

# Thinking Through the Lens: Reframing Experiences of Breast Cancer

by

Taylor Elyse Cain  
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## INTRODUCTION

While each monocular vision, each touching with one sole hand has its own visible, its tactile, each is bound to every other vision, to every other touch; it is bound in such a way as to make up with them the experience of one sole body before one sole world, through a possibility for reversion, reconversion of its language into theirs, transfer and reversal...Now why would this generality, which constitutes the unity of my body, not open it to other bodies? The handshake too is reversible; I can feel myself touched as well and at the same time touching.<sup>1</sup>

(Merleau Ponty 1968: 142)

I encountered the opening quotation in the edited book, *Thinking Through the Skin*, which described itself as an addition to the ever growing feminist literature on lived and imagined embodiment. Initially I was intrigued by the title and its definition as: “a thinking that reflects, not on the body as the lost object of thought, but on inter-embodiment, on the mode of being-with and being-for, where one touches and is touched by others.”<sup>2</sup> All too often I had encountered the body and skin as synonymous, both as things to be read externally. Here, however, an alternative pathway seemed present, one that could expand the possibilities of embodiment. Understanding skin as a point of engagement to facilitate a different means of thinking about the ways we interact with and touch ourselves and others was an exciting prospect. The Merleau Ponty quotation explained how the experiences which make the body ‘my body’, mirror the experiences that expose ‘my body’ to ‘other bodies’. There exists a certain synchronization in touch and being touched, and seeing and being seen, meaning that ‘my body’ does not necessarily ‘belong to me’ but rather is opened up to others through every metaphorical touch of the skin.

Touching was not always as obvious as a handshake but can manifest in other forms as well, like that of photography. Through this artistic medium the camera and

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<sup>1</sup> Sara Ahmed, Jackie Stacey, *Thinking Through the Skin* (London: Routledge, 2001) 142.

<sup>2</sup> Sara Ahmed, Jackie Stacey, *Thinking Through the Skin* (London: Routledge, 2001) 1.

the photographer touch the thing captured in the lens and frame. This touching was just as meaningful and exposing as that of a handshake. My thoughts about how individuals engage with themselves and others led me to this project as I made the decision to explore the work of three artists who photograph and print their experiences with cancer. Thinking through the lenses is a mode of thinking that muses over the positioning of being both behind and in front of the camera, where one treats and is being treated by others. The selected artists were meant to serve as representations of a more critical breast cancer experience. Their photography and words were not meant as prescriptive but rather serve as indicators of the limitations inherent in the status of a breast cancer patient. In looking to the work of artists as patients I saw different ways of experiencing patienthood and perceptions of illness.

The artists: Jo Spence, Deena Metzger and Hannah Wilke, were all published as artists prior to their diagnosis of cancer. The time span of their careers and the historical period they were patients during were of particular importance. In conceiving this project, I wished to focus on artists who had produced work before they became ill because I envisioned there to be a difference and internal difficulty in coping with the transition from the total artistic control over the body in their early work and the vulnerability of being a treated patient in later work. I saw the chosen artists as offering insight and further possibilities into the experience of the breast cancer patient. The artists received their respective diagnoses during the 1980s, an era defined by changes in biomedicine and emerging patient activism. Out of the three artists, only one was a non-American, Spence, her experience showing the wide

reaching hold of the western medical model and perceptions of illness. My project firmly situated itself in the social climate of the late twentieth century United States.

To characterize the recommendation given to those undergoing treatment for breast cancer during this time frame I found it prudent and necessary to look toward Betty Ford and her notable declaration of: “Once it’s done, put it behind you and go on with your life.”<sup>3</sup> The 1970s was a time in which the United States was immersed in the tradition of “coming out” and “going public,” allowing celebrity figures like Betty Ford, Happy Rockefeller, and Shirley Temple Black to all speak publicly about their experiences with breast cancer and mastectomy. These once private and unspoken matters of the body and illness where all of a sudden permitted airtime outside of the home and plastered on newspapers and television screens. The immense publicity granted to these women was not spontaneous, but rather indicative of burgeoning feelings of discontent among breast cancer patients across the country. These patients long given the silent treatment by media and devoid of means to connect with other cancer patients during diagnosis and treatment, found America post-Vietnam ready to open the container of silence that had previously surrounded the disease and willing to address injustices both at home and abroad. While a vast array of breast cancer activism formed over the course of the late twentieth century, a general sentiment of widespread public reform proved a unifying goal.

Some efforts for change were more successful than others, which was substantially influenced by what Americans were willing to see and talk about. The stories that were broadcast and included in magazines and pamphlets shared

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<sup>3</sup> Barron, Lerner, *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth Century America* (New York: Oxford University Press 2001) 173.

overarching themes of adherence to physicians and familial support as the keys to ensuring a speedy and successful recovery. There appeared very little space for frank conversations about the scars of mastectomy or the impact of cancer on one's sex drive. Instead early biographies written by cancer patients focused on returning to a sense of normalcy and not dwelling on the experience post-treatment. The term "normalcy" referred to a pre-cancerous state and demanded a sweeping denial of the difficulties incurred during the cancer experience. A defining feature of the closet that successfully contained breast cancer and its many patients was authentically American-the philosophy of "pulling yourself up by your bootstraps" persevered even in considerations of cancer treatment.

To fully grasp the historical situation of this project I found it necessary to include a conversation about neoliberalism and the distinction between what has been considered individual versus shared. Breast cancer impacted both the individual body and society as a whole but has historically been portrayed as an individual experience. Through changes in biomedicine and the subsequent reactions by patients and physicians to procedures like the mastectomy, patient activism emerged that allowed for a community of breast cancer patients, connected by their collective experiences. For the purposes of my project I sought to depolarize the ideas of individual and shared, instead bringing them into conversation by delving into personal narratives of cancer while at the same time recognizing the functioning of medical and other public interventions. The organization of the chapters was influenced by the artists' relationship to the concepts of production and consumption, as the artists interacted with selling and distribution of knowledge regarding breast cancer, like the following:

For the person afflicted with cancer, its physical and psychological consequences are enormous and (if one is lucky enough to survive the disease) long-lasting. The disease is devastating for society as well. The costs include the loss of life, loss of economic productivity, increases in collective health care expenditures, and frustration in the long, valiant search for cures.<sup>4</sup>

In order to theorize the photographs and experiences of the chosen artists I turned to Michel Foucault and his genealogy of medical knowledge. I focused on the emergence of the clinic and the constantly changing relationships within clinical discourse. Through my reading of Foucault I discovered a framework to conceptualize illness as internalized within a person, which created the concept of an individual, a reality the artists fiercely resist:

...whereby the question: 'What is the matter with you?', with which the eighteenth century dialogue between doctor and patient began (a dialogue possessing its own grammar and style), was replaced by that other question: 'Where does it hurt?', in which we recognize the operation of the clinic and the principle of its entire discourse.<sup>5</sup>

For Foucault, the localization and distribution of illness existed in a state of flux, influenced by the understanding of the body held during the time period. Following the eighteenth century the doctor to patient relationship underwent a marked change. Whereas before the patient played a significant role in the process of diagnosis, the new expectation was that the doctor must look inside the body of the patient in order to determine accurate diagnosis. By defining the only permanent feature of medicine as its consistent inclination to change offered me a sense of hope as I sought to give

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<sup>4</sup> Maren Klawiter, *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (Minneapolis: University of Minnesota, 2008) 13.

<sup>5</sup> Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception* (New York: Pantheon Books, 1973) xviii.



indication of new trajectories for conceptualizing disease and experience portrayed through the work of the artists.

Initially I had intended to write the chapters from the perspective of the three artists. In the course of research and writing however, I found myself acting as a ventriloquist, a position I felt was counterproductive to my aims. The photography of the artists are meant as another mode of expression, a mode open and conducive to entertaining many different perspectives. As I engaged the artists with institutions of biomedicine and popular perceptions of illness and the female body I discovered that they allowed me to adopt a more critical eye towards medicine, the art itself and lastly my own beliefs. The intention of the project was not to see the world through the eyes of the artists but rather to acknowledge them as a particular perspective, from a unique vantage point of both existing behind and in front of the camera.

The first chapter, “Governing Patient Bodies: The Establishment of Individual Responsibility” described the artists as immersed in the realm of biomedicine, and tracked the movement of the patient in medical discourse during illness. The emergence of risk and patient responsibility had consequences for the artists’ subjectivity as patients. In Chapter Two: “Meanings of Metaphor and Fetish in Breast Cancer Discourse”, I drew upon cues from Susan Sontag’s *Illness as Metaphor* and questioned the fetishization of breasts in literature, specifically through the procedures of mastectomy and reconstructive surgery. Drawing upon a variety of definitions of “fetish,” for example the Marxian understanding as “...the process whereby material objects, which had certain characteristics imputed to them by the

fact of complex social relations, appeared as products of nature.”<sup>6</sup> the chapter looked to analyze the displacement of the breast cancer patient and their physical body through medical practices and popular perceptions of the breast. In the case of breast cancer, the breast and its connection to femininity acted as a “product of nature,” a socially constructed relationship that was portrayed as inherent. The third chapter developed out of themes of visibility and illness that surfaced in the preceding sections. Throughout the project I attempt to assess the social reflectivity of visual images and pose the questions of: ‘What is/is not allowed to be seen?’ and ‘What response does the visibility of the previously “invisible” illicit?’. Such questions were prompted by the text, *Researching the Visual: Images, Objects, Contexts, and Interactions in Social and Cultural Inquiry*, and authors, Philip Smith and Michael Emmison’s exploration of the factors which led to the transition from grand narratives to an emphasis on the visual. Grand narratives referred to the key stories of time: progress, reason, science and emancipation.<sup>7</sup> Such a mode of textually based expression gradually gave way to a more visual sensibility. The image based culture came as a more modern development and represented a significant aspect of social life. My reading of such literature on the visual influenced my understanding of representation both in relation to the artists and the breast cancer movement which is often envisioned a public rendering of cancer.

### The Artist as Patient

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<sup>6</sup> Jeffrey Weeks, *New Keywords: A Revised Vocabulary of Culture and Society*, ed. Tony Bennett, Lawrence Grossberg, Meaghan Morris (New York: Blackwell Publishing, 2005) 132.

<sup>7</sup> Michael Emmison, Philip Smith, *Researching the Visual: Images, Objects, Contexts and Interactions in Social and Cultural Inquiry* (London: Sage Publications, 2000) x.

Topless, braless, and shameless, Deena Metzger, Jo Spence and Hannah Wilke gave the public a new picture of cancer: their own pictures of cancer. In the photographs shown in the course of this project there are multiple points of inquiry ranging from the authority of biomedicine to the loss of agency. The subjects of the pieces however, prove the artist themselves. It felt important to note the intentionality behind these artists' images as they make the conscious decision to offer art that was both easily readable and open to vast interpretation, requiring no advanced degree or special training. Some of the themes located in their visual and written work reflect the subsections of the upcoming chapters. Because these photographs of the artists served as the inspiration for this research endeavor, I thought it fitting to begin most of the chapters with brief vignettes about the artists and their relationship to this scholarship. Following the vignettes of the introduction I begin by exploring the material and knowledge active in the biomedical sphere. As patients the artists discussed the imposition they felt by medical professionals, and I use such sentiments as a way to then look at the information taken in by patients as they navigate the biomedical system. From there I move to how the artists portrayed their physical experience as patients and how their bodies and identities changed as a result of their interactions with institutions of medicine.

Deena "Illness Heals the World" Metzger

Standing atop a hill, a woman is posed in the yoga position of warrior, topless. Hands extended, palms facing up, she displays perfect posture. Her right breast is absent. This image circulated widely across the United States. Plastered on refrigerators and mailed as postcards, it made the woman pictured, Deena Metzger, a

cultural icon and the photograph itself something of a cult object.<sup>8</sup> The photograph was taken as an illustration for her book, *Tree: Essays and Pieces*, which recounted her experience with cancer. Metzger's display was the first of its kind, one where both mastectomy and the patient were the focus. The reality of breast cancer from the physical pain experienced to its emotional toll on the individual, had long been suppressed, but with the click of the photograph on the hill, Metzger rebelled, exposing her breast cancer for the public to view. Her publishing company, however, refused to use the photograph in the book. Metzger made the decision to bypass the publishing company; she distributed the poster independently.<sup>9</sup>

In 1977 such a brazen display of mastectomy was unheard of, but reflected a burgeoning population of individuals and informal support communities who sought to bring cancer into everyday conversations. Metzger was not the only individual to make public her experience with cancer and express her dissatisfaction with the constraints on breast cancer discourse. When discussing the emergence of the genre of breast cancer narratives, many academics refer to Audre Lorde, a poet whose own bout with breast cancer spurred her to conceptualize mastectomy as a gendered stigma.<sup>10</sup> Lorde has long been considered the authority on feminist theory of breast cancer but has not often been engaged with when confronting visual images of illness. Lorde's realm of inquiry provides a strong foundation for insight into Metzger's defiant decision and I use her further theorize the artistic contributions of Metzger. Through her poster and writings, Metzger expresses the barrage of radiation and

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<sup>8</sup> Sarah Jain, "Cancer Butch" *Cultural Anthropology* 22 (4) 501-538.

<sup>9</sup> Elizabeth Van Schaick, *Palimpsest of Breast: Representations of Breast Cancer in the Work of Deena Metzger and Jo Spence*, <http://www.temple.edu/gradmag/volume1/schaick.htm> (Spring 1997)

<sup>10</sup> Sarah Jain, "Cancer Butch" *Cultural Anthropology* 22 (4) 501-538.

surgical procedures that characterize the breast cancer experience and indicated the impact such measures had on the relationship of the patient to her body.

### Hannah "Visual Prejudice" Wilke

The next artist presents herself as a femme fatale, a creature in her element as she poses topless, boldly displaying an arrangement of temporary tattoos, including a toy gun and a series of other war paraphernalia around her breast region, making no effort to cover herself up. Heavy makeup and flowing hair frame the face of Hannah Wilke, the woman who both shocked and awed the world with her use and depiction of the female body. Situated next to Wilke is an older woman, eyes downcast. She mirrors Wilke as an individual baring her chest, the only difference is the scarring over her absent left breast. Each woman pictured was subject to a particular type of gaze that read their bodies in different ways. Wilke's body was portrayed through the hegemonic male gaze, hyper-sexualized and clearly meant to entice and excite. Despite its similarity in showing off the female figure, the figure of Wilke's mother posed complications for the male gaze. Selma Butter's age, coupled with her removal of one breast and her thinning hair, failed to entice and instead caused the male gaze to read her as decrepit and ill. The external mapping and subsequent objectification of the female body came as a recurring theme in the work of Wilke. The previously described photograph called *Portrait of the Artist with her Mother, Selma Butter, 1978-81* debuted in 1978. The common consensus among many art critics was to focus on how Wilke's work spoke to the consumption of the female body in Western culture.<sup>11</sup> Upon surveying her whole portfolio of work, historians have subsequently

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<sup>11</sup> Thomas Kochheiser, *Hannah Wilke: A Retrospective* (Columbia: University of Missouri Press, 1989) 20.

identified her as either a narcissist, a feminist artist, or a combination of both. Her pieces, like the portrait with her mother and a later series titled *Intra Venus*, continued to engage with the themes identified by critics but also engaged with the theme of health, specifically the social construction of the healthy body.



Hannah Wilke, *So Help Me Hannah Series: Portrait of the Artist with her Mother, Selma Butter*, 1978-81. color photograph. 40 x 30 inches. Courtesy of Donald and Helen Goddard and Ronald Feldman Fine Arts, New York.

### Jo "How Do I Begin to Take Responsibility?" Spence

Noteworthy for both her visual images and witty commentary, Jo Spence explained her breast cancer treatment decisions by simply stating that they were, "in defiance of medical orthodoxy." The 1982 diagnosis found the photographer at the height of her artistic career. Instead of taking a reprieve from work, Spence brought her camera into the hospital and aimed it at herself and her doctors. Documenting her engagement with medical personnel and practices became a form of therapy for Spence, as if each photograph allowed her to regain a sense of self. To Spence,

entering the doors of the hospital meant succumbing to the medical machine and becoming subject to the production line of medical orthodoxy. While her surgeon recommended mastectomy followed by radiation, Spence declined opting instead for a lumpectomy accompanied by traditional Chinese medicine.<sup>12</sup> This rejection of the surgeon's advice was one way in which she demanded attention and emancipation from her physicians. As a patient Spence often found herself ignored and unrecognized as a being with volition. The challenge expressed in her decisions to pursue options outside of current medical practice and her use of the camera in the hospital setting were Spence's ways of engaging with: "the power of Western science and medicine to fragment lived experience, to reduce people to bodies, and to create passive patients".<sup>13</sup> What Spence sought was more medical accountability, more social responsibility, and more self-responsibility.

These are the artists and their complete stories. Their actual experiences however were fragmented, defined by particular points of engagement with their doctors, themselves, and their surrounding environment. I begin my inquiry with a broad look into the position of the patient in the biomedical system and posing an important question of: "How did the artists come to arrive in the office of a physician?"

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<sup>12</sup> Terry Dennet, "Jo Spence's Auto-therapeutic Survival Strategies", Jo Spence Memorial Archive UK, (2011).

<sup>13</sup> Susan Bell, "Artworks, collective experience, and claims for social justice: a case of women living with breast cancer," *Sociology of Health and Illness* 29:3 (2007) 366-.

## CHAPTER ONE

### Governing Patient Bodies: The Establishment of Individual Responsibility

The governing of female bodies within neoliberalism presents women with a range of impossible dilemmas that they are invited and urged to resolve through the adoption of a variety of self-care and body techniques. The self-made woman, rather than enacting choice and freedom is obliged to disavow any desires for emotional security and safety, and to experience these as the outcome of her own desire for personal authenticity and self development. (Lisa Blackman “It’s Down to You” in *Governing the Female Body* 36)

The shifts in self perception that came out of the artists’ movement from photographer to patient were analogous to the changes in perceptions of responsibility within the field of biomedicine. As individuals, the artists transgressed and questioned previously definitive boundaries such as that between doctor and patient, forming new relationships to the body.

#### Health, Risk and Prevention

A risk does not arise from the presence of particular precise danger embodied in a concrete individual or group. It is the effect of a combination of abstract factors which render more or less probable the occurrence of undesirable modes of behavior (Robert Castel, *Biomedicalization* 332).

Initially it felt irreconcilable to compare the earlier work of the three artists with their later work dealing with the subject of terminal illness. I found it almost inconceivable that such vibrant and healthy-looking women would soon be diagnosed with life threatening diseases. But as many medical professionals would insist, symptoms need not be visible themselves for a patient to be considered ill. The growing irrelevance of the symptom developed from the mounting influence of pharmaceutical agents and new conceptions of risk reduction.<sup>14</sup> A pivotal moment in the history of health risk was the Framingham Study of 1957, which represented an effort to gain greater insight into the “modern epidemic” of coronary heart disease.

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<sup>14</sup> Jeremy Greene, *Prescribing by Numbers: Drugs and the Definition of Disease* (Baltimore: The Johns Hopkins University Press, 2007) 4.



The concept of coronary risk factors was developed after tracking the cardiovascular history of a number of residents from a small Massachusetts city. These risk factors were: “physiological variants believed to be mechanistically connected to heart disease: hypertension (high blood pressure), hypercholesterolemia (high blood cholesterol), and, later, diabetes (uncontrolled elevation of blood sugar)”<sup>15</sup> were envisioned as deviations, which, if controlled, could manage the chronic disease. Though the researchers had been searching for a cause of the heart disease epidemic, the discovery of risk factors solved the prescription drug industry’s dilemma of limiting their potential market with “efficacious drugs.”<sup>16</sup> After the results of the study were publicized the relationship between public health and pharmaceutical companies was solidified in history.

Beginning in the twentieth century as the interest in the intangibility of symptoms gave way identifying risk and precursors of disease, medications were targeted to broader and broader groups of individuals. Instead of solely placing the focus on specific populations, determined by factors such as age and ethnicity, medicine adopted a more universal approach, erring towards the concept of the “problematization of the normal.”<sup>17</sup> With this approach all individuals were perpetually in a state of “becoming ill”<sup>18</sup> and this established health as a phase which one gradually moved towards. Everyone acquired the status of a potential patient who was subsequently judged according to varying degrees of risk, estimated as: low,

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<sup>15</sup> Jeremy Greene, *Prescribing by Numbers: Drugs and the Definition of Disease* (Baltimore: The Johns Hopkins University Press, 2007) 2.

<sup>16</sup> Jeremy Greene, *Prescribing by Numbers: Drugs and the Definition of Disease* (Baltimore: The Johns Hopkins University Press, 2007) 2.

<sup>17</sup> David Armstrong, “The Rise of Surveillance Medicine,” *Sociology of Health and Illness* 17 (June 1995): 393-404.

<sup>18</sup> Alan Peterson, *Risk, Governance, and the New Public Health*, ed. Alan Peterson, Richard Bunton (New York: Routledge, 1997), 190.

moderate, or, high: “Specifically, health becomes an individual goal, a social and moral responsibility, and a site for routine biomedical intervention.”<sup>19</sup> The degree of risk determined which prevention strategy an individual sought to stave off future illness potential:

There are three types of prevention: primary prevention to keep breast cancer from ever occurring (which is obviously the best prevention); secondary prevention, which seeks to detect the cancer as early as possible so as to ensure the best chance of survival (an example is mammography); and tertiary prevention, which is reducing the rate of recurrence and disability in the women who have breast cancer.<sup>20</sup>

With such a philosophy in place even before the moment of diagnosis, every individual was expected to assume the responsibility for the prevention of illness. Sociologist Maren Klawiter identified the evolution of healthy women into risky subjects as a result of what she termed, the “regime of biomedicalization,” characterized by the shift in the message of early detection from “Do Not Delay” to “Go in Search.”<sup>21</sup> The slogan “Do Not Delay” was the one of the original advertisement campaign strategies for mammography and the transition to “Go in Search” represented another period of shifting power dynamics. The activeness implicit in the latter phrase marked the opening of a new era that placed the onus of prevention on the individual who was automatically determined a “risky subject.” For breast cancer patients, the biomedicalization of risk became particularly salient.

Research abounds on risk factors that may serve as precursors to cancer and

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<sup>19</sup> Adele Clarke, Laura Mamo, Jennifer Fosket, Jennifer Fisher, Janet Shim, *Biomedicalization: Technoscience, Health, and Illness in the U.S.* (Durham: Duke University Press, 2010) 63.

<sup>20</sup> Roberta Altman, *Waking Up/Fighting Back: The Politics of Breast Cancer* (Boston: Little, Brown, and Company, 1996) 91.

<sup>21</sup> Maren Klawiter, *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (Minneapolis: University of Minnesota Press, 2008) 102.

with each new finding; further restrictions are placed on the patient's responsibility and decision making abilities. Coupled with such restrictions was the imposition of greater expectations of proper prevention and treatment tactics. The uncertainty of risk created an atmosphere of hyper vigilance, demanding individuals to be ever aware and on guard against disease. In many respects risk factors localized breast cancer within the body, a move that required engagement with the hospital setting and for patients to differentiate between their mind and cancer susceptible body parts. Such localization also limited the inquiry made into the environmental agents involved in breast cancer. I posit that the confinement of patients to a system so riddled with imbalances of power further placed restriction on the identity a patient was able to form and the decisions they are able to make.

### The Impressionable Patient

By means of his oracles, a Zande can discover the mystical forces which hang over a man and doom him in advance, and having discovered them he can counteract them or alter his plans to avoid the doom which awaits him in any particular venture. Hence a man's future health and happiness depend on future conditions that are already in existence and can be exposed by the oracles and altered. (E.E. Evans-Pritchard, 1937)

In the chapter, "It's Down To You": Psychology, Magazine Culture, and the Governing of Female Bodies", Lisa Blackman pinpoints an important shift in scholarship regarding the degree of influence popular media had over audiences. Magazines and other media were once considered powerful enough to dictate and control women's lives, but in the move from structuralism to culturalism, scholars began to credit audiences with the wherewithal to recognize and resist media influence. As a concept, structuralism assumes a top-down approach in the discourse on popular culture. It posits that mainstream television and films impose hegemonic

ideologies upon a defenseless and impressionable public. Culturalism, alternatively, denounces such a top down philosophy and instead portrays popular culture as a genuine representation of mass society. From such a vantage point, popular culture merely reflects the interests of the public. The transformation in question--the impact of magazines--was fueled by an American discourse of empowerment, a conversation that infiltrated other disciplines, including medicine. Just as the extent of media influence constantly changes, so too does frequent transition present itself in the genealogy of medical knowledge:

Not only the names of diseases, not only the grouping of systems were not the same; but the fundamental perceptual codes that were applied to patients' bodies, the field of objects to which observation addressed itself, the surfaces and depths traversed by the doctor's gaze, the whole system of orientation of this gaze also varied.<sup>22</sup>

As further evidence of the movement that takes place within medicine, Michel Foucault called into question the assumed stability of the unhealthy body and medical practices by tracing their invention. As he documented the development of hospitals and theorized the origins of present understandings of the body, he showed how the medical gaze had changed, specifically how what was seen and known had evolved. Shifts like those identified by Blackman and Foucault were neither wholly good nor bad. They created dilemmas and contradictions that complicated the agency of audience members but also made new identities possible through the discovery and creation that could only come with change. With every acquisition of power the audience gains the opportunity for greater expression distinct from the rhetoric provided by popular media or, in the case of Foucault, biomedicine. The artists used

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<sup>22</sup> Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception*, (New York: Pantheon Books, 1973) 54.

in this project contest the authority yielded by these institutions and indicate alternative routes for others to pursue.

The networks and peoples experience of power--exerting and resisting--are the focus of this chapter as I explore the development of authority and argue that the wielding of knowledge and expertise as it exists in biomedicine is never stagnant. I am particularly interested in the inequities of power between doctor and patient and I question the claims of progress in regard to the relationship of the treated patient and the stethoscope yielding physician in medical and popular literature during the mid-to-late twentieth century. Has the development of biomedicine allowed for as much personal change as discourses suggests and are decisions that diverge from the western model of medicine truly supported? Each era in the history of medicine has opened up certain possibilities for patients. While the possibilities are varied, all have taken place within the dominant regime of the given time period, in the case of this project, the regime of biomedicalization. Patients often experience the restrictions imposed by that model are often stifling, inhibiting true freedom and identity creation for some patients. From the prevention, diagnosis and treatment of breast cancer, all are moments of the artists' experiences and prove other arenas in a constant state of transition. Their stories in conversation with literature on biomedicine show that with each passing day authority transfers from doctors to patients to the state, in a seemingly never-ending game of hot potato. The artists accepted the task of navigating the intricacies of the shifts that take place in the realm of biomedicine, documenting the exclusion they felt when their perspective as a patient was lost.

Homogenizing Patients through Risk

The volumes of advice circulated by everyone--from medical professionals to women's magazines to television shows--has resulted in a literature of prevention against breast cancer that ranges in scope, though the locus of research remained on what biomedical authorities deemed rational. For example, discussion on the hormonal hazards associated with breast cancer was heavily undertaken in the 1970s and yielded inconclusive results. Since doctors were only able to speak in terms of likelihood such research continued and led to a statement made by Lynn Rosenberg from the Boston University School of Medicine in 1993. She concisely addressed the preponderance of literature regarding breast cancer risk factors while suggesting that fruitful contributions to breast cancer research are to be found elsewhere: "If a woman wanted to conduct her entire life so as to reduce her risk for breast cancer, she could have ten to fifteen kids and breast feed continuously from age seventeen on. But that's clearly not a good solution."<sup>23</sup> Such cautioning by Rosenberg was apt as research findings have shown that even the most widely agreed upon risk factors for invasive breast cancer---low or late childbearing, early onset of menstruation, consumption of alcohol, postmenopausal obesity, use of hormone replacement therapy, ductal carcinoma in situ, lobular carcinoma in situ, exposure to ionizing radiation, and intrauterine exposure to diethylstilbestrol, have limited predictive value and are present in women without breast cancer.<sup>24</sup>

Up until the middle of the twentieth century chronic disease such as breast cancer was conceptualized in degenerative terms. A diagnosis of cancer was seen as the body beginning its inevitable breakdown, a belief that remained securely in place

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<sup>23</sup> Judy Foreman. "The Cancer Risk in Delayed Pregnancy." *Boston Globe*. 9/27/93.

<sup>24</sup> Maren Klawiter, *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (Minneapolis: University of Minnesota Press, 2008) 2.

entering the 1920s and the decline of infectious disease mortality. With the success in reduced deaths from infectious disease, the spotlight of the country shifted to more chronic disorders. Researchers began to apply infectious disease epidemiology to chronic diseases, a move which resulted in preventative understandings of chronic disease and the development of risk.<sup>25</sup> Such news and emphasis on active research, treatment and prevention was alive and well leading up to the early 1970s, when mammography reigned supreme. In 1972 the Breast Cancer Detection Demonstration Project (BCDDP), sponsored by the American Cancer Society, went into effect as an effort to screen thousands of women for what were then believed to be curable breast cancers.<sup>26</sup> From then until the early 1980s physicians referred to and many patients unquestionably adhered to the knowledge of radiologists before determining whether or not to recommend further treatment for breast cancer.

### Screening for Risk and Responsibility

The introduction of mammography screening into breast cancer discourse had immediate ramifications for a variety of populations. The most obvious group was the patients themselves, as the procedure offered a chance for earlier engagement with the biomedical system in the treatment of breast cancer. The term ‘patients’ was loosely applied as diagnosis of illness had not yet been determined for those undergoing mammography. Another population impacted by the application of mammography was that of the physicians and other medical personnel. The tool

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<sup>25</sup> Jeremy Greene, *Prescribing by Numbers: Drugs and the Definition of Disease* (Baltimore: The Johns Hopkins University Press, 2007) 5.

<sup>26</sup> Anne Kasper and Susan Ferguson, *Breast Cancer: Society Shapes an Epidemic* (New York: St. Martin's Press, 2000) 34.

reified what Foucault designated the external space of the clinic and the internal space of the body. The very nature of the mammogram permitted doctors to determine the localization of the disease, a task completed in a clinical environment by looking into the body. In the act of looking into the body, physicians were able to create a distinction between the patient and the potentially cancerous body, the latter receiving greater attention. During the procedure of mammography the breast was flattened in parallel plates. The compression process reduced the thickness of the tissue and allowed the x-rays to properly penetrate the area. The machine usually only required the operation of one medical professional, making the ratio of the room an even one to one balance of biomedical authority to patient. However, as Foucault would argue, while the clinic, or doctor's office in the previous case, was the setting where physicians and patients met, their authority in the space was unbalanced. Doctors were assigned the responsibility of pinpointing disease based on their reading of the patient's body and were additionally faced with the reality that an incorrect assessment could mean the difference between wellness and death. The type of relationship supported by such a setting left the patient as an objectified being, reduced to a body instead of the subject of their own illness experience:

In order to determine the space of disease, to precisely locate the 'pathological fact' within the patient's body, 'the doctor must abstract' the patient. 'Paradoxically, in relation to that which he is suffering from,' Foucault notes, 'the patient is only an external fact; the medical reading must take him into account only to place him in parentheses'.<sup>27</sup>

The abstraction of the patient called for by the process of determining disease was often overshadowed by the excitement that surrounded new technologies.

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<sup>27</sup> Lisa Diedrich, *Treatments: Language, Politics, and the Culture of Illness* (Minneapolis: University of Minnesota Press, 2007) 5.



Mammography was celebrated as a means of preventing breast cancer and a way of rendering the invisible disease visible. Prior to the 1970s the country had seen little in the way of progress in the detection and control of breast cancer. The disease still remained the leading cause of death for women aged forty to forty-four and the only hope stemmed from research that indicated survival rates for American women with breast cancer were improving.<sup>28</sup> The statisticians who compiled the data, Sidney Cutler and Roger Connelly, credited such success to the early detection of breast cancers at more curable, less advanced stages. The American Cancer Society, which had long praised the benefits of early detection, openly welcomed these findings and used them to increase the scope of the BCDDP. Arthur Holleb, the Senior Vice President for Medical Affairs and Research of the American Cancer Society, set a goal of enrolling 270,000 women, ages thirty-five to seventy-four in a program that would allow participants to undergo free annual testing for five years.<sup>29</sup> With such a push by the American Cancer Society, the availability of early-detection technologies became widespread and cast blame on women who failed to take advantage of the available resources. Mammography had the support of researchers and physicians alike, a fact that made the decision to forgo early detection appear foolhardy.

Jo Spence personally experienced the blame imposed by medical professionals towards those who opted out of traditional early detection practices. In the United Kingdom Spence underwent a mammogram as her doctor recommended, but her commitment to photographing the experience was her way of challenging

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<sup>28</sup> Barron Lerner, *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth Century America* (Oxford: Oxford University Press, 2001) 202.

<sup>29</sup> Barron Lerner, *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth-Century America* (Oxford: Oxford University Press, 2001) 206.

medical authority and reframing her body which had been fragmented during the procedure:

Passing through the hands of the medical orthodoxy can be terrifying when you have breast cancer. I determined to document for myself what was happening to me. Not to be merely the object of their medical discourse but to be the active subject of my own investigation. Here whilst a mammogram is being done I have persuaded the radiographer to take a picture for me. She was rather unhappy about it, but felt it was preferable to my holding the camera out at arm's length and doing a self portrait.

In the photograph Spence stands with her breast wedged between mammogram plates, a position that was assumed countless times over the course of the 1970s in the United States as the American Cancer Society attempted to reach its breast cancer screening goal. Each new patient enrolled into the program helped to fill some quota, including age, ethnicity, and socioeconomic status, and subsequently became an object whose primary purpose was to prove the efficacy of mammography and uphold its glorified position within breast cancer discourse. My intention at this juncture is not to condemn the practice or invention of mammography as I very much believe in its purpose to save lives. The dissatisfaction comes from the blanket prescription of mammography and the potential harm of exposing individuals to radiation during the procedure. The vice grip of the mammography plates seemed to maintain a firm hold on the public, but the work of Spence spoke to its deficiencies and its consequences of use for patients and their sense of agency.



Mammogram,' Spence, J. (1988). Page 153 *Putting myself in the picture: A political, personal and photographic autobiography*. Seattle, WA: The Real Comet Press. Courtesy of Terry Dennett

The perceived infallibility of the mammogram which Spence had problematized in her photography was not a new phenomenon, the practice came under suspicion in 1976 and even today remains a point of controversy. In December of 2001, the *Lancet*, one of the world's leading medical journals, published a meta-analysis of clinical trials that sparked a media frenzy over the benefits of mammographic screening. The results of the study found: "...no convincing evidence that mammographic screening reduced the risk of dying from breast cancer for any age group of women."<sup>30</sup> The longstanding debate around mammography clearly manifested in an article "Mammography: A Contrary View" which appeared in the *Annals of Internal Medicine* of January 1976 and greatly damaged the reputation of

<sup>30</sup> Maren Klawiter, *The Biopolitics of Breast Cancer* (Minneapolis: University of Minnesota Press, 2008) 259.

the mammography. The author of the piece, John Bailar, identified two major issues with the BCDDP and other cancer projects. According to Bailar, the benefits of routine mammography for reducing breast cancer mortality rates were inconclusive and the risks of radiation during the screening process were underestimated, particularly for women under fifty. Bailar also suggested that the problems he discovered continued to exist because of biases inherent in the screening programs, biases that allowed doctors to assume authority in the lives of the patients participating in the program. Though their approaches were dissimilar, Spence and Bailar were both able to acknowledge the drawbacks of the philosophy behind early screening.

### Visualizing Risk

The science of mammography comes as one of the more recent additions to the field of medical imaging. The image based culture mentioned earlier found a place in medicine as well, making the idea of visibility another point of inquiry. The technology of mammography afforded doctors the ability to visualize breast cancers before they became palpable. The reading and analysis of mammography was a professional skill, meaning only doctors and certified technicians could share the meaning of the image with patients. Medical imaging thus fostered a unidirectional relationship between doctors and patients, raising questions of who could determine what was considered fact. In the case of mammography I wondered whether it was the machine itself that determined breast cancer diagnosis or if diagnosis only came after a viewing of the image by a professional. Scholar, Steven Shapin's, historical analysis of consensus within the scientific community through the invention of the air

pump offered a way to contextualize and think about the relationship between doctor and patient initiated by improvements in medical imaging:

In the system of physical knowledge the fact was the item about which one could have the highest degree of probabilistic assurance: “moral certainty.” A crucial boundary was constructed around the domain of the factual, separating matters of fact from items that might be otherwise and about which absolute, permanent, and even moral certainty should not be expected.<sup>31</sup>

The mammography and other imaging instruments produced visual evidence that physicians wished to characterize as matters of fact. Whereas the air pump invention demanded the “multiplication of witnessing experience,” medical imaging remained a domain founded in meaning making by a single professional.

This expansion of the doctor’s sight was indicative of a desire to render disease visible, a move which began with the other technologies like that of the X-ray. The medical X-ray was happened upon in November 8, 1895 by Wilhelm Roentgen as he worked on his cathode ray generator and ushered in an era of interest into what existed inside the body. Many would argue that the X-ray marked the start of a revolution that forever altered the landscape of diagnostic medicine. The original X-ray was born out of advances in chemistry, physics, and photography. Initially its gaze was severely limited, only capable of illuminating bones and foreign objects inside the human body. In the years following, the X-ray was refined and further discoveries were made, contributions which allowed generations of people to become accustomed to viewing their insides as snapshots or moving images on a doctor’s screen:

Things that had been opaque, like skin, were now transparent, and what had been hidden could now be known. What had seemed a surface disappeared,

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<sup>31</sup> Steven Shapin, Simon Schaffer, *Leviathan and the Air-Pump: Hobbes, Boyle, and the Experimental Life* (Princeton: Princeton University Press, 1985) 24.

and volume stood out as a mist of overlapping layers. The black and white images of the early X-rays simplified interior spaces that, until then, had been seen mostly by surgeons--bloody, messy, and confused with a multiplicity of colors and textures, the reality of the X-rayed body was redefined as a receding series of gray-toned planes.<sup>32</sup>

The X-ray symbolized great progress, shifting moral and social boundaries regarding privacy. However it also came with many a catch, most of which had to do with its readability. The X-ray and subsequent devices of medical imaging, all produced visual products that had meaning and value only after being read by a specific type of medical professional. In the case of mammography a patient could view the results of the screening but the image itself would hold little to no meaning in the biomedical system until seen by a radiologist. The deference to a medical expert removed the patient from the process of diagnosis, as breast cancer could only be properly verified through the professional assessment of medical images. The limited readability of medical imaging differs greatly from the accessibility of images produced by artists like those used in this project. In publicly showing their personal experience with illness the artists meant their photographs to serve as topics of discussion, widely observed and interpreted by the general public. Unlike technologies of mammography and X-ray, where significance can be offered only through the mouth of the doctor, the photographs of the artists allow for meaning and understanding to vary from individual to individual and thus facilitate more inclusive and holistic dialogue.

### Production and Distribution of Biomedical Knowledge

A downstream approach to solving health problems means that interventions focus on the afflicted individual without awareness of and attention to the upstream causes and contexts of the afflictions. Such an approach potentially shifts attention away from efforts at identifying and eliminating the elements that put women at risk in the first place. (Jennifer Fosket, *Biomedicalization: Technoscience, Health and Illness in the U.S.* 349.)

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<sup>32</sup> Bettyann Kevles, *Naked to the Bone: Medical Imaging in the Twentieth Century* (New Brunswick: Rutgers University Press, 1997) 2.

As the reign of mammography was threatened the expectation was that patients would continue to follow the recommendations of their physicians. The limitations of early detection screening were finally brought up for discussion after Bailar's article, but even with the controversy the practice of early screening continued. The American Cancer Society amended some of its practices, rewriting the consent form for the BCDDP to include the possible risks of mammography and ending "routine" mammography on women under fifty unless they were identified as "high risk."<sup>33</sup> This term however was broadly defined and the conviction of Philip Strax, a researcher on the first randomized trial of mammography, remained entrenched in cancer discourse, "Women who declined to be screened were thus playing Russian roulette with their lives."<sup>34</sup> In breast cancer etiology certain anomalies persisted, including: the preemptive acceptance of the mammography, the adherence to technology despite its faultiness and the use of tools that could potentially increase the chances of breast cancer. That the very treatment that could cure cancer could also harm the body seemed an inevitability that patients were expected to accept. Barbara Ehrenreich happened upon that realization in her book, *Bright Sided: How the Relentless Promotion of Positive Thinking Has Undermined America*.

But I could tell from a few hours of investigation that the career of a breast cancer patient had been pretty well mapped out in advance: you may get to negotiate the choice between lumpectomy and mastectomy, but lumpectomy is commonly followed by weeks of radiation, and in either case if the lymph nodes turn out, upon dissection, to be invaded or "involved", as it's less

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<sup>33</sup> Barron Lerner, *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth Century America* (Oxford: Oxford University Press, 2001) 215.

<sup>34</sup> Barron Lerner, *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth Century America* (Oxford: Oxford University Press, 2001) 217.

threateningly put--you're doomed to months of chemotherapy, an intervention that is on par with using a sledge hammer to swat mosquitoes.<sup>35</sup>

The rigidity of the breast cancer experience, particularly the clear distinction made between the mind and body, clearly comes across through Ehrenreich's narration of her personal tale. In *Bright Sided* the prescription of harsh treatment found in the biomedical system proves a recurrent theme. As Ehrenreich engages in a critique of the construction of the proper receptivity of patients and the judgment of medical professionals and their guidelines, I was again reminded of Lisa Blackman and wondered whether her understanding of influence would situate breast cancer patients in the space of culturalism or structuralism. It seemed that Ehrenreich was advocating for the medical system to reflect the desire of patients to be more greatly engaged in their own treatment. However, it appeared that the western medical model privileged the knowledge of physicians as opposed to true collaboration between experts and lay people.

The dominant discourse of risk and prevention in breast cancer research has further aided in the power imbalance between patients and medical experts. Throughout the twentieth century, cancer prevention efforts made a mission out of educating women about symptoms of cancer, utilizing rhetoric of early detection and response. Initially emphasizing primary prevention, biomedical experts soon realized that secondary prevention, "the reduction of mortality via the detection of cancer in its earliest and most treatable manifestations"<sup>36</sup> was more plausible. The construction

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<sup>35</sup> Barbara Ehrenreich, *Bright-Sided: How the Relentless Promotion of Positive Thinking has Undermined America* (New York: Metropolitan Books, 2009) 19.

<sup>36</sup> Adele Clarke, Laura Mamo, Jennifer Fosket, Jennifer Fishman, Janet Shim, *Biomedicalization: Technoscience, Health and Illness in the U.S.* (Durham: Duke University Press, 2010) 335.



of cancer as a “curable” disease that emerged in the mid-1940s with the renaming of the American Society for the Control of Cancer to the American Cancer Society, also enabled the construction of an ideal breast cancer patient. The ideal patient was an important creation that originated from the “longstanding theory that breast cancer began as a tiny focus that grew locally in a predictable and gradual manner before spreading.”<sup>37</sup> Dominate discourse used themes of responsibility and proper adherence to treatment to emphasize the creation of a character who succumbed to such recommendations. Drawing from information provided by medical professionals it is possible to use their own words to craft this model patient. She would be heterosexual by default, participating in live birth at an early age. While much of the research surrounding the risk factors for breast cancer is controversial, the increased risk attached to oral contraceptives has significant impact on the characteristics of the ideal patient and is inadvertently reflective of medicine as a male privileged domain: “Since there is an undefined risk for women taking oral contraceptives, why hasn't more been done to develop a male contraceptive?”<sup>38</sup> The uncertainty of that particular risk alone serves as sufficient cause for the model patient to reconsider the prolonged use of such medication. The ideal patient would also have adequate access to resources that enable a healthy lifestyle and diet, and have the familial connections that permit the dissemination of knowledge regarding family history. Daily exercise and health insurance would be givens, and regular doctor visits a commonality. This ideal patient however, would not see the doctor as responsible for preventing breast

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<sup>37</sup> Barron Lerner, *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth Century America* (Oxford: Oxford University Press, 2001) 74.

<sup>38</sup> Women’s Environment and Development Organization (WEDO) Public Hearing of the Commission on the Status of Women. City Hall, New York City, 3/2/93.

cancer, instead responsibility would be internalized. The expectations imposed on the model patient, a model that all patients are expected to aspire to, makes major assumptions about the resources of individuals and the importance of health care and risk factors:

Dr. Susan Love says, “It’s not that you have a one hundred percent or even fifty percent risk of getting breast cancer. A lot of these risk factors are statistical. They increase your risk a little bit, but it’s not that much and the majority of women who have risk factors do not get breast cancer. The greater number of first degree relatives who have had breast cancer, the greater the risk. If the mother is diagnosed before menopause, the risk is greater than if she were diagnosed post menopausally.”<sup>39</sup>

Numbers have become increasingly important to the biomedical system as epidemiological studies of risk reduction have given way to the formation of risk reducing therapeutics. This emphasis partially came from the insurance industry, a sector which crafted physiology in terms of risk to better assess broad population-based policies in quantifiable terms. The treatment of an individual patient was not the focus of the insurance industry, a trend which filtered into research on chronic disease like breast cancer, through the adoption of population based mortality study, periodic health examinations and annual physical examination. Research of populations became ubiquitous, overshadowing the experience of the singular patient.

As Ehrenreich, shows certain paths are open to patients but the actual trajectory of those courses is severely limited. In many of the historical narratives written by breast cancer patients the late 1970s are portrayed as an era of dethronement for physicians. The negative publicity of mammography in 1976

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<sup>39</sup> Roberta Altman, *Waking Up/Fighting Back: The Politics of Breast Cancer* (Boston: Little, Brown and Company, 1996) 44.

seemingly proved that medical professionals no longer had the ability to determine whether the benefits of screening surpassed the risks. Regardless of the available scientific evidence casting doubt on early detection, the mammography continued as a method sought by both patients and physicians alike. While the weight of the doctor's recommendation may have lessened, early screening seemed consistent with American notions of risk aversion and individual responsibility for disease prevention.<sup>40</sup>

The subtle transition of healthy women to “risky subjects,” almost mirrored the shift in responsibility from doctor to patient that came about during the campaigns for early detection. Though the intent was to establish definitive categories, for example that between healthy subject and risky subject, the initial identity remained an important facet of the new one. Breast cancer risk campaigns instructed their audiences to assume practices to ward off disease by remembering to make “healthy choices.” Such a tactic was successful in its broad reach because it implied the existence of healthy individuals who were not at risk for developing cancer.<sup>41</sup> All those placed into the category of “risky subjects” were then expected to adhere to the recommendations of doctors, absorbing the rhetoric of risk factors and their adverse relationship to health and wellness.

The meaning and maintenance of health are subjects of particular interest to Deena Metzger and her piece, *Thinking About Healing*. In general her work provides a much needed contrast to the category of “risky subjects” that is found in biomedical

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<sup>40</sup> Barron Lerner, *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth Century America* (Oxford: Oxford University Press, 2001) 246.

<sup>41</sup> Laury Oaks, *The Politics of Health Risk Warnings: Social Movements and Controversy over the Link between Abortion and Breast Cancer*, ed. Barbara Harthorn, Laury Oaks (Westport: Praeger Publishers, 2003) 81.

discourse. Metzger places emphasis on the social and physical climate of the world, suggesting that the causes of cancer and other diseases can be traced to the environment society has created. Metzger took a divergent path from the existing biomedical discourse on breast cancer. The blame that follows “risky subjects” is decidedly absent from Metzger’s writing; instead she enlists all individuals to take part in healing the world:

After I write this, I realize that we are taking responsibility for the understanding of health and of illness as we are taking responsibility for our own lives. We were wrestling such concerns from the hegemony that western medicine had presumed until then. As the questions we were asking then seemed like personal questions, we could not quite see what the social, political, and cultural consequences of asking such questions might turn out to be. Though many of the women who gathered were professional women and many also involved in the healing arts, being a professional was not a criterion for taking responsibility for one’s life and the lives of those around one.<sup>42</sup>

Metzger argued that the hegemony of Western medicine placed severe restrictions on what patients were able to take in and understand about their illness and its treatment. Such limitations were dangerous because they prevented patients from being able to hold any meaningful responsibility for their own bodies. The responsibility Metzger speaks to is distinct from the responsibility that developed out of the rhetoric asserting the importance of risk factors, as Metzger intends for patients to be conscious of the many facets of responsibility that extend into the social and environmental realms.

### Transformations of Bodies and Identities

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (Susan Sontag *Illness as Metaphor*) *Fractured Borders* 11

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<sup>42</sup> Deena Metzger, *Tree: Essays and Pieces* (Berkeley: North Atlantic Books, 1997)

Thus far I have focused predominantly on the external mapping of responsibility and risk onto the bodies and minds of breast cancer patients. In this section I make the conscious move to the experience of patients' physical bodies as they respond to shifts in responsibility. The term "patients" is not meant to be totalizing as I recognize the impossible and ultimately unproductive task of speaking for all who identify by such a term. In the context of this project the artist-patients of Wilke, Spence, and Metzger as well as the characters from illness narratives written in the late twentieth century serve as participants and critiques of the breast cancer experience offered through the terms of biomedicine. As I engage with the photographs of the artists I acknowledge and embrace my own bias in their interpretation. As artistic works they lend themselves to variation in thought and processing, a noteworthy distinction from the rigidity and standardization of the artists treatment in biomedical spaces. With such thoughts in mind it is here that I assess the extent to which the relationship between patient and doctor has been changed and shaped since the end of the regime of medicalization. As the individuals in question engage in treatment and navigate the biomedical system, they seem to discover that patients are still very much objects, that their bodies and minds are subject to prodding, critique, and blame. The artists can be read as engaging in a fight for autonomy, seeking to become the subjects of their art as well as the subjects of their illness.

Over the years the biomedical system has changed drastically in some respects and remained eerily similar in others. One site of change involves the patient. With the demise of the reign of physicians, patients were expected to adopt a more active

role, engaging in discussions about treatment options and the meaning of illness. Where the doctor once ruled as the supreme authority, the rhetoric of self-help has infiltrated the institution of medicine, supposedly redistributing power by knighting patients as responsible for their own health outcomes. The move towards making patients responsible remains in keeping with a system that has historically privileged cellular, hormonal, and genetic causes over environmental influences.

Prior to the emergence of breast cancer activism in the United States during the 1970s and subsequent interest in the feelings of patients, the relationship of patient to doctor was best characterized as one-sided. Many patients viewed their physicians as saviors and all-knowing, rarely thinking to question their judgment or recommendations. An example of such reverence for medical professionals comes in the form of George Pack, Chief of the Gastric Service at Memorial Sloan Kettering Cancer Center in 1931. Pack was once world renown for his radical surgical techniques in the treatment of breast cancer. Though such techniques were eventually denounced as unnecessary, providing no additional benefits over less invasive surgery, and overly traumatizing to the body, his procedures were performed on hundreds of patients including Eva Peron.<sup>43</sup> Pack's surgical accomplishments were celebrated in a rhyme written by his colleagues to the tune of a popular song of the time "Mack the Knife":

In the morning  
In the O.R.  
Comes a surgeon  
Big as life.  
And they tell me  
He needs no urgin

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<sup>43</sup> Barron Lerner, *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth Century America* (Oxford: Oxford University Press, 2001) 72.

For they call him  
Pack the knife.<sup>44</sup>

The growth of hospitals like Memorial and the standardization of medical education in the early twentieth century made the practice of radical surgery ubiquitous among surgeons practicing in the same time as Pack and in the following years. The hegemony of radical surgery lasted well into the 1970s and old school surgeons continued such operations into the 1980s.<sup>45</sup> The rhyme is recited from the perspective of the patient, describing the surgeon as the subject of the piece and omitting any acknowledgement of the patient's sentiments. In reality such a balance was not far off. While the patient was decidedly human, defined in terms of her mortality, the doctor remained a specter who appeared during the initial stage of diagnosis only to disappear with the patient's breast should the prognosis prove positive. The objectification of patients often proved the point of intervention for feminist activists who were concerned with the rights and needs of those undergoing treatment for breast cancer.

In the narratives of Rose Kushner and Audre Lorde, the recurring theme of patient disembodiment is painfully evident. Kushner and Lorde launched a movement against the biomedical model as they took their personal stories of breast cancer and claimed that the patient's perspective was valuable and legitimate. In one of Kushner's books, *Breast Cancer: A Personal History and Investigative Report*, she challenges the privilege inherent in the position of the medical professional, a privilege that allowed for the removal of body parts and the commencement of

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<sup>44</sup> Barron Lerner, *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth Century America* (Oxford: Oxford University Press, 2001) 73.

<sup>45</sup> Maren Klawiter, *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (Minneapolis: University of Minnesota Press, 2008) 64.

treatment without prior consent of the patient. Her aim was to use her personal experience to educate women about their bodies and the medical system that attempted to dictate the treatment of all patients. In the model of exchange that Kushner described, the doctor determined both what the patient wanted and subsequently received. More than merely a passive recipient, the patient became reduced to the status of an object that was treated and observed. Moving the patient, the silent object, and breast cancer itself, the silenced subject, into public debates and discourse was a daunting task during the 1970s but Kushner's political activism and commitment created a space for women's agency. She advocated for a two-step biopsy and surgery and also denounced the Halsted mastectomy.<sup>46</sup> Kushner both as an individual and through the views expressed in her work, represented an aware patient who was knowledgeable and in want of attention from medical professionals. Most of her literature and speeches posed questions like: "Why do surgeons feel they have the right to make the decision for their unconscious patients? Why not allow them to wake up, be told the diagnosis and the alternatives and options available?"<sup>47</sup> The conversation about women's agency that Kushner sparked brought real complications and consequences for patients with breast cancer.

Jo Spence provides visual representations that document the ramifications of the debates initiated by Kushner. Though the language of responsibility emerged over time, here I revisit it in a different light. Responsibility before was addressed in regard to decision-making and the development of cancer but in this section it refers

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<sup>46</sup> Marcy Knopf Newman, *Beyond Slash, Burn, and Poison: Transforming Breast Cancer Stories into Action* (New Brunswick: Rutgers University Press, 2004) 88.

<sup>47</sup> Marcy Knopf Newman, *Beyond Slash, Burn, and Poison: Transforming Breast Cancer Stories into Action* (New Brunswick: Rutgers University Press, 2004) 89.



to responsibility of the body and the relationships that breast cancer patients develop with their physical body and self. As the patient assumes responsibility in the discourse of Kushner, how does this then affect the patient's perception of ownership over her body? There are two photographs necessary to engage with such a question. One I have chosen to describe and the other is visually featured. Both images were created by Jo Spence. The first photograph includes a series of snapshots taken of Spence's back, stomach, forearm, collar bone, forehead, inner arm and hand. In the series, one snapshot captures the full upper body of Spence as she gazes into a mirror. The picture is accompanied by the following caption:

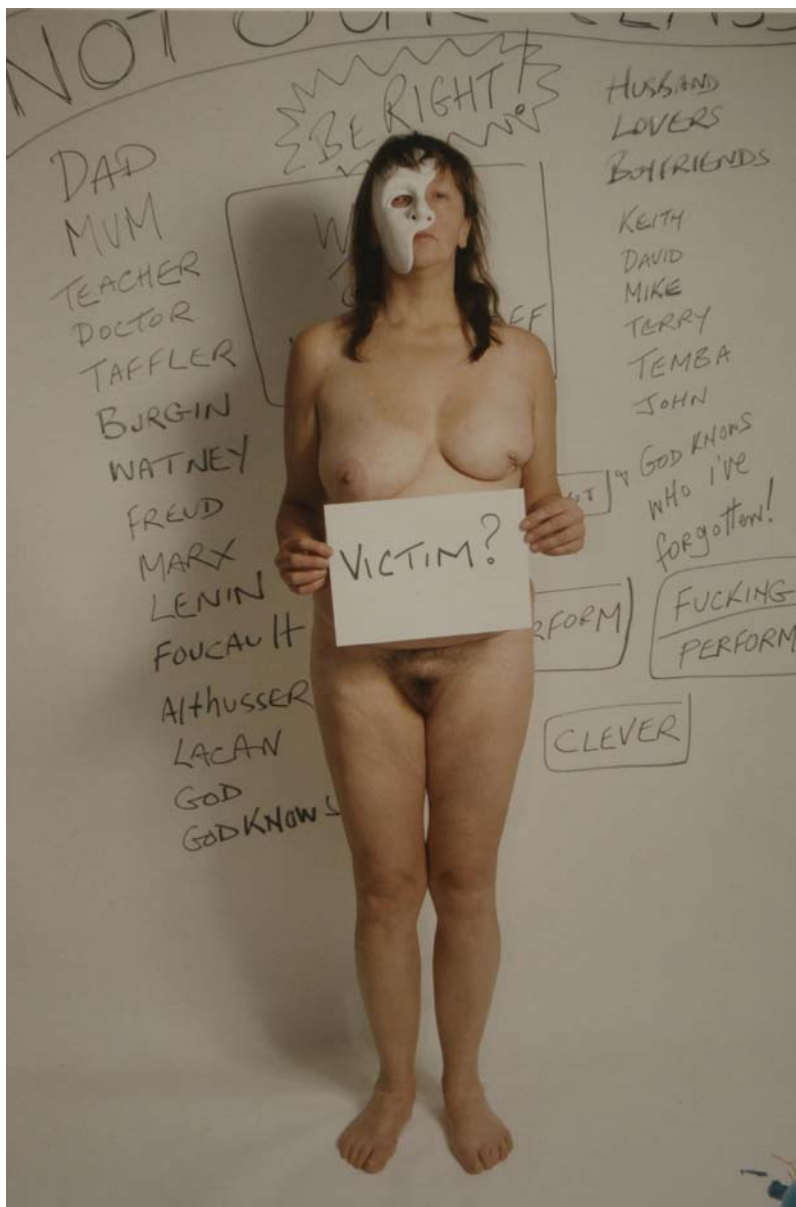
Adding a documentary photograph taken by Maggie Murray into images of my fragmented body which had been written on and staged for the camera in a photo therapy session with Roy Martin. My aim is to try and form a bridge between work done on health struggles, usually dealt with through documentary photography, and work done on body as image. An understanding of how these spheres relate seems to me essential to being healthy and well-balanced.<sup>48</sup>

Though the photograph featured only Spence and her body parts, I was keenly aware of another presence, that which Spence considers the "aggression and dogmatism" of western medicine. Her negative descriptors of western medicine manifest again in the piece, *Victim*, where Spence's face is obscured by a white mask. In her hands Spence holds a placard with the word "victim" followed by a question mark, as if she does not quite know her culpability in her diagnosis of breast cancer. These characteristics that Spence identifies play a key role in her subsequent feelings of bodily fragmentation. Though doctors are no longer privileged to make treatment decisions

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<sup>48</sup> Jo Spence, *Putting Myself in the Picture: A Political, Personal, and Photographic Autobiography* (London: Camden Press Ltd, 1986), 168.

without referring to the patient, the standardization of prevention and treatment accomplish similar results.



Jo Spence. "Victim" 1982. Courtesy of Terry Dennett

The pointed critique that characterized the tone of Spence was ever-present in Audre Lorde's personal narrative. In her piece, *The Cancer Journals*, she portrayed herself as hyper conscious of the reality that a definitive cause for breast cancer did not yet exist. As Lorde posed difficult questions aimed towards Western notions of

illness I began to wonder whether the talk of risk and responsibility stealthily obscured breast cancer as a disease without a cure or a definitive cause. It seemed a possibility that the emphasis of risk by the biomedical system and the intensified surveillance of the patient's body that followed was merely another manifestation of the power of western ideologies of illness. These ideologies that are built into medical institutions themselves experience the shifts that take place in medicine and still somehow manage to ensure the limited expressivity of the patient:

My silences had not protected me. Your silence will not protect you. But for every real word spoken, for every attempt I had ever made to speak those truths for which I am still seeking, I had made contact with other women while we examined the words to fit a world in which we all believed, bridging our differences.<sup>49</sup>

While biomedicine seemed to demand the fragmentation of experience and body, constructing specific expectations for its patients, the artists and individuals such as Lorde represented possibilities to reassemble oneself and questioned the very existence of such division.

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<sup>49</sup> Audre Lorde, *The Cancer Journals* (Argyle: Spinsters, 1980)

## CHAPTER TWO

### Meanings of Metaphor and Fetish in Breast Cancer Discourse

My point is that illness is not a metaphor, and that the most truthful way of regarding illness-- and the healthiest way of being ill--is one most purified of, most resistant to, metaphoric thinking. Yet it is hardly possible to take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped. It is toward an elucidation of those metaphors, and a liberation from them, that I dedicate this inquiry. (Susan Sontag *Illness as Metaphor* 4)

When Jo Spence was diagnosed with cancer in 1982, the protocol for treatment was heavily standardized. Her body was not her own, but merely one of many female breast cancer patients being treated. Tests were run and assumptions made based on the experiences of the women who had come before her. Mastectomy coupled with radiation was presented as her single option, any other routes, according to her doctors, would be futile. As her body and voice became further inscribed within the medical system her physical body was swiftly removed of markers associated with femininity. The removal of her breast, the falling out of her hair were obvious symptoms of cancer treatment that situated her body in what she refers to as an “abyss” or “morass”, a space unintelligible and unacknowledged by American society. This state of being without intelligent definition differed from her earlier work during the 1970s on the family and self image<sup>50</sup>, a distinction that further highlighted the potentially destructive metaphors inherent to breast cancer discourse.

Hannah Wilke documented her mother's experience with breast cancer through photography. Taking pictures of her mother's chest post-mastectomy and placing her own breasts and body in the frame, Wilke imagined herself as a figure testing and exposing the boundaries of beauty and womanhood. When Wilke herself was diagnosed with lymphoma her work continued to probe the precarious

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<sup>50</sup> Terry Dennet, *Jo Spence's Auto-therapeutic Survival Strategies* (London: Jo Spence Memorial Archive UK, 2011) 1.

construction that is the female body. The body depicted in the photographs with her mother, Selma Butter, showed a vibrant and youthful Wilke, a far cry from the states of being captured in the frames of the “Intra Venus” series. Both age and treatment for lymphoma had drastically altered Wilke’s body. Where her skin was once taut, her body was now marked by the loss of elasticity, her curvaceous frame, and other traditional markers of femininity. Over the span of her artistic career she engaged in a commentary on the expectations imposed on the representation of the female in American culture, adopting both suggestive poses and more pious ones traditionally associated with women, like that of the Virgin Mary. As Wilke stared fixedly at the camera, all the while embracing her quickly disappearing hair and heavily scarred body, she threatened popular conceptions of the female and ultimately suggested a re-envisioning or rather, unmasking, of the woman, particularly the female patient.

Deena Metzger chose to focus on healing and understanding the depths of her new relationship to her body because of cancer. In her experience of breast cancer she regularly sought options outside of the medical model, favoring natural remedies and meditation. Her route was one of celebration of both her body and spirit, trusting her inner ability to stave off cancer. Metzger eventually made the decision to undergo mastectomy, removing her right breast. The scar left from the procedure was eventually turned into a tattoo, that of a tree branch. The relationship of Metzger to her breast was distinct from the connection she developed with her tattoo and its representation of her bodily and emotional engagement with cancer. As a cancer patient Spence experienced the breast as a body part heavily marked by both society

and medicine, the tattoo and the scar it was made out of, held meaning defined by the individual and assisted in her healing process.



Deena Metzger, as she appeared in her “Warrior” poster, 1979. Courtesy of Deena Metzger.

These three artists purposefully decided to depict their own engagements with medicine and disease. While each experience is unique and significant in its own right and offer power when read individually, if placed into conversation with each other it is possible for these experiences to support deeper inquiry into the fetish and dominant metaphors associated with cancer. I was struck by the commonality of nude images in the artists’ work and their almost uniform call for the demarkation of breasts as sites of femininity. I read the similarities as a shared retaliation against the absence of such imagery in popular cancer discourse and the depersonalization of their bodies by medicine. As I delved further into the project an additional point of interest manifested; the differences in the photographs of the artists. All of the artists

appeared to challenge the construction of a singular identity of the breast cancer patient and their vastly dissimilar approaches hint at the endless alternative identities available but unspoken and ultimately unimagined. After looking at such pieces my question was not: “Why are these visuals only engaged with through the discipline of art?” but rather: “What public phenomenon sparked the creation of such work?”

Through an analysis of both the artists’ text and photographic work I found it possible to see that the selected artists identify the phenomenon in question as the totalizing expectations applied to breast cancer patients by biomedicine and society during the late twentieth century. The imposed expectations were not created in a vacuum nor inherent, they effectively incorporated American fantasies about the breast and its importance to femininity. Here the concept of “fetish” plays a crucial role as the breast experienced the symbolic attribution of power that over time was constructed into intrinsic value. My interpretation of fetish comes from postcolonial studies which address fetishism in terms of global marketing and advertising. As scholars like Laura Mulvey, who researches the influence of male fantasies on gendered representations in film, and Beverley Hooper, who draws connections between the objectification of Western and Chinese women, have articulated, it is possible to incorporate fetishism into the role and representation of women in Western visual culture. Similar to how Freud understood the fetish as “ a substitute for the woman’s phallus which the little boy once believed in and...does not wish to forgo”<sup>51</sup> I argue that the bodily stereotype apparent in literature, that all women possess breasts is a fetish which constructs a sense of trauma and discomfort towards

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<sup>51</sup> Sigmund Freud, ‘Fetishism’, Standard edition of the Complete Works of Sigmund Freud, J. Strachey (ed), London, Hogarth Press, 1953, Vol. 21, p.152.

one breasted individuals. The fetish of the two breasted form thus associated the sight of the one breasted women with one of lack. In looking to the development of the breast as an eroticized object of specific value in the 1980s, I hope to draw a connection to popular renditions of breast cancer and highlight how the artists attempt to remove and engage with the fetish in question. Empowered with language and image the artists' push for the space to discuss being without the breast and suggest a demarkation of the breast as the site of femininity.

### The Composition of Breasts

In this chapter I will argue that the diagnosis of breast cancer has historically developed as a moment of bodily malfunction in the otherwise blemish free existence of the female body. American society assumed that the female body was a coherent identity, marked by the presence of certain features, namely the breast.<sup>52</sup> By “coherent” I most nearly mean “stable” in that representations of the female body were often relegated to the binary of the Virgin Mother and set in opposition to the dangerous temptress. While I struggled to answer questions regarding the construction of the female body, I was reminded of questions posed by the theorist Judith Butler: “To what extent does the body come into being in and through the mark(s) of gender? How do we conceive the body no longer a passive medium or instrument awaiting the enlivening capacity of a distinctly immaterial will?”<sup>53</sup> In the spirit of Butler I attempt to engage in a feminist critique and acknowledge gender as a set of relations. Within the provided literature I note the hegemonic Western

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<sup>52</sup> James Olson, *Bathsheba's Breast: Women, Cancer, and History* (Baltimore: The Johns Hopkins University Press, 2002) 10.

<sup>53</sup> Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity* (New York: Routledge, 1990) 12.



perception of breasts and their equation with the maternal, the erotic and female identity.

Starting in the 1960s many scholars of evolutionary theory argued that breasts evolved as sexual signs, though some discrepancy existed as to whether or not they visibly marked reproductive ability or were instead sexual ornaments to promote pair bonding. Such scholarship made major assumptions: firstly, that men were inherently attracted to breasts and, secondly, that breasts were predominantly developed to be desirable for men. The focus on the heterosexually oriented function of the breast slowly gave way the understanding of breasts as capsules of femininity. The move to determine the significance of breasts effectively bypassed the relationship of the woman to her own breasts. The external application and mapping of the female body that characterized such research is representative of an era of heavily gendered and patriarchal regime of practices in medicine. Because breasts were associated with reproduction, sites of nourishment for infants and a condition requiring medical attention, breast themselves eventually became medicalized as physicians took control over women's bodies. Maren Klawiter, identified the 1960s as the regime of medicalization where, "the sovereign rulers were male surgeons who wielded absolute power in the medical setting over breast cancer patients and demanded total obedience."<sup>54</sup> While I found it difficult to envision the formation of understandings of the breast outside of cultural norms, I think it necessary for breast cancer discourse to engage with individuals, like the artists, who push for the disentanglement of the breast from femininity and question the valuation of the body part.

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<sup>54</sup> Maren Klawiter, *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (Minneapolis: University of Minnesota Press, 2008), 75.

Adding to the work produced by the discipline of evolutionary theory, scholars from psychoanalysis to Greek mythology took up an interest in breasts and ascribed them various meaning. For example, in Freud's theories of psycho-sexual development of the late nineteenth century he described breast feeding as a crucial component of the oral stage. In Greek myths dating from 900-800BC onward, breasts were portrayed as both compassionate and erotically vulnerable.<sup>55</sup> The appearance and significance of breasts differs in the two accounts and, in general, a certain amount of variety in size and shape of breasts is permitted in discourse surrounding the female body. The presumption of heterosexual mating patterns and male attraction to breasts proves a recurring theme in literature across disciplines and all assume symmetry as the possession of two breasts. Breasts, as opposed to the singular breast, dominate discourse and suggest that the absence of such a set of anatomy results in much ambiguity. This ambiguity was located elsewhere. The characterization of female body builders as masculine not only because of their muscular structure but because of their absence of fatty breast tissue is a more modern example. Since their bodies appear devoid of breasts, and thereby have little association with femininity, they are instead moved more towards the domain of masculinity. The slippage caused by the female with little to no breasts forced me to then wonder, where do we situate the one-breasted woman? If masculine was defined by absence of the breast and feminine by the possession of breasts, the one-breasted woman posed unwelcome issues for the gender binary.

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<sup>55</sup> Carolyn Latteier, *Breasts: The Women's Perspective on an American Obsession* (New York, The Haworth Press, 1998) 145.

## Making Proper Breasts

...where the superficial is supreme, the idea that a woman can be beautiful and one breasted is considered depraved, or at best bizarre, a threat to morale. (Audre Lorde, *Breast Cancer: Society Shapes An Epidemic*, 62.)

In the United States, a country that has historically privileged perfection and proper categorization, any degree of “disfigurement” or ambiguity was frightening, and warranted correction. Psychological studies have shown differing impacts of disfigurement based on gender, with lesions on the faces of young and female as prompting the greatest negative response.<sup>56</sup> The medicalization of women’s bodies, breasts in particular, has perhaps aided in the development of such feelings toward body image. The history of breast augmentation is another explanatory variable. Before the twentieth century, breast surgery was conducted primarily for the purposes of removing tumors or minimizing breasts that posed issues for overall health and well being. When physicians first began the practice of breast implants, wax and paraffin were the substances injected into breasts. In the early 1920s women began to return to their doctors with complaints from the injections, but, regardless, patients continued to seek the procedure and doctors continued to perform the operation. The beauty image prevalent during the 1900s was the “curvy; full breasted women”, and from the increased demand for augmentation, it appeared American women sought to embody such an ideal. The development of the ideology that women’s breasts were “deformed” and “diseased” came from medical professionals from this same period, who defined breast deformity as breasts whose size and shape differed substantially

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<sup>56</sup> Matthew Gardiner, Ashley Topps, George Richardson, Amanda Sacker, Alex Clarke, Peter Butler, “Differential Judgments about Disfigurement: The Role of Location, Age, and Gender in Observers”, *Journal of Plastic, Reconstructive and Aesthetic Surgery* 63 (January 2010) 73-77.

from the “correct breast shape.”<sup>57</sup> Imbed in the ideology was the assumption that “correct breast shape” was the norm and that its lack marked the “Other”.

Breast cancer patients of the twentieth century were not immune to the undeniable American obsession with breasts and, in many ways, they experienced the emphasis of perfection more intensely than most. Not only were their bodies subject to critique as they faced decisions about mastectomy and whether or not to undergo reconstruction but additionally their mentality in how they handled the “malfunction” of self seemed up for debate. Breast cancer had the potential to make seemingly clear cut binaries, including gender, messy which resulted in measures to temporarily allow for the normalization of breast absence, provided this absence was swiftly followed by procedures for reconstruction.<sup>58</sup> While physicians offered many therapies to treat and aid in the prevention of breast cancer, the consequences and open discussion of invasive surgery, namely mastectomy, remained the one of the most silent facets of cancer discourse. The scars of mastectomy and absence of a breast undoubtedly had a long lasting impact on the patient. During the 1980s American society was not able to provide a forum for discussion or display and instead demanded the camouflaging of those experiences, a move which caused their devaluation. I posit that the chest of the one breasted women thus became a marker of illness and deformity, a threat to American ideals of femininity.

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<sup>57</sup> Susan Ferguson, *Deformities and Diseased: The Medicalization of Women’s Breasts*, ed. Anne Kasper, Susan Ferguson (New York: St. Martin’s Press, 2000) 55.

<sup>58</sup> David Cantor, *Before Survivorship: The Moment of Recovery in Twentieth Century American Cancer Campaigns* (Bethesda: National Institutes of Health, 2010).

## Cancerous Breasts: The Meeting of Medicine and Femininity

The attribution of femininity to breasts recast breast cancer as disruptive to gender ideals. As previously mentioned, disfigurement and ambiguity proved problematic to socially created gender binaries. As women, female breast cancer patients were already deeply entrenched in issues of femininity. Such a reality brought about the use of tools to regain symmetry, both in mind and body, a historical moment in the twentieth century often overlooked. Terms such as *symmetry*, *correction*, and *natural* pervade breast cancer discourse. From the standpoint of both medical and cultural perceptions of the body, cancer holds the potential to destabilize identity through the removal of the breast.<sup>59</sup> My reading of literature written by women with cancer, led me to assert that the removal of the breast, a feature so closely associated with femininity, was damaging both to the individual person operated on and society as a whole.

It seems telling that the first public image of a scar from mastectomy, that had not been retouched, did not appear until 1993. The picture was featured on the cover of the *New York Times Magazine*.<sup>60</sup> The self-portrait, titled, “Beauty out of Damage”, was of artist Matuschka, a woman over treated for cancer after her diagnosis in 1991. The artist refused reconstruction surgery, instead channeling a desire to take possession of her scar. This desire for ownership also manifested as a commitment to commanding complete control over the process of representation of her body:

But the way society has constructed female beauty made my task enormously challenging! How could I take such an asymmetrical situation, remove it from the look available in medical books, and bring it to the level of my earlier

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<sup>59</sup> Jackie Stacey, *Teratologies: A Cultural Study of Cancer* (London: Routledge, 1997)

<sup>60</sup> Simon Richter, *Missing the Breast: Gender, Fantasy, and the Body in the German Enlightenment* (Seattle: University of Washington Press, 2006) 262.

work without provoking pity? Could I actually show a mastectomy woman who looked proud and beautiful? Could I create a picture which would evoke power and strength instead of self-indulgence?<sup>61</sup>

The mastectomy had taken away what was once convex and rendered it concave. In preparing for operation, Matuschka's doctor assumed that she would opt for breast reconstruction. The immediate jump to reconstruction surgery by her doctor and the media storm that preceded and followed the magazine cover's debut all assumed the intrinsic nature of the breast for female identity, which Matuschka's refusal for surgery and public unveiling of her mastectomized torso called into question. While the cover was revolutionary in that it drastically differed from all other imagery of breast cancer available at the time, the actual article about breast cancer in the magazine made no mention of the cover photograph.

Matuschka's case pointed to a reassessment in the meaning of breasts both to cancer patients and women in general during the 1980s. The prior lack of inquiry into the relationship between women and breasts assisted in perpetuating certain American conceptions of feminine identity. The following image from Jo Spence's 1982 series "The Picture of Health?", and titled, *Property of Jo Spence?* marks a similar historical moment. In her experience with breast cancer Spence underwent traditional Western treatment and also sought ancient Chinese medications. Spence used the series, "The Picture of Health" as a self proclaimed form of phototherapy, a means of coping with the depression that manifested over the course of cancer treatment. The picture explicitly addresses questions of ownership over the female's body, specifically her chest, and considered the assumed inherence of breasts to her identity as a woman.

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<sup>61</sup> Simon Richter, *Missing the Breast: Gender, Fantasy, and the Body in the German Enlightenment* (Seattle: University of Washington Press, 2006) 264.

After looking at Spence I was left with the following questions: “Whom does Spence suggest determines how breasts should look?” and “How is the breast seen by the public?”



Jo Spence, “The Property of Jo Spence?” in *Putting Myself in the Picture*, 1982. Courtesy of Terry Dennett.

Spence accomplishes a similar goal as Matuschka and her cover shoot, both created a space to address characteristics associated with femininity and the social meaning attributed to breasts. Matuschka’s own commentary, featured in more left

leaning publications, and the photo itself express dissatisfaction towards the conflation of the breast with feminine beauty, a sentiment that was not popularly acknowledged in breast cancer activism and treatment of the 1980s and even up into the 1990s. In contrast to early breast cancer narratives, Matuschka's and Spence's mastectomized chests had no connection to the recurring character of the healthy, vibrant, and optimistic breast cancer patient. During the 1970s white, married, young to middle age women dominated the early breast cancer scene both as the authors of personal narratives and the targeted audience for popular breast cancer campaigns. From the individuals akin to Betty Ford and Happy Rockefeller, the breast cancer experiences initially made public, had overarching themes of early detection, positive attitude, and a strong desire to return to "normal" once patients were granted a clean bill of health by institutions of medicine. These actions, along with the prescribed trajectory of the breast cancer experience, had much to do with the relationship of women to femininity. Early detection meant regular self-examinations, undergoing mammography, and maintaining a positive attitude, which referred to the way women handled mastectomy or other treatments that compromised the integrity of breasts. The return to normalcy was typically characterized as an event experienced both by the woman and her significant other. In the situations of both Rockefeller and Ford, corrective surgery was performed to return symmetry, a move that was ultimately affirmed in declarations that femininity was still intact by each of their respective husbands.<sup>62</sup>

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<sup>62</sup> Roberta Altman, *Waking Up/Fighting Back: The Politics of Breast Cancer* (Boston: Little, Brown and Company, 1996) 250.



By establishing a collective around the shared experience of breast cancer, the movement that developed in 1980s began to require women to adopt the identity of a breast cancer patient even as women were permitted to physically return to a pre-cancer state. With such a distinction in place, women living with the disease were much entrenched in the construction of specific gender roles and expectations.

### Normalizing Women Through Cancer

The entanglement of femininity and the breast holds meaning for more than women with cancer. The Sunday following the appearance of “Beauty Out of Damage,” on the cover of the New York Times Magazine, their office received 125 calls from patients and non-patients alike. The sentiments expressed ranged from extremely positive to harshly critical.<sup>63</sup> While the positive responses mainly centered on praise of exposing the previously unacknowledged body after mastectomy, the negative feedback fell into two categories. In an interview with the magazine, *Glamour*, Matuschka reported that some women felt a violation of privacy because the photograph threatened their own sense of normalcy regarding the appearance of their bodies. Another group considered the photograph a deterrent for mammography or self examination, as women who viewed it would worry they would meet a similar outcome.

Breast cancer research and treatment has followed many different trajectories, but certain procedures garnered more public attention. The impact of chemotherapy and mastectomy on the body are popular topics for those discussing breast cancer. On the website for the American Cancer Society (ACS), resources for reconstruction

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<sup>63</sup> Tacey Rosolowski, “Women as Ruin” *American Literary History* 13 (Fall 2001):544-577.

surgery and methods to look better abound, but absent are options for those not interested in erasing all physical traces of their experience. Language to articulate doing nothing post-mastectomy failed to make it into popular breast cancer discourse and instead the focus was directed to how cancer could change one's body image, for the worse. Coupled with the existence of organizations like the Look Good, Feel Good campaign, the more authentic appearance of wigs, and undergarments that gave the appearance of perfect symmetry, it was possible for breast cancer patients to present themselves as unchanged by cancer and "properly" feminine.<sup>64</sup> That these products and organizations proliferated in an era characterized by enthusiastic breast cancer activism seems telling of the fading mutually exclusive categories between adopting a breast cancer as an illness identity and being considered a feminine woman:

"At a time in which people in western societies are both encouraged to 'display' and 'confess' their emotions but also to 'manage' their emotions carefully by conforming to expectations about the expression of emotional states in specific social settings, the emotions are integral to the conduct of social life and relationships with others."<sup>65</sup>

In looking through the images offered by organizations such as the Susan G. Komen Foundation, I noted the reiteration of a coherent feminine identity. The photographs of women with any visible markers of breast cancer were rare and prevalent were the images of women suggestively cancer-free and smiling. As a viewer, I found the society alluded to through such imagery was one where cancer was secretly imminent. Literary scholar, Judy Segal also makes reference to the secret

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<sup>64</sup> Audre Lorde, *The Cancer Journals* (Argyle: Spinsters, 1980).

<sup>65</sup> Deborah Lupton, *Going with the flow: some central discourses in conceptualizing and articulating the embodiment of emotional states*, ed. Sarah Nettleton and Jonathan Watson (London: Routledge, 1998) 82.

immanence of cancer, exploring what she considers the standard story of breast cancer. Like the images of the Komen Foundation, most illness narratives written by patients reiterate a particular hierarchy of values for the breast cancer experience: “humor is good; despair is bad; surviving is noble; dying, by implication, is not.”<sup>66</sup> All of the women featured in the work of the foundation have, had, or may develop breast cancer. Their talent and unifying feature proved their ability to maintain femininity by adhering to proper steps from self-exams to treatment and ultimately recovery.

From the tools offered it appeared as though feminine identity was maintained through the adoption of specific troupes associated with being a woman. Wigs offered luscious locks that were before stripped away by chemotherapy and cosmetics provided flush to cheeks and lips made wallow by treatment. The photograph, *Intra Venus # 1*, shows Hannah Wilke’s depiction of the rituals assumed in the female identity. Throughout her series, “*Intra Venus*,” Wilke invokes the costumes traditionally donned by women. This dressing however was problematized by her status as a patient suffering with lymphoma, a cancer which removed markers like hair and greatly changed the composition of her body. In her earlier work, Wilke was distinguished by what many deemed as erotically charged and suggestive poses. The stark contrast between her early and late artwork speaks to the precarious boundaries of feminine identity. Once more, ambiguity in this context cannot be tolerated. In Joan Riviere’s essay, “*Womanliness as Masquerade*” she draws a connection between the significance of displaying characteristics of one’s sex and how said characteristics

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<sup>66</sup> Judy Z. Segal, “Breast Cancer Narratives as Public Rhetoric: Genre Itself and the Maintenance of Ignorance”, *Linguistics and the Human Sciences* 3 (May 2007): 3-23.

are understood to reflect apparent sexual orientation. The “imaginary formation” of sex as heavily contingent on the perceptual act complicates the gender attribution of one breasted women. As Wilke and the other artists experienced, breastlessness is absent from cancer discourse and instead patients are offered methods to masquerade behind treatment procedures themselves but also behind the rhetoric of prevention and coping with disease.



Hannah Wilke, *Intra-Venus #1*, June 15, 1992/January 30, 1992, 1992-93. 2 panels: chromagenic supergloss prints, 71 1/2 x 47 1/2 inches each. Courtesy of Donald and Helen Goddard and Ronald Feldman Fine Arts, New York.

Breast cancer, and its subsequent diagnosis and treatment techniques have fostered the establishment of bodily norms and manners in which to regulate the body that American culture has identified as feminine. These norms and regulations are effectively reiterated in society, helping to create a unitary and easily commodifiable

breast cancer identity. Looking specifically at the procedures of mastectomy and reconstruction surgery it was possible to see the production of the previously mentioned ideal breast cancer patient. This patient was knowledgeable, able to both assert herself with doctors and negotiate effectively within the medical realm and was defined solely by their mentality and appearance. The knowledge made available to the patient had enveloped breast cancer within femininity and caused one to consider mastectomy as loss, a move which allowed the individual to perpetuate the normalization of the female body as a form with two breasts.

### **Mastectomy: The Site of Lost and Found Femininity**

I am no longer afraid of mirrors where I see the sign of the amazon, the one who shoots arrows. There was a fine red line across my chest where a knife entered, but now a branch winds about the scar and travels from arm to heart. Green leaves cover the branch, grapes hang there and a bird appears. What grows in me now is vital and does not cause me harm. I think the bird is singing. I have relinquished some of the scars. I have designed my chest with the care given to an illuminated manuscript. I am no longer ashamed to make love. Love is a battle I can win, I have the body of a warrior who does not kill or wound. On the book of my body, I have permanently inscribed a tree.<sup>67</sup>

Deena Metzger underwent mastectomy after her cancer diagnosis in 1977, and she refused reconstruction surgery. The photograph entitled, “Warrior,” that she had taken after her mastectomy, quickly became the most famous published breast cancer image in the world. Striking the yoga position, virabhadra, in the photograph Metzger removes her shirt, openly showing and celebrating her absence of breast. The events that preceded and influenced the publication of “Warrior” mainly took place within the hospital setting as Metzger interacted with doctors who were treating her cancer. She envisioned herself in conflict with what she considered the “logic of the knife” and her own inner reserves in the form of alternative solutions beyond the medical

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<sup>67</sup> Deena Metzger, “I am no longer afraid,” and Poster, *Her Soul Beneath the Bone*, ed. Leatrice Lifshitz (Chicago: University of Illinois, 1988) 240.

model. When she finally decided to move forward with the mastectomy, Metzger also made the decision to “cut the cancer out of my body.”<sup>68</sup> In that moment, Metzger argued that she had moved beyond a phallogentric construction of the breast. No longer valued as an object or privileged based on its proximity to the ideal female figure, her breast instead become fluid and a nonessential component of her femininity.

While mastectomy serves as the intermediary, coming after breast cancer diagnosis and prior to long term treatment, its implications and assumed meaning often defined a woman’s engagement with breast cancer and her body. In the surgical domain mastectomy was portrayed as a tool of salvation, preventing the spread of the cancer. There are many options to treat breast cancer but I decided to focus my attention on mastectomy because it uniquely holds dual meanings of loss. As I hope to place my work in conversation with the discourse of biomedicine it felt logical to investigate the treatment historically considered the first medical response to a diagnosis of breast cancer. The literature surrounding mastectomy comes from both medical and social perspectives, but it is the convergence of the two that offers the most interest. As a medical practice the mastectomy literally removes the breast or a portion of it. As Metzger’s experience suggested, at that moment, not only was the physical breast lost but according to most biomedical and popular literature the loss also extended to the emotional, as patients must mentally cope with the loss of the American signifier of the feminine.

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<sup>68</sup> Deena Metzger. Annual Convocation of the American Academy of Osteopathy. Birmingham, Alabama. March 2006.

In 1894 William Stewart Halsted reported on a new procedure for breast cancer, the removal of all suspicious tissue in one piece. The report, delivered at the College of Medicine at Johns Hopkins University, marked the arrival of radical surgery and the Halsted mastectomy. One of the most significant periods in the history of breast cancer research came at the end of the nineteenth century. Surgeons opened the early 1900s with the widespread implementation of the Halsted radical mastectomy. Its eventual denouncement occurred many years later. As Klawiter explains, the procedure left patients with heavy scarring and reflected a wide held theory of “contagious” development, meaning that cancer originated in the breast and then spread to the rest of the body:

Most importantly, instead of being viewed as a systemic disease, cancer was re-conceptualized as “a localized disease that spread centrifugally in a slow, ordered manner.” If local diseases could be removed through local procedures, breast cancer could, in theory, be excised from the body. Breast cancer was re-conceptualized within medical journals and textbooks as a disease for which radical surgery, if performed early enough, could be curative.<sup>69</sup>

In his operations, William Halsted would remove the breast, axillary lymph nodes, and underlying chest muscles. Though often critiqued as barbaric and too aggressive of a treatment, the results of the method were believed unquestionably positive: nearly 85% of women that received the procedure were still alive five years afterwards.<sup>70</sup> The American Society for the Control of Cancer (ASCC) aided in the popularization and institutionalization of the Halsted procedure in medicine. The organization spearheaded a campaign in the beginning of the twentieth century with

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<sup>69</sup> Maren Klawiter, *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (Minneapolis: University of Minnesota Press, 2008) 63.

<sup>70</sup> James Olson, *Bathsheba's Breast: Women, Cancer and History* (Baltimore: The Johns Hopkins University Press, 2002) 67.

the goal of convincing patients and medical professionals alike that breast cancer if diagnosed early was successfully treatable by surgery.<sup>71</sup> While such findings about the success of the Halsted procedure were initially effective in promoting the early detection campaign, the procedure itself was slowly discredited because of findings which later showed that the procedure was no more successful at preventing recurrence than less radical surgery. This revelation ushered in an era of research for less debilitating treatment.

The rejection of the Halsted mastectomy during the 1960s received mixed reaction from professionals and patients. Surgeons saw the benefits of the one-step procedure as it prevented the risk of second general anesthesia and, from a practical standpoint, avoided the scheduling and additional time of a second operation. Patients on the other hand varied in their responses. Ranging from discouragement to rejoicing in the move away from harsh bodily treatment there was no uniform reaction to Halsted's dethronement. Many women had previously avoided the Halsted procedure because of the fear of becoming permanently wounded and disfigured, and it appeared that America post-World War II was ready to pursue new technology in finding a cure and treatment for cancer. As a historical moment, the 1960s showed the country capable of bringing to fruition the dreams of President John F. Kennedy to put a man on the moon. Once this goal was achieved however, public response indicated a desire for the pursuit of a crusade with tangible rewards. President Richard Nixon responded to the desire, initiating a war on cancer with his signing of the National Cancer Act of 1971. Every year over 200,000 Americans died from

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<sup>71</sup> Maren Klawiter, *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (Minneapolis: University of Minnesota Press, 2008) 65.



cancer, causing many to adopt the sentiments of columnist, Ann Landers who declared in a 1971 piece, “If the United States can place a man on the moon, surely we can find the money and technology to cure cancer.”<sup>72</sup> Researchers began to seek alternative methods of treatment, particularly ones less invasive and damaging to the breast. A study from The Netherlands Cancer Institute, conducted in 1984, found that women undergoing breast conserving therapy had more positive body image and less fear of recurrence than those who opted for the radical mastectomy.<sup>73</sup> These findings were in congruence with numerous other results that found women who had total mastectomy to show higher levels of depression and poor body image.<sup>74</sup> While the research came from doctors and scientists who were part of the medical model, its historical situation in a period marked by an American obsession with breasts has significance.

During the years that followed mastectomies and lumpectomies were used in the treatment process, usually followed by the standardized procedure of reconstruction surgery. Often touted as empowering and a means of regaining breast shape and femininity, reconstruction surgery actually proved that stigma never truly left the breast. It was the one breasted form created out of mastectomy that was characterized as imbalanced and in need of correction. For many women living in America during this period, the removal enacted by mastectomy symbolized a deeper

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<sup>72</sup> James Olson, *Bathsheba's Breast: Women, Cancer and History* (Baltimore: The Johns Hopkins University Press, 2002) 125.

<sup>73</sup> Harry Bartelink, Frits Van Dam, Joop Van Dongen, “Psychological Effects of Breast Conserving Therapy in Comparison with Radical Mastectomy”, *International Journal of Radiation Oncology* 11 (February 1985): 381-385.

<sup>74</sup> James Olson, *Bathsheba's Breast: Women, Cancer and History* (Baltimore: The Johns Hopkins University Press, 2002) 85.

loss than that of the breast or even femininity, it suggested a loss of self identity. In Jackie Stacey's book, for example, *Teratologies: A Cultural Study of Cancer*, according to the author, the loss created by mastectomy was similarly problematized. Mastectomy not only admitted but advertised itself as loss, giving further rise to the notion of the privilege of "the conventionally aestheticised female form."<sup>75</sup>

### **Reconstruction and the Materiality of the Breast**

The meaning of breasts and the choices made in regard to them, took place in a particular context. For cancer patients, the long entanglement of breasts with femininity transformed the breasts into sites of disease actively reiterated as feminine through American culture and engagement with medicine. This change comes at the expense of the materiality of breasts. In looking to the work of Susan Bordo in, "Material Girl": The Effacements of Postmodern Culture", the materiality of the body is an unfortunate victim of the postmodern imagination. According to Bordo it was the acceptance of ideals of freedom and self determination that served to negate the previous understandings of the body and ultimately redefine states of embodiment:

If we are never happy with ourselves, it is implied, that is due to our female nature, not to be taken too seriously or made into a political question. Second, the content of fashion, the specific ideals that women are drawn to embody (ideals that vary historically, racially, and along class and other lines) are seen as arbitrary, without meaning; interpretation is neither required nor even appropriate. Rather, all motivation and value come from the interest and allure- the "sexiness"- of change and difference itself.<sup>76</sup>

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<sup>75</sup> Jackie Stacey, *Teratologies: A Cultural Study of Cancer* (New York: Routledge, 1997) 207.

<sup>76</sup> Susan Bordo, *Unbearable Weight: Feminism, Western Culture, and the Body* (Berkeley: University of California Press, 1993) 48.

As Bordo articulated through her analysis of the taping of an episode of the Donahue show from 1988, where the focus was a number of commercials for Durasoft colored contact lenses, there existed a popular disavowal of non-democratic values. The host, Phil Donahue, looked to his audience with the following question, “Are these ads racist?” The conversation that ensued took a different trajectory than the host anticipated as most members of the audience found nothing wrong with the advertisements, and in many respects expressed a desire to politically neutralize the topic at hand.

While the commercials were introduced as works that suggested blue eyes and the intensified colors allowed by contacts were “better” than those with those with naturally brown eyes, the audience instead ventured into conversation about styling products and make up as mere forms of creative expression. The move away from cultural criticism and recognition of the homogenizing power of institutions was significant in that it imbued individuals with greater expectations and responsibilities. While the merits of postmodernism are still very much debated, its influence, particularly in the realm of embodiment deserves much attention. If I were to use Bordo’s conceptualization of a postmodern conversation as one where, “all sense of history and all ability (or inclination) to sustain cultural criticism, to make distinctions and discriminations that would permit such criticism, have disappeared”<sup>77</sup> discussions of reconstructive treatment post mastectomy would simply be read as a matter of personal preference. But as Bordo makes clear, these issues are far greater than

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<sup>77</sup> Susan Bordo, *Unbearable Weight: Feminism, Western Culture, and the Body* (Berkeley: University of California Press, 1993) 49.

individual choice and it is necessary to look at the other factors at play in influencing decisions.

At this juncture the breast as a culturally identified marker of femininity has been explored at length. The making of the breast from the evolutionary perspective to its importance for feminine identity have all been important topics in this conversation to more completely assess the relationship of breast cancer identity to the breast. I approached the subject of mastectomy as a procedure constructed as loss, which leads to the next question of, “What happens next and what role does the patient play in the process following mastectomy?”

By the end of the 1950s both medical discourse and popular culture had successfully characterized mastectomy as destabilizing to the body and the individual. As the one breasted woman signified a lack and caused difficulties for the gender binary, a balancing agent proved necessary. This agent of correction both needed to address the visible imbalance of the body and keep patients within the realm of biomedicine. It was in the profession of surgery that the field of reconstructive surgery grew into the method of regaining shape, femininity and one’s lost sense of self. Surgeons, the characters who crafted breast cancer into a treatable disease made reconstruction a logical extension of such treatment. The language of “regaining” and “balance” permitted patients to return to the natural female form, a form that was subsequently normalized as the position of symmetry. By employing reconstruction surgery as a device of correction, the experience of the “treated” body for women was changed. Treatment no longer ended with mastectomy, but continued until some degree of normality was reassumed:

Although reconstructive surgery offered some of these women the promise of an enhanced or more normalized femininity, all those who considered reconstruction said that their real motivation for undergoing this procedure was that they wanted to still look like a woman post surgery. As Neill “et al.” (1998) have observed, breast reconstruction is frequently perceived as a way of achieving normality following therapeutic mastectomy.<sup>78</sup>

As the quotation suggested, the employment of reconstruction surgery by patients and doctors alike was considered a return to either the pre cancer state or the “normalized” feminine form. This disciplining of the body through surgery is reminiscent of Foucault’s analysis. The procedure reiterated the embodied and power-relations of discipline. The underlying motivation for surgery that was referenced serves to indicate issues of embodiment for breast cancer patients, and where they felt their bodies do or do not belong. The experience of one’s body in and after the treatment process was a matter taken up extensively by Arthur Frank. He identified four types of body work in medicine but it was the “mirroring body” which I felt best described the cancer patient’s body:

The mirroring body fears disfigurement, which some disciplined bodies might regard as signs of battles well fought. Their respective attempts to ensure predictability will also differ. The disciplined seeks predictability of performance; the mirroring body seeks predictability of appearance. If the disciplined body marches to the commands of an internalized drill sergeant, the mirroring body grooms itself in conformity to an internalized set of ideal images.<sup>79</sup>

The “conformity to an internalized set of ideal images” proved of particular importance to breast cancer identity and reconstruction surgery. A host of factors contributed to the move towards reconstructive surgery in the 1970s, namely the

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<sup>78</sup> Laura Potts, *Ideologies of Breast Cancer: Feminist Perspectives* (New York: St. Martin’s Press, 2000) 166.

<sup>79</sup> Arthur Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: University of Chicago Press, 1995), 44.

introduction of silicone gel implants. The development of such implant technology allowed doctors to offer a means for patients to re-ascribe to norms of femininity and additionally gave women the opportunity to put the cancer experience behind them. There was no uniform feminist response to implants and reconstruction surgery, but most erred on the side of critique like feminist writer Kathryn Morgan who considered breast reconstruction as non-aligning with the mission of the women's movement, "Rather than aspiring to self-determination and woman-centered ideals of health or integrity...women's attractiveness is defined as attractive to men."<sup>80</sup> Such sentiments however, seemed to diverge with the experiences of actual breast cancer patients as evidenced by the statistic that between 1965 and 2000, more than 700,000 women opted for breast reconstruction.<sup>81</sup>

### **The Woman with One Breast**

The normalization of a two symmetry form through American culture and biomedicine resulted in a silencing of those outside of the two form model. This assertion finds itself on the absence of adequate discourse regarding women who forgo the route of reconstruction surgery, prosthetics, or any other modifying/correctional medium. The absence reflects the lack of discursive space afforded to those who make the decision to explore pathways that extend beyond or push against the standards of femininity associated with breast cancer identity. The suggested inherency of femininity to breast cancer identity is a noteworthy realm of

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<sup>80</sup> James Olson, *Bathsheba's Breast: Women, Cancer and History* (Baltimore: The Johns Hopkins University Press, 2002) 119-120.

<sup>81</sup> James Olson, *Bathsheba's Breast: Women, Cancer and History* (Baltimore: The Johns Hopkins University Press, 2002) 120.

scholarship. Theories of performativity offer additional insight into the characteristics of the role expected of breast cancer patient. The conflation of femininity with the breast and subsequent breast cancer identity has aided in the one dimensionality in the role afforded to those with breast cancer:

“The normative force of performativity--its power to establish what qualifies as “being”--works not only through reiteration, but through exclusion as well. And in the case of bodies, those exclusions haunt signification as its abject borders or as that which is strictly foreclosed: the unlivable, the nonnarrativizable, the traumatic.<sup>82</sup>

Much work on performativity has focused on the aspect of reiteration, but the act of exclusion proved a further point of interest, in that it was relevant to breast cancer identities. In looking back to the experiences of Spence, Wilke and Metzger it was possible to see how they diverged from some norm of being and how they were subsequently relegated to positions of ambiguity by medical professionals. According to Butler by defining the experiences of those on the outskirts of the norm as “unlivable”, society can then justify demanding their silence. In the case of breast cancer patients it appeared that the reasoning behind such silencing, through the displacement of states of being outside definable borders, came from the threat such bodies pose to constructed images of masculine and feminine bodies. The dual usage of metaphor and fetish in cancer discourse serves different roles as one sanitizes the trauma of disease while the other renders the mastectomied body traumatic. For the artists, both metaphor and fetish however limited the bounds of their engagement with breast cancer. With the emphasis on regaining balance, correcting the lost breast

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<sup>82</sup> Judith Butler, *Bodies that Matter: On the Discursive Limits of Sex* (New York: Routledge, 1993) 188.

and subsequent femininity, cancer discourse and the type of patient it constructed, the available literature lent itself more to a sense of moving on or hiding the disease instead of allowing for any visible disease identity.

In this process of hiding, the patient was also denied the ability to connect with others experiencing similar feelings during illness. The greater social value bestowed upon reconstructive surgery and the preservation of femininity were both depicted as stifling agents in the work of the artists. The lack of visibility that comes from the normalization of reconstruction surgery was potentially detrimental. The “abnormal subjects” whose breast cancer was visible through their mastectomy or loss of other markers of the feminine, troubled ideologies of gender, femininity, a reality that suggested they could also push further the discourse of breast cancer. The work of the aforementioned artists and the further theorization of the relationship between breast cancer and femininity spoke to the dream Audre Lorde set up in her book, *The Cancer Journal*. Lorde committed herself to discussing the possibilities that during her time were unimagined and she establishes challenges for future generations to take up.

When other one breasted woman hide behind the mask of prosthesis or the dangerous fantasy of reconstruction, I find little support in the broader female environment for my rejection of what feels like a cosmetic sham. But I believe that socially sanctioned prosthesis is merely another way of keeping women with breast cancer silent and separate from each other. For instance, what would happen if an army of one breasted women descended upon Congress and demanded that the use of carcinogenic, fat stored hormones in beef-feed be outlawed?<sup>83</sup>

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<sup>83</sup> Audre Lorde, *The Cancer Journals* (Argyle: Spinsters, 1980) 16.



In the 1980s with the exposure of one-breastedness confined to the discipline of art, Lorde's envisioning of a one breasted army seemed farfetched but indicated future trajectories. In the spirit of the expansion of discourse and visibility I follow Lorde's suggestion by looking to the formation of breast cancer communities and their engagement with patients and non patients as the next point of inquiry.

### CHAPTER THREE

#### The Consumption of Cancer: Existing in "Cancerland"

Thus far I have attempted to elucidate the limited possibilities for thoughtful engagement with identities beyond the ideal patient in breast cancer discourse of the mid-to-late twentieth century. By placing observations about biomedicine and writing on mastectomy in conversation with the art of Wilke, Spence, and Metzger, we can better realize the confines of identity and expression placed on the women living with breast cancer. The distribution and exchange of power and expertise are alluded to throughout this project, but here their relevance and importance will hopefully become evident. My definition of power comes from Foucault who recognized "the new methods of power whose operation is not ensured by right but by technique, not by law but by normalization, not by punishment but by control, methods that are employed on all levels and in all forms that go beyond the state and its apparatus."<sup>84</sup> In keeping with Foucault my focus has not solely rested on the repressive forces of power but instead expanded into its creative agents, socially constructing options, preferences and subjects. This chapter in particular looks to question the embodiment of power, particularly how women adopted certain forms of behavior and simultaneously reiterated social norms.

The disciplinary practices described in this chapter, which is about consumption, come in the form of print and picture, both of which depict a specific type of breast cancer patient experience. The widespread availability and marketing of these items to the public raises questions of production: "Where are these images

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<sup>84</sup> Clare Chambers, *Sex, Culture, and Justice: The Limits of Choice* (University Park: The Pennsylvania State Press, 2008) 22.

and words coming from?” it also raises questions of consumption: “Who is influenced by popular culture and biomedical practices?” The work of the artists mentioned does not depict the privileged body of breast cancer discourse, but rather shows their own deviation from such a model and the social consequences of this deviation.

Openly viewing the explicit scars of mastectomy, thinning hair, and many other signs of a cancer diagnosed and treated body, I was struck by how uncomfortable I felt when I first saw these pictures. Many of the photographs were accompanied by text written by the artists and proved another source of discomfort. The combination of the visual and textual scholarship left me questioning my own understandings of what it meant to have breast cancer and wondering about the origins of the image of a cancer patient that was engrained in my mind. Aside from Metzger, the artists’ images have mostly been relegated to the realm of art galleries and academic settings, only recently becoming more popularly acknowledged.

The works of the artists are distinct from the socially and medically constructed ideal patient. The notion of the ideal patient has been influenced by changes in biomedicine, where there is a move towards the responsibility of the patient. The ideal has also been influenced by the social and historical climate that encouraged the disappearance of any physical signs of illness when engaging with the general public.

The breast cancer movement began in the midst of such denial of cancer, and it started with small groups of women gathering to discuss their personal tribulations with breast cancer. As women across the country met and shared their stories, they formed communities, which served as the basis for what would eventually become a

larger, more collective movement. The system of relations which determined the public face of breast cancer and served as a way of contextualizing the breast cancer movement and support groups consisted of the following: illness identity, collective identity and politicized collective illness identity. I will first explore the terms individually and conclude by drawing them together.

In this chapter the lived experiences and work of the artists will serve as one way of understanding the events defining and ultimately culminating in the culture of breast cancer of the 1970s, specifically the program of Reach to Recovery. Wilke, Spence and Metzger each received their diagnoses during the late 1970s to early 1980s. The timing of their diagnoses was crucial to contextualizing the art they produced and better understanding the breast cancer movement which sought to draw in all individuals who could be considered “women living with cancer.” I found it possible to see an analogous yet distinctive relationship between the strategies used by the artists and the breast cancer movement, as both privileged the biological body, emphasizing the importance of personal narratives and experience, but differed in their meaning making practices. In the book *Revaluing French Feminism*, Nancy Fraser placed the explanation of the social movement in “the historically specific social context [in] which this movement emerged.”<sup>85</sup> The women participating in and building the breast cancer movement in the United States had grown up during the era of women’s liberation and may have witnessed or even taken part in the abundance of consciousness-raising groups that characterized the period.<sup>86</sup> As patients began to

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<sup>85</sup> Nancy Fraser, *Revaluing French Feminism: Critical Essays on Difference, Agency, and Culture* (Bloomington: Indiana University Press, 1992) 177.

<sup>86</sup> Patricia A. Kaufert, *Women, resistance, and the breast cancer movement*, ed. Margaret Lock and Patricia Kaufert (Cambridge: Cambridge University Press, 1998), 290.

congregate around the shared identity of women living with breast cancer, people entered the conversation with varying expectations, which led to the manifestation of different factions and goals. The mission the women's health movement has historically been to address the deficiencies of the male orientation of medicine and specific to the breast cancer movement was the commitment to legitimizing the understanding of breast cancer illness experience as deeply rooted in being a woman. In this section I will discuss the organization called the Reach to Recovery Program, focusing on its merit as a site of exchange and engagement for breast cancer patients, as well as on its limitations as a space which reiterated heteronormative values regarding the "sick woman." The program served as a widely recognized example of a representation of the breast cancer experience for patients and non patients alike and I will thus compare and contrast it with the work of the three artists who also provide images of cancer for those same populations. None of the artists mention the program in their photography or written work but by engaging the artists in conversation with ideologies from the program I found myself understanding how the artists envisioned community and identity creation in the midst of totalizing forces.



Hannah Wilke, Intra-Venus Series # 4, July 26 and February 19, 1992, 1992-93. 2 panels: chromagenic supergloss diptych. 71 1/2 x 47 1/2" each. Courtesy of Donald and Helen Goddard and Ronald Feldman Fine Arts, New York.

### Adopting an Illness Identity

As individuals found ways to establish a definitive relationship between themselves as the disease, breast cancer transformed into a means of organizing. Whether this relationship was a source of tension or transformation, identifying cancer as having some connection to the self was crucial to the foundation of the breast cancer movement. Both Jo Spence and Hannah Wilke participated to some degree in identification with their disease, as illness was featured prominently throughout their later artwork. Their engagement with cancer however, was decidedly unique from that of the early breast cancer movement. While both the artists and early movement were critical of the biomedical system, their portrayal and understanding

of being a woman with breast cancer had little overlap. Spence spent much time reflecting on the change in positioning that followed her breast cancer diagnosis, wondering where her body and self fit:

Providing images in order to have a dialogue with myself. The question is “Will I be a heroine or a victim?” The answer I gave myself was that I had no desire to be either; I merely wanted to be ‘seen’ as a person in the daily struggle to restore equilibrium and health to myself.<sup>87</sup>

The *Picture of Health*, an exhibit that became a touring show, made its debut in 1985. Spence, had taken documentary photographs of her time spent in the hospital while undergoing treatment for breast cancer. Most of the photographs were taken from the vantage point of the patient and included images both of herself and other women being treated on her ward. Finding power in knowledge, Spence set about the task of deciphering how institutions of “orthodox medicine” used photography and representation to assert their power over patients. Considering patients just as important as the parties who controlled the means of production, Spence placed emphasis on the consumers themselves and how what was being produced by medicine influenced the patient’s perception of self. Her identification with her illness in many ways dictated and determined the type of engagement she sought with establishments of medicine. Initially Spence did not envision disease as crucial to her identity but upon further reflection and engagement with systems of medicine she began to think otherwise:

I wouldn’t say that I ever saw myself as an ‘ill’ person. Yet in retrospect, illnesses of one sort or another had dogged most of my life- most especially asthma, hayfever, eczema and bronchitis. These don’t sound much but were like a long running soap opera, appearing regularly at times of stress, exhaustion, over indulgence, environmental extremes- always being treated by

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<sup>87</sup> Jo Spence, *Putting Myself in the Picture: A Political, Personal, and Photographic Autobiography* (London: Camden Press, 1986), 158.

drugging or surgery. At 28 years I developed an ovarian tumor (14 pounds weight at the time of my operation), as a result of the ‘side effects’ of steroid treatment for asthma. And still I didn’t learn. Years later, after two attempts to detoxicate myself through naturopathic medicine (my liver having virtually packed up) and each time running out of money to continue with such private treatment, I eventually had breast cancer diagnosed.<sup>88</sup>

In the journey and eventual arrival to a diagnosis of breast cancer Spence personally experienced the isolation of certain medical treatment, and her physical body felt the impact of powerful chemicals and drugs, that in her case, caused further harm. These moments--from her early interaction with asthma, to her later cancer diagnosis--all served to build her identity as one influenced by disease.

Wilke similarly incorporated illness into her sense of self, continuing her tradition of self exposure following her diagnosis of lymphoma. She not only sought to establish connection with herself and her changing body but also encouraged others in her audience to reevaluate their own perceptions of the human form.

Women do need to fall in love with themselves, to be positively narcissistic, self-exploratory. In general, society does not foster this for women or men, but the way in which society directs women to its/their obsession with feminine appearance is a gender-specific channeling and abuse of energy that discourages women from deep self reflection. Such thinking could serve as a catalyst for change, and societies tend to preserve their traditions. Narcissus died looking at his reflection, but women who submit to the negative tradition of narcissism will die knowing only a false reflection.<sup>89</sup>

Consumption came as a recurring theme in the work of Wilke. Building a career on the manipulation of her body, Wilke produced pieces that challenged the male gaze and asserted her sexuality as independent from such gender normative ideologies.

Thinking through Wilke’s lens, I understood the sometimes indulgent celebration of

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<sup>88</sup> Jo Spence, February 1986. SPARERIB, no. 163.

<sup>89</sup> Thomas Kochheiser, *Hannah Wilke: A Retrospective* (Columbia: University of Missouri Press, 1989) 63.



self to be extremely powerful but often confused with the consumption of “gender specific channeling.” While Wilke offered her viewing public images of what she distinguished as “positive narcissism,” she acknowledged that every day the public, women in particular, were bombarded with images of a less transformative variety that served to re-inscribe individuals within the web of heteronormative traditions. Disease became yet another vessel through which she could express the objectification of women.

### Creating Collective Space

Cultural accounts of cancer such as those coming from these artists gave voice to metaphorical and ideological ideas about disease and the bodies it inhabited. Themes of domination, objectification and transformation run throughout the various images produced by Wilke, Spence, and Metzger, themes that were often both echoed and ignored when breast cancer entered the realm of popular media and culture. The cultural messages expressed through mainstream popular media, specifically film and print, and the work of the artists themselves command the main focus of this chapter. My usage of such an array of mediums is an attempt to argue their position as part of a spectrum, speaking to different possibilities of experience. While the two realms are not mutually exclusive noteworthy differences exist between them. After contextualizing the time period I make the shift to discussing the program of Reach to Recovery, illuminating how it was truly a product of breast cancer discourse and how it has been engaged with during the mid to late twentieth century.

If analyzed in a vacuum the art produced by Wilke, Spence, and Metzger would merely remain examples of an individual illness experience and identity. Their

critique and response to biomedical discourse and social pressures would be overlooked. However, as work existing and prominently displayed in public settings like that of an art gallery, their individual experiences have become something more than personal renditions of a particular reality. They spark reaction. Using Della Porta and Diani's definition of social movements as "informal networks based on shared beliefs and solidarity which mobilize around conflictual issues and deploy frequent and varying forms of protest,"<sup>90</sup> it is possible to envision how the photographs in question could function as a means of bringing about informal networks and the emergence of collective identity. The art produced made demands for some type of response about cancer from the viewing audience and reflected certain ideas about the deficiencies of medicine and the importance of the individual. Such themes are echoed in the tenets of health social movements which are forces that as a collective pose "challenges to medical policy, public health policy, and politics, belief systems, research and practice that include an array of formal and informal organizations, supporters, networks of cooperation and media."<sup>91</sup> Both the work of the artists and the development of health social movements were precipitated by an emerging public belief in the limitations of medical science and political authorities in solving persistent health problems, ethical issues of scientific knowledge production, and a desire for greater participation in policies impacting the lives of the general public. The breast cancer movement is not only exemplary of a health social movement but more specifically of an embodied health movement which is distinctive based on its

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<sup>90</sup> Phil Brown, Stephen Zavestoski, "Social movements in health: an introduction," *Sociology of Health and Illness* 26 (2004) 679-694.

<sup>91</sup> Scott Frickel, Kelly Moore, *The New Political Sociology of Science: Institutions, Networks, and Power* (Madison: University of Wisconsin Press, 2006), 254.

reliance and use of embodied experiences of people with the disease to challenge existing medical knowledge and practice, as well as its recruitment of activists and commitment to collaboration with scientists and health professionals.

The moves made against the Halsted radical mastectomy by doctors and patients alike represent some of the first indications of a burgeoning movement. The publication of *Our Bodies, Ourselves* by the Boston Women's Collective and the emergence of the "cancer narratives" genre in the 1970s sparked the first wave of the breast cancer movement. The goal was to make women greater participants in their own health outcomes and to give public acknowledgement to the presence of cancer. The previously mentioned stories of First Lady Betty Ford and "Happy" Rockefeller were the first indications that breast cancer had begun to enter media and public consciousness. A few years later the first national breast cancer organization, Y-ME, was established in 1978. Operating bilingual (Spanish and English) national hotlines, the organization distributed information and offered support to women with breast cancer and their families. During this period: "The mainstream breast cancer awareness movement replaced the stigmatisation, isolation and invisibility of women with breast cancer with a new public culture overflowing with symbolic gestures of support, solidarity, respect and recognition. The public identity of women with breast cancer was transformed from tragic victim to heroic survivor."<sup>92</sup>

### The Privatization of the "Big C"

Popular media became a vessel of knowledge for the masses because of its accessibility. This great impact of film, magazines, and books has been long

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<sup>92</sup> Maren Klawiter, "Breast cancer in two regimes: the impact of social movements on illness experience", *Sociology of Health and Illness* 26 (2004) 845-874.

recognized by the government of the United States, which has subsequently relied on mass media to disseminate information about various health issues: “The potential for democratization integral to mass media initiated with printing technology during the Renaissance, and developed through the rise of the publishing industries, and now newspapers, radio and film technologies have transformed class distinctions that used to determine access to the production and reception of culture.”<sup>93</sup> Particularly during times of war and conflict newsreels, pamphlets, and posters conveyed to the American public what they should be looking out for in regard to disease. The anti-venereal disease campaign of World War II provides a salient example of the impact media played in popular understandings of disease. Through health education films and posters the United States army effectively conveyed the dangers of the disease and subtly cast women--both American and those from abroad--as the sole carriers, equating them with the foreign enemy. More than just purveyors of knowledge, media also presents “those images, concepts and premises which provide the frameworks through which we represent, interpret, understand, and ‘make sense’ of some aspect of social existence.”<sup>94</sup> In examining women’s magazines and pamphlets created by the American Cancer Society and the American Society for the Control of Cancer (ASCC), it is possible to see the promotion of certain cultural ideologies, specifically ideologies about womanhood, the body and disease. It is important to acknowledge that most of the magazines and other documents drawn from the period leading up to the 1970s privileges and target women who are white, middle class, heterosexual, and/or willing to adopt an optimistic outlook towards cancer. The privileging of a

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<sup>93</sup> Claire Pajaczkowska, Fiona Carson, *Feminist Visual Culture* (New York: Routledge 2001) 223.

<sup>94</sup> Stuart Hall, *The Whites of Their Eyes: Racist Ideologies and the Media* ed. Gail Dines, Jean Humez, (London: Sage Publications, 2002) 18.

specific experience not only lessened the importance and attention given to other communities, but also implied their inconsequence.

When the ASCC was founded in 1913, it was during an era marked by a general reticence to undergo regular checkups when the individual felt well. The fear of finding disease and experiencing painful treatment kept many out of the doctor's office, while others expressed cynicism about the possibility of researchers developing a cure for cancer. To appease such apprehension the ASCC set about the task of creating a public education campaign to bring informed knowledge to the masses. In an article in progress, David Cantor analyzed the first breast cancer education movie distributed by the ASCC. The film features a series of characters, one set of which is a married couple, the Flints. Initially, Mrs. Flint turns to an oral treatment unrecognized by the medical profession, "Radiumized Paste," but before the transaction for the product is completed her husband intervenes. The next scene finds them six years later after Mrs. Flint has undergone a medically approved operation. Thanking her husband from saving her from the swindle Mrs. Flint states: "Yes, but I might have waited too long except for you. Dr. Clinton says it was only successful because it was taken in time."<sup>95</sup> The campaign spawned by the ASCC was meant to expose the hazards of quackery and direct the public towards trusting and exclusively consulting with physicians. Within the film was a marked disregard for anything beyond the Western medical model, a sentiment that was then passed along and adopted by the viewing public.

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<sup>95</sup> David Cantor, *Before Survivorship: The Moment of Recovery in twentieth century American cancer campaigns* (Bethesda: National Institutes of Health History Office, 2010) 10.

In moving into the 1940s and 1950s, popular publications depicted the major threats to health as residing in the environment right outside the body, such as the home. Most literature heavily emphasized the idea of cleanliness, identifying it as the main line of defense against disease. An elementary school text book, from the era cautioned, “You must be on guard at all times. Disease germs are always on hand to attack. Be clean in everything you do. Remember, you must keep your hair and scalp, your fingernails and toenails, and your clothing clean as well as your skin. Keep fighting to destroy disease germs. Form habits that will protect you from harm.”<sup>96</sup> Not necessarily directed towards the defense against cancer, the attention to cleanliness indicated the perceptions society held towards disease in general. The ideas of health from the 1950s brought about a heightened importance of domesticity, as homes became sites where women had to ensure everything was hygienically clean; “commodities of cleanliness, from Lysol to an automatic washer, became the housewife’s companions”<sup>97</sup>.

The first mention of personal responsibility for detection appeared in a 1953 publication of *Woman’s Home Companion*, in the article titled, “You Can Fight Cancer in Your Own Home.” The title alone underscores the beginnings of a blurring divide between the individual versus the shared, bringing the disease of cancer into the intimate setting of the personal household as opposed to the physician’s office or another more communal setting. It seemed then that early detection would be public prescribed but would remain a personal family matter. The privatization of early

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<sup>96</sup> Emily Martin, *Flexible Bodies: Tracking Immunity in American Culture--From the Days of Polio to the Age of AIDS* (Boston, Beacon Press, 1994) 27.

<sup>97</sup> Emily Martin, *Flexible Bodies: Tracking Immunity in American Culture--From the Days of Polio to the Age of AIDS* (Boston: Beacon Press, 1994) 31.

detection implicit in the article was aided by the connection it drew between domesticity and breast self examination, recommending women utilize early detection strategies that take “less time than it takes to darn a pair of socks.”<sup>98</sup>

During the 1950s the expectation was that the domestic sphere was the woman’s domain, a relationship the magazine capitalized on to get the message of personal responsibility across. The message put forth by *Woman’s Home Companion* was in some ways ahead of its time as the theme was absent in many women’s magazines throughout the 1960s, only to resurge in the 1970s as a result of the Women’s Health Movement. Though spatially separated by a number of years both the film and the *Woman’s Home Companion* article represented the same regime of breast cancer discourse. The unquestioned knowledge of medical professionals, and the generalized fear of cancer diagnosis and treatment characterized this period. Many public health campaigns chose to predominantly focus on eliminating the fear, thus placing more emphasis on early detection and procedures of treatment. Absent from film and literature were discussions about what happened next and outlets for patients to express their frustrations and concerns. The campaigns were able to convey cultural messages about breast cancer but as evidenced by the content of cancer narratives detailing experience during the 1960s and 1970s those living with the disease were not satisfied.

#### Reach to Recovery

Reach to Recovery first began as a booklet published in 1953 and was then crafted into a mutual support organization by Terese Lasser. Lasser identified as a breast cancer patient who had undergone radical mastectomy and recognized an

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<sup>98</sup> J.D Ratcliffe, “You Can Fight Cancer in Your Own Home” *Woman’s Home Companion* (May) 44.

absence of resources and advice for others in her position. In the early history of the Reach to Recovery Program, Lasser attempted to partner with the American Cancer Society, but the Society held out on incorporating the Reach to Recovery program into its folds until 1969. The design of the group was that of a peer--based, one-on-one, hospital visitation program. Lasser often managed to sneak herself into the rooms of patients with breast cancer, bringing them starter 'falsies' which simulated breasts, and educating them about exercises to help with post mastectomy arm function as well as talking to their spouses about sexual intercourse. At that time, though much literature regarding the program suggested uniform disfavor of her work among hospital staff, as more and more women underwent mastectomy doctors acknowledged the need for more information on post-operative life. Once Reach to Recovery formalized its partnership with the American Cancer Society, volunteers for the program were forbidden from bestowing any medical advice to the patients they visited.<sup>99</sup> Also in order for an individual to receive a visit from a Reach to Recovery volunteer the doctor, not the patient, had to submit the request.

While Reach to Recovery served the purpose of creating social supports for new mastectomees, the program's philosophy towards illness subsequently rendered the cancer experience invisible and thwarted certain trajectories in the development of illness identity. Emotional support was understood as a significant component of the organization, but support was provided only through portraying breast cancer as a survivable disease. The use of the word *only* is of utmost significance since the experience and recovery process of cancer was anything but universal. In Klawiter's

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<sup>99</sup> Susan Ferguson, *Breast Cancer: Society Shapes an Epidemic* (New York: St. Martin's Press, 2000) 327.



book on breast cancer she included the chapter “Biomedicalization and Anatomico-Politics,” where further explored the philosophy of Reach to Recovery through its choice of volunteers:

To this end, Reach to Recovery volunteers, all ex-breast cancer patients, were required to be (ostensibly) cancer-free, to behave in an upbeat and optimistic manner, and to present an attractive, heterofeminine appearance that was wholly indistinguishable from the appearance of cancer-free women. They were required, in other words, to appear as “normal” and as “normalized” as could be.<sup>100</sup>

The selection criteria for a program volunteer further illustrated the specificity of illness identity and expectations for those living with breast cancer by support groups. According to the Reach to Recovery International website, an ideal volunteer was a breast cancer survivor who: “is physically fit, has adjusted psychologically to treatment, has completed her treatment more than one year before, models a return to good health, is recommended as suitable by her doctor, is ready to work as part of a team, is able to articulate effective coping strategies, is committed to continuing training, education, and supervision.”<sup>101</sup> Prominently featured in the criteria was the strict adherence to the biomedical model and the presentation of being both mentally and physically “cured” of breast cancer. By giving the appearance of a large group of survivors as being beyond breast cancer, Reach to Recovery was able to construct the disease as a fleeting moment in time. After completing treatment, patients could resume their lives, and the volunteers were meant to serve as their guiding examples. In many ways Reach to Recovery was born out of disparagement with the previously

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<sup>100</sup> Maren Klawiter, *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (Minneapolis: University of Minnesota Press, 2008) 119.

<sup>101</sup> Reach to Recovery International, *The Reach to Recovery Volunteer*, [http://www.reachtorecoveryinternational.org/index.php?option=com\\_content&view=article&id=111&Itemid=117](http://www.reachtorecoveryinternational.org/index.php?option=com_content&view=article&id=111&Itemid=117) (January 2010)

available messages about breast cancer. The implicit trust of physicians and the emphasis on the medical practices of treatment as opposed to the patients themselves shaped its establishment. But as Klawiter made clear, though patients in general were the focus of the program and former patients executed its mission, all are also expected to normalize themselves, an expectation not all that different from the health campaigns of the 1950s and 1960s.

As a peer-based organization, the creation of community became an important tenet of Reach to Recovery. Providing women with breast cancer a space where they could connect and communicate with other women who shared similar experiences served as the very foundation of the organization. This community was met with a favorable response by many patients but to others, and to people outside of the experience, the organization presented a potentially problematic image of breast cancer. In describing the program after its partnership with the American Cancer Society during the 1970s, Dr. William Markel shared the following statement:

I think the big bang in Reach to Recovery is when the patient in the bed looks up and a woman comes through the door. (And we insist [that she] wear a tight fitting gown so that both breasts show and her hair is all combed.) We think we've made it then at that point.<sup>102</sup>

The functioning of the program reiterated the temporary nature of breast cancer, taught women how to conceal their illness, and emphasized the return to normality. These measures were taken to help prevent women from thinking of breast cancer as a type of disability or ongoing hardship. When Audre Lorde reflected on her own

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<sup>102</sup> Maren Klawiter, *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (Minneapolis: University of Minnesota Press, 2008) 119.

visit by a volunteer from Reach to Recovery she was turned off as her visitor discussed “what man I could capture...[and] whether my two children would be embarrassed by me in front of their friends.”<sup>103</sup> Then handed stuffing to put in her bra, Lorde articulated that the whole ordeal felt like a denial of her pain and loss, ending discussion about her survival, cure and cause. The limitations and deficiencies of the philosophy for Reach to Recovery were issues taken up in all of the artists featured in this project. Though the program was never explicitly mentioned in the writings published by Spence, Metzger, or Wilke, by looking to their work it was possible to understand their distinct understanding of breast cancer identities and the communities that they sought in response to the discursive forces that confined their means of experience.

### **Questioning the Consumption of Breast Cancer Discourse**

In the “Intra Venus” series, “The Picture of Health”, and the photograph of “Warrior,” it was clearly evident that the pictured subject was suffering from illness. No barrier obstructed the image between viewer and subject, leaving each viewer to fully come to terms with what was being shown. Whereas the relationships formed through Reach to Recovery were most often based upon collusion to move past illness both in presentation and mentality, the relationships born out of viewing the chosen art differ in foundation. The point here is not to ascertain which relationship is “better” but rather to speak the infinite possibilities that should be available for expression of living with breast cancer as opposed to the limited options initially

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<sup>103</sup> Audre Lorde, *The Cancer Journals* (Argyle: Spinster, 1994), 35.

offered. Audre Lorde experienced the following realization in her personal narrative: “Off and on I kept thinking. I have cancer. I’m a black lesbian feminist poet, how am I going to do this now? Where are the models for what I’m supposed to do in this situation? But there are none.”<sup>104</sup> Moving away from behaving in the manner that was expected, Lorde and the artists ventured into the unknown, reconstructing their own identities based on their cancer experience.

On October 15th, 1984 Spence had pictures taken of herself that showed her body following lumpectomy. While I had normally distinguished Spence’s artwork by the unwavering eye contact of the pictured subject, in the October 15th photographs her head and eyes were downcast. This image was precisely what the Reach to Recovery program avoided, instead opting to return to some assimilation of “normal”. Though healing for some as Spence described, it was not the space for her:

Women attending hospital with breast cancer often have to subject themselves to the scrutiny of the medical photographer as well as the consultant, medical students and visiting doctors. Once I had opted out of orthodox medicine I decided to keep a record of the changing outward condition of my body. This stopped me disavowing that I have cancer, and helped me to come to terms with something I initially found shocking and abhorrent.<sup>105</sup>

The spatial, temporal, and social relations of breast cancer in the work of Spence drastically diverged from that of the Reach to Recovery Program, with the former extending and exaggerating each domain of space, time and social engagement. Breast cancer became an important component of Spence’s identity, using it in her artwork and thus transforming it into a lens through which to understand and present

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<sup>104</sup> Audre Lorde, *The Cancer Journals* (Argyle: Spinster 1986) 28.

<sup>105</sup> Jo Spence, *Putting Myself in the Picture: A Political, Personal, and Photographic Autobiography* (London: Camden Press Ltd, 1986) 166.

herself. Alternatively, Reach to Recovery was often seen as adopting anti-identity policies, that necessitated the severance of ties from the disease and to continue on as though nothing happened.



Jo Spence, *Cancer Lumpectomy* (1986) "The Picture of Health". Courtesy of Terry Dennett

### **Autopathography: "Life writing about illness"**

Thomas Couser, a scholar of disability studies considers autopathography, "a sign of cultural health--an acknowledgment and an exploration of our condition as

embodied selves.”<sup>106</sup> In much of her writing Spence referred to her photography as a form of catharsis, a means of expressing her frustrations and questions regarding her body as she faced her experience with cancer. The selected artists in this project provided visual displays of personal engagement with disease. Their work comes out of the historical development of cancer narratives, a type of literature whose roots are attributed to the high death toll in the United States from breast cancer, the “slash, burn, and poison” of cancer treatment, and activist approaches spawned from the budding social movement around cancer. Emerging in the 1970s, much of this literature spoke to the borders that confined women living with breast cancer. The most well known examples of autopathography include--Rose Kushner’s *Breast Cancer: A Personal History and an Investigative Report*; Betty Rollin’s *First, You Cry*; Susan Sontag’s *Illness as Metaphor*; Audre Lorde’s *The Cancer Journals*; and Leatrice H. Lifshitz’s anthology of poetry, *Her Soul beneath the Bone*.<sup>107</sup> Much of this literature offers counter-hegemonic treatments of cancer but others on the list perpetuate popular conceptions of cancer as “ultrafeminine”:

In the mainstream of breast cancer culture, one finds very little anger, no mention of possible environmental causes, few complaints about the fact that, in all but the more advanced, metastasized cases, it is the “treatments” not the disease, that cause illness and pain. The stance toward existing treatments is occasionally critical...but more commonly grateful; the overall tone, almost universally upbeat.<sup>108</sup>

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<sup>106</sup> Thomas Couser, *Recovering Bodies: Illness, Disability, and Life Writing* (Madison: University of Wisconsin Press, 1997) 218.

<sup>107</sup> Mary DeShazer, *Fractured Borders: Reading Women’s Cancer Literature* (Ann Arbor: University of Michigan Press, 2005) 4.

<sup>108</sup> Barbara Ehrenreich, “Welcome to Cancerland: A Mammogram Leads to a Cult of Pink Kitsch”, *Harper’s Magazine*, 2001.

The themes and metaphors offered in cancer literature vary greatly but it is possible to identify three areas of meaning that seem to appear throughout narratives of cancer: (1) breast cancