestyle-related-breast-cancer-risk-factors.html>. Accessed 6 Mar. 2017.

Linder, Arlene and Michelle Linder. “Don’t Touch Me.” 1996. Pen and ink. Tasch, p. 86.

Linderman, Marlene Gharbo. “My Surgery.” Tasch, p. 27

“Lorraine Hutchinson.” *Susan G. Komen*, 7 Mar. 2017.

<http://ww5.komen.org/Breast-Cancer-Stories/Lorraine-Hutchinson.html>

Lord, Catherine. *The Summer of Her Baldness*. University of Texas Press, 2004.

Lorde, Audre. *The Cancer Journals*. Aunt Lute, 1997.

MacDonald, Helen. *Human Remains: Dissection and its Histories*. Yale University Press, 2006.

MacIntyre, David. *After Virtue: A Study in Moral Theory*. 2nd ed. Oxford University Press, 1984.

Mallinger, J.b., et al. “Family Communication and Mental Health after Breast Cancer.”

*European Journal of Cancer Care*, vol. 15, no. 4, 2006, pp. 355–361.,

doi:10.1111/j.1365-2354.2006.00666.x. Accessed Mar. 2015.

Marchetto, Marisa Acocella. *Cancer Vixen: A True Story*. Alfred A. Knopf, 2006.

Martin, Leslie R., et al. “The Challenge of Patient Adherence.” *Therapeutics and Clinical*

*Risk Management* , vol. 1, no. 3, 2005, pp. 189–199.,

<https://core.ac.uk/download/pdf/4131473.pdf>. Accessed Mar. 2015.

Miller, Anthony B, et al. “Twenty Five Year Follow-up for Breast Cancer Incidence and

Mortality of the Canadian National Breast Screening Study: Randomised

Screening Trial.” *BMJ*, vol. 348, 16 Jan. 2014, doi: doi:

<https://doi.org/10.1136/bmj.g366> . Accessed Sept. 2015.

O'Toole, Marie T. “Constitution.” *Miller-Keane Encyclopedia and Dictionary of*

*Medicine, Nursing, and Allied Health*, 7th ed., Saunders, an Imprint of Elsevier,

dictionary.thefreedictionary.com/constitution . Accessed Dec. 2016.

Morrow M., et al. "Access to Breast Reconstruction After Mastectomy and Patient Perspectives on Reconstruction Decision Making." *JAMA Surgery* vol.149, no.10, 2014, 1015-1021.<https://www.ncbi.nlm.nih.gov/pubmed/25141939>  
Accessed Dec. 2016

Murakami, Violet. "Physician's Report II." *Tasch*, p. 73.

Mukherjee, Siddhartha. *The Emperor of All Maladies: A Biography of Cancer*. Scribner, 2010.

National Cancer Institute, 2016, <https://seer.cancer.gov/statfacts/html/breast.html>.  
Accessed 6 Mar. 2017.

Neighmond, Patti. "The Hidden Cost Of Mammograms: More Testing And Overtreatment." *NPR*, 13 Apr. 2015,  
[www.npr.org/sections/health-shots/2015/04/13/398818949/the-hidden-cost-of-mammograms-more-testing-and-overtreatment](http://www.npr.org/sections/health-shots/2015/04/13/398818949/the-hidden-cost-of-mammograms-more-testing-and-overtreatment). Accessed 14 Mar. 2017.

Nelson, Hilde Lindemann. *Damaged Identities, Narrative Repair*. Cornell UP, 2001.

---. *Stories and Their Limits: Narrative Approaches to Bioethics*. Routledge, 1997.

Nisbett, Richard, and Lee Ross. "Judgmental Heuristics and Knowledge Structures."  
*Human Inference: Strategies and Shortcomings of Social Judgement*.  
Prentice-Hall. Reprinted in *Naturalizing Epistemology*. Edited by Hilary Kornblith. 2nd ed. MIT Press, 1994.

Notaro, Tig. "Tig Notaro: Live." *The Largo*, Los Angeles, CA, Aug. 2012.

Nuland, Sherwin B. *How We Die: Reflections on Life's Final Chapter*. A.A. Knopf, 1994.

Ofri, Danielle. "When the Patient Is "noncompliant."” *The New York Times*, 15 Nov.

2012,

<https://well.blogs.nytimes.com/2012/11/15/when-the-patient-is-noncompliant/>.

Accessed 7 Mar. 2017.

Pickett, Brent L. "Foucault and the Politics of Resistance.” *Polity*, vol. 28, no. 4, 1996,

pp. 445–466., doi:10.2307/3235341. Accessed Oct. 2016.

"Pinkwashing—Breast Cancer Awareness Month Inspires Crass Marketing Pitches.” *The*

*Post-Standard.*, 17 Oct. 2011, p. A10. Proquest,

[blog.syracuse.com/opinion/2011/10/](http://blog.syracuse.com/opinion/2011/10/)

[pinkwashing\\_breast\\_cancer\\_aware.html](http://pinkwashing_breast_cancer_aware.html). Accessed Mar. 2016.

"Pinkwashing Depicts Ideal Patient in Breast Cancer Awareness.” *US Federal News*

*Service*. 21 Oct. 2010. Proquest. doi: 759297554. Accessed Mar. 2016.

Pantsios, Anastasia. "Outrage Continues at Susan G. Komen's 'Frack for the Cure'

Pinkwashing Campaign.” *Ecowatch: Transforming Green*, 24 Oct. 2014,

[www.ecowatch.com/outrage-continues-at-susan-g-komens-frack-for-the-cure-pin](http://www.ecowatch.com/outrage-continues-at-susan-g-komens-frack-for-the-cure-pinkwashing-cam-1881963209.html)

[kwashing-cam-1881963209.html](http://kwashing-cam-1881963209.html). Accessed Mar. 2016.

Parker-pope, Tara. "A Grim Breast Cancer Milestone for Black Women.” *The New York*

*Times*, 29 Oct. 2015, [https://well.blogs.nytimes.com/2015/10/29/a-grim-](https://well.blogs.nytimes.com/2015/10/29/a-grim-breast-cancer-milestone-for-blak-women/)

[breast-cancer-milestone-for-blak-women/](https://well.blogs.nytimes.com/2015/10/29/a-grim-breast-cancer-milestone-for-blak-women/). Accessed 6 Mar. 2017.

Parton, C. M., et al. "Womens Construction of Embodiment and the Abject Sexual Body

- After Cancer.” *Qualitative Health Research*, vol. 26, no. 4, Apr. 2015, pp. 490–503., doi:10.1177/1049732315570130.
- Parvin, Paige. “Fitting Lesbians into Breast Cancer Activism: An Interview with Dr. Susan Love.” Brownworth. pp. 90-94.
- Post, Pamela. “Cancer Says.” *Raz*, p. 4.
- Pool, Lea. Dir. *Pink Ribbons, Inc.* First Run Features, 2011.
- Rabin, Roni Caryn. “You’re on the Clock: Doctors Rush Patients out the Door.” *U.S.A Today & Kaiser Health News*, 20 Apr. 2014, <http://www.usatoday.com/story/news/nation/2014/04/20/doctor-visits-time-crunch-health-care/7822161/>. Accessed 7 Mar. 2017.
- Raz, Hilda. *Living on the Margins: Women Writers on Breast Cancer*. Persea, 1999.
- Rich, Adrienne. “A Woman Dead in Her Forties.” *The Dream of a Common Language*. W.W. Norton, 1978.
- Robson, Ruthann. “not//a story. *Coming out of Cancer*. Brownworth. pp. 47-54.
- Russo, Mary. “Female Grotesques: Carnival and Theory.” *Feminist Studies/Critical Studies*, 1986, pp. 213–229., doi:10.1007/978-1-349-18997-7\_13.
- Showalter, Elaine. *The Female Malady: Women, Madness, and English Culture*. Pantheon, 1985.
- Skloot, Rebecca. *The Immortal Life of Henrietta Lacks*. Crown Publishing Group, 2010.
- Smith, David Woodruff. “Phenomenology.” *The Stanford Encyclopedia of Philosophy*. Edward N. Zalta, ed. Dec. 2016,

plato.stanford.edu/archives/win2016/entries/phenomenology/.

Accessed Dec. 2016.

- Soerjomataram, Isabelle, et al. "An Overview of Prognostic Factors for Long-Term Survivors of Breast Cancer." *Breast Cancer Research and Treatment*, vol. 107, no. 3, 22 Mar. 2007, pp. 309–330, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2217620/>. Accessed 6 Mar. 2017.
- Sugg, Richard. *Murder After Death: Literature and Anatomy in Early Modern England*. Cornell University Press, 2007.
- Suppli, Nis P., et al. "Increased Risk for Depression After Breast Cancer: A Nationwide Population-Based Cohort Study of Associated Factors in Denmark, 1998-2011." *Journal of Clinical Oncology*, vol. 32, no. 34, 2014, pp. 3831–3839., doi:10.1200/jco.2013.54.0419. Accessed Apr. 2015.
- Theriot, Nancy M. "Negotiating Illness: Doctors, Patients, and Families in the Nineteenth Century." *Journal of the History of the Behavioral Sciences*, vol. 37, no. 4, 2001, pp. 349–368., doi:10.1002/jhbs.1065.
- "Women's Voices in Nineteenth-Century Medical Discourse: A Step toward Deconstructing Science." *Signs: Journal of Women in Culture and Society*, vol. 19, no. 1, 1993, pp.1–31., doi:10.1086/494860.
- "Think Before You Pink." *Breast Cancer Action*, [thinkbeforeyoupink.org/resources/before-you-buy/](http://thinkbeforeyoupink.org/resources/before-you-buy/). Accessed 14 Mar. 2017.
- "Topic: Is There Any Hope for Long Term Survival?" *Breast Cancer Topic: Is There Any*

*Hope for Long Term Survival?*,

community.breastcancer.org/forum/5/topics/796302. Accessed 14 Mar. 2017.

Ussher, Jane M. *Managing the Monstrous Feminine: Regulating the Reproductive Body*.  
Routledge, 2006.

Vega, B. Rodriguez, et al. "Mindfulness-Based Narrative Therapy for Depression in  
Cancer Patients." *Clinical Psychology & Psychotherapy*, vol. 21, no. 5, 2013, pp.  
411–419., doi:10.1002/cpp.1847.

Vernon, Lorraine. "Slant." Lifshitz, p. 34.

Williams, Garreth. "Responsibility." Internet Encyclopedia of Philosophy,  
www.iep.utm.edu/responsi/#SH2a. Accessed 14 Mar. 2017.

Williams, Terry Tempest. *Refuge: An Unnatural History of Family and Place*. Vintage,  
1992.

Winnow, Jackie. "The Politics of Cancer." Brownworth, pp. 20-29.

#### Works Consulted

Abrams, Lindsay. "Fracking Company Teams up with Susan G. Komen, Introduces Pink  
Drill Bits 'for the Cure.'" *Salon.com*, Oct. 2014, www.salon.com/2014/10/08/  
susan\_g\_komen\_teams\_up\_with\_fracking\_company\_introduces\_pink\_drill\_bits\_f  
or\_the\_cure/. Accessed 6 Mar. 2017.

Anniston, Jennifer, Dir. *Five*. Echo Films, 2011.

Avrahami, Einat. *The Invading Body: Reading Illness Autobiographies* University of  
Virginia, 2007.

- Bal, Mieke. *Narratology: Introduction to the Theory of Narrative*. University of Toronto, 1985.
- Barnett, Richard. *The Sick Rose, Or, Disease and the Art of Medical Illustration*. Thames & Hudson Ltd., 2014.
- Barr, Donald A. *Health Disparities in the United States: Social Class, Race, Ethnicity, and Health*. Johns Hopkins University Press, 2008.
- Bernstein, Steven, director. *Annie Parker*. Koch Media, 2015.
- “Breast Cancer Trends.” *Centers for Disease Control and Prevention*, 24 May 2016, [www.cdc.gov/cancer/breast/statistics/trends.htm](http://www.cdc.gov/cancer/breast/statistics/trends.htm). Accessed 14 Mar. 2017.
- Broyard, Anatole. *Intoxicated by My Illness: And Other Writings on Life and Death*. C. Potter, 1992.
- Campo, Rafael. *The Desire to Heal: A Doctor's Education in Empathy, Identity, and Poetry*. W.W. Norton, 1997.
- Charon, Rita. “Narrative Medicine: Form, Function, and Ethics.” *Annals of Internal Medicine*, vol. 134, no. 1, Feb. 2001, p. 83., doi:10.7326/0003-4819-134-1-200101020-00024.
- Charon, Rita, and Martha Montello. *Stories Matter: The Role of Narrative in Medical Ethics*. Routledge, 2002.
- Chertok, Karen M. *Teosinte*. Publish on Demand Global LLC, 2014.
- Eakins, Thomas. *The Agnew Clinic*. Oil on canvas. University of Pennsylvania, Philadelphia, 1889.

- Davies, Douglas James. *A Brief History of Death*. Blackwell Pub., 2005.
- DeShazer, Mary K. *Fractured Borders: Reading Women's Cancer Literature*. University of Michigan, 2005.
- Greenfield, Susan C., and Carol Barash. *Inventing Maternity: Politics, Science, and Literature, 1650-1865*. University of Kentucky, 1999.
- Jensen-Johansen, M. B., et al. "Effects of an Expressive Writing Intervention on Cancer-Related Distress in Danish Breast Cancer Survivors - Results from a Nationwide Randomized Clinical Trial." *Psycho-Oncology*, vol. 22, no. 7, 2012, pp. 1492–1500., doi:10.1002/pon.3193.
- King, Susan Deborah. *One-breasted Woman: Poems*. Holy Cow!, 2007.
- Kleinman, Arthur, Veena Das, and Margaret M. Lock. *Social Suffering*. University of California, 1997.
- Kawase, Eri, et al. "Estimation of Anxiety and Depression in Patients with Early Stage Breast Cancer Before and After Radiation Therapy." *Breast Cancer*, vol. 19, no. 2, Mar. 2010, pp. 147–152., doi: 0.1007/s12282-010-0220-y
- Mishler, Elliot George. *The Discourse of Medicine: Dialectics of Medical Interviews*. Ablex Pub., 1984.
- Parker, Anne. *Annie Parker Decoded: The Story That Inspired the Film*. Annie Parker Books, 2014.
- Porter, Roy. *Blood and Guts: A Short History of Medicine*. W.W. Norton, 2003.
- Potts, Laura. *Ideologies of Breast Cancer: Feminist Perspectives*. St. Martin's, 2000.

Price, Janet, and Margrit Shildrick. *Feminist Theory and the Body: A Reader* Routledge, 1999.

Rollins, Betty. *First, You Cry*. Lippincott, 1976.

Sargent, John Singer. *The Big Four*. The Alan Mason Chesney Medical Archives of The Johns Hopkins Medical Institutions, Baltimore, 1906.

Sontag, Susan. *Illness as Metaphor*. Farrar, Straus and Giroux, 1978.

Ussher, Jane M. *Women's Madness: Misogyny or Mental Illness?* University of Massachusetts, 1992.

Ussher, Jane M. *Body Talk: The Material and Discursive Regulation of Sexuality, Madness, and Reproduction*. Routledge, 1997.

Weise, Jillian Marie. *The Amputee's Guide to Sex*. Soft Skull, 2007

Woodward, Ashley. "Jean Francois Lyotard." Internet Encyclopedia of Philosophy. <http://www.iep.utm.edu/lyotard/>. Accessed Dec. 2014.

Zaner, Richard M. *Conversations on the Edge: Narratives of Ethics and Illness*. Georgetown UP, 2004.

## CURRICULUM VITAE

Jessica C. Hume

1280 Springdale Dr.

Louisville, KY 40213

(502) 552-2297

jhume@bellarmine.edu

### Education

**PhD in Interdisciplinary Humanities** (in progress), University of Louisville, Aug.,  
2013-present (anticipate completion in May, 2017)

Dissertation (in-progress): "Unthink Pink: Master Narratives and Counterstories of Breast Cancer"

Interest areas: Health humanities; history of anatomy/medicine; medicine and the body in literature; female bodies in culture, health, and health care; illness narratives, specifically those of breast cancer (mammographies); the history of medicine and anatomy in literature; and the body in fairy tales.

**MFA in Writing**, Spalding University, 2007

Concentration: Poetry

Extended Critical Essay: "Turning the Key: Changes Induced by Anne Sexton's *Transformations*"

Graduation Lecture: "Red-Winged Words: Adjectival Appositives in Greek Poetry"

Small Group Discussion: "The Eyes Have It: Symbolic Representation of the Eye in Anne Sexton's *Live or Die*"

Creative Thesis: *Burning Daylight*, A Collection of Poems

Interest areas: gender and the body in fairy tales, feminist revisions of fairy tales, Anne Sexton, Grimm's fairy tales

**BA in English**, Cum Laude, Bellarmine University, 2005

Minor: Theatre

Creative Writing Track

Undergraduate studies at the University of Cincinnati, College Conservatory of Music, 2000-2001

Major: Theatre Design and Production

Focus: Stage Management

Presentation Academy, College-prep, 2000

## **Skills & Qualifications**

- Experience as a published writer spanning thirteen years and several genres.
- Teaching experience spanning ten years and a wide variety of arenas from one-on-one work, to small groups, to a college setting (including study abroad).
- Excellent research skills.
- Proficiency in many arenas of verbal and written communications, including grammar, proofreading, public speaking, and composition skills.
- Familiarity with MLA and APA format.
- Basic reading proficiency in Spanish.
- Basic reading proficiency in French.
- Training, certification and two years of experience teaching GRE preparation workshops
- Training and two years experience in Lindamood-Bell cognitive learning programs for reading, spelling, and comprehension.
- Training and one year experience in administering, scoring, and analyzing educational assessments.
- Over thirteen years experience in an office environment.
- Computer skills: proficient with Microsoft Word, Outlook, Moodle, Powerpoint, Prezi, iMovie, Audacity, and the internet. Some experience with Excel.

## **Work History & Experience:**

\*Any gaps in work history were filled by temporary, non-field experience.

**English Instructor, Galileo Learning Community (GLC),** Bellarmine University,  
August 2012-Present

- Collaborate with partner teacher to create new English 101 curriculum designed for health sciences majors in the GC
- Teach three sections of English 101 (fall)
- Teach one section of Freshman Focus (a one-credit-hour, “introduction to college life” course for freshmen) (fall)
- Teach three sections of IDC 101 (an interdisciplinary, writing intensive general education course) (spring)
- Teach English 200: reading Literature as necessary  
Serve as academic advisor for freshmen
- Maintain office hours in the residence hall

- Collaborate with GC coordinator and partner teacher to plan and execute educational events and gatherings for students in the GLC

**Director of Writing & Parent Communications**, Bellarmine University, June 2009-July 2012

- Manage BU Writing center and 5-6 undergraduate employees
- Teach English 251, “Writing Center Theory and Practice”
- Teach English 101
- Write, compile, edit and distribute two parent e-newsletters monthly
- Write, compile, edit and distribute two printed parent newsletters per year
- Supervise newsletter video intern in monthly creation of video for parents of freshmen
- Create short videos for parents and students
- Assist in planning programming for parents including Parent Orientation, parent events for move-in day, a wine tasting, and Parents’ Homecoming Bash
- Write/maintain an academic advising blog for parents and contribute to BU Parent Programs facebook page
- Assist academic advisors in various other duties such as re-structuring/maintaining Blackboard pages for Freshman Focus classes, meeting with a “Refocus” group (students on academic probation)

**Lead Instructor/Assessment Specialist** Langsford Learning Center, Mar. 2007-June 2009

- Coordinated and administered several types of academic assessments related to phonemic awareness, comprehension, composition, and visual-motor skills.
- Scored tests, prepared all paperwork and research regarding client educational profile, and assisted in diagnosis and treatment plan.
- Wrote formal reports detailing assessment results and client profiles.
- Worked one-on-one and in small groups with students to teach basics of phonemic awareness, comprehension, and composition.
- Worked in conjunction with Learning Coordinator to assure tailor-made learning plans are executed for students.
- Participated in Leadership Team meetings and contribute to decisions and activities regarding direction and guidance of the company.
- Attended extended training sessions and continual training in order to master Lindamood-Bell reading, spelling, comprehension, and visual motor teaching programs.
- Managed general administrative responsibilities related to scheduling and coordinating client information.
- Taught small groups at an offsite location (Lincoln Elementary School) as part of a literacy program in coordination with the National Center for Family Literacy (fall of 2007).

**Adjunct Expository Writing Professor**, Bellarmine University, Aug. 2008-Dec.2008

- Created syllabus and lesson plans including homework and project assignments.
- Maintained grade book and other necessary paperwork.
- Planned lectures and conducted classes around course requirements outlined by the college.

\*

**Freelance Writer**, *First Draft* literary magazine (Montgomery, AL), Aug. 2007-Aug. 2008

- Generate ideas and receive book review assignments from editor.
- Read, annotate, and evaluate assigned books in preparation for reviewing them.
- Research, complete, and submit pieces to editor according to deadline.

\*

**Graduate Assistant**, Spalding University MFA office, June 2007-Nov. 2007

- Assisted administrators in preparation for student residencies.
- Independently conducted and organized major research projects for administrators.
- General office work.

\*

**Interim Secretary/ English Coordinator**, Bellarmine University, Academic Resource Center Nov. 2006-Dec. 2006

- Coordinated scheduling for faculty and staff of Academic Resource Center.
- Managed ordering supplies, purchasing and payroll.
- Proctored student examinations.
- Helped students improve academic papers and writing skills.
- Provided general assistance to the Dean of Academic Advising and Developmental Advisor.

\*

**Adjunct Composition Instructor**, Brown-Mackie College Aug. 2006-Sept. 2006 (one student term)

- Created syllabus and lesson plans including homework and project assignments.
- Maintained grade book and other necessary paperwork.
- Planned lectures and conducted classes around course requirements outlined by the college.

\*

**Freelance Writer**, *St. Matthews Voice-Tribune*, Mar. 2006-Mar. 2007

Generated story ideas and received regular assignments from managing editor.

Scheduled and conducted interviews.

Researched, completed, and submitted features pieces to editor according to deadline.

\*

## **Publications and Presentations**

### **Book Chapters**

Chapter proposal accepted for *Still There: Memoirs of Illness and Trauma*, edited by Fiona Giles Ph.D, University of Sydney

“Dining Room & Kitchen: Food-Related Spaces and Their Interfaces with the Female Body in Adichie's *Purple Hibiscus*,” which will appear in the peer-reviewed anthology, *A Companion to Chimamanda Ngozi Adichie*, from Boydell & Brewer Publishers in 2017

### **Paper Presentations**

“The Problematics of Hope: Hope as a Commodity in the Breast Cancer Awareness Movement,” International Health Humanities Symposium, 2017

“Thinking Pink: Problematic Cultural Representations of Breast Cancer in the United States” International health Humanities Conference in Seville, Spain 2016

“Depression as Vogue: *The Sorrows of Young Werther* as Illness Narrative,” Fashionable Diseases Conference, Newcastle, England, 2015

“Depression as Vogue: *The Sorrows of Young Werther* as Illness Narrative,” Postgraduate Medical Humanities Conference, Exeter, England, 2015

Presenter of “James Joyce’s ‘Aqueous Epiphanies,’” Louisville Conference on Literature and Culture Since 1900, 2014

“Penelope Panel” at the International Joyce Symposium, Utrecht, Amsterdam, 2014 (round table panelist)

### **Workshops**

“Poetry and Identity: How to Lead a Poetry Workshop for Those with Cancer,” at the International Health Humanities Conference in Seville, Spain, 2016

“Poetry and Identity: How to Lead a Poetry Workshop for Those with Cancer,” at the Emerging Diversities in Health Humanities Seminar at Hiram College, June 2016

## **Presentations**

“College Would Be Great if Not for Those Pesky Classes: Engaging 21<sup>st</sup> Century Students,” Student Success Conference at Bellarmine University, 2015  
“Face-to-Face: Co-Curricular Events in the Galileo Learning Community,” Student Success Conference at Bellarmine University, 2015  
“Copters, and Knights, and Hawks, Oh My!,” 2011 (co-presenter)  
“Using Developmental Information and Resources to Engage Parents without Stereotyping” at the Kentucky Academic Advising Association conference (KACADA), 2011 (co-presenter)  
“Successful Parent Programs-The Importance of an Institutional Philosophy And Interdivisional Partnerships,” at the Association of Higher Education Parent Programs Professionals (AHEPPP) conference, 2010 and the ACT Summit, 2010 (co-presenter)

## **Poems**

“Living in the Sideways House,” forthcoming in the Spring 2017 issue of the *Bellarmino Magazine*  
“Sonnet for My Mother's Garden,” Oct. 2006, *Today's Woman* magazine.

## **Articles**

“The Ringing Ear: Black Poets Lean South,” (book review) Nov. 2007, *First Draft* (literary magazine of the Alabama Writer's Forum).  
“Bleeding Blue: The Kentucky Anthology,” (book review), Oct. 2007, *First Draft*.  
“Test Tube Derby,” (reportage), May 2006, *St. Matthews Voice Tribune*.

## **Memberships & Associations**

International Health Humanities Network, 2016-present  
British Society for Literature and Science, 2015-present  
International James Joyce Society, 2013-2015  
Association of Higher Education Parent Programs Professionals, 2010-2011  
Association of Writing Programs Professionals (AWP) 2006-2009 & 2012-2013  
Kentucky Academic Advising Association, 2010-2011  
Kentuckiana Beekeepers Association, 2011

## **Service and Other Notable Achievements**

Graduate Dean's Citation, 2017  
Reviewer for Prize in Ethics essays, 2017

Moderator for Panel with Henrietta Lacks Family, January 2017  
Nominee for Phi Mu Appreciation Dinner 2016, 2017  
Faculty Sponsor for Narrative Health Club, 2015-present  
Director of Health Humanities Minor Committee, 2015-present  
Member of QEP Topic Committee, Spring 2016  
Member of “Inclusivity and Diversity” committee for white paper, a sub-committee of the QEP Topic Committee, Spring 2016  
Member of the CAP Assessment of Commuter Service Committee, Spring 2016  
Acting Director of First Year Writing, Fall 2015  
Guest speaker for Mercy Scholars program, Mercy Academy, Spring 2015, Fall 2016  
Faculty Mentor, 2014  
Spalding University MFA Homecoming Alumni Reading Committee, 2014  
Faculty Sponsor for Creative Writing Club, 2012-2015  
QEP grant for research project, “Living at a Little Distance from the Body: Medicine and the Body in Irish and British Literature,” 2013/14  
Community Engagement Committee, 2013  
Member of BU Writing Committee, 2011  
Member of BU Academic Integrity Task Force 2009-2011  
Member of the Merton Institute Programming Committee, 2011-2012  
Co-recipient of the “Most Creative Institutional Initiative” Award at AHEPPP conference, 2010  
First-round judge for the Thomas Merton Poetry of the Sacred Contest, 2008- 2009 & 2011-2014  
Guest speaker, Lexington Catholic High School, 2007 and 2008.  
Graduate Assistant for Spalding University MFA in Writing program, 2008.  
Guest speaker on Elvis Presley, Bellarmine University, 2006.  
Cum Laude graduate of Bellarmine University, 2006.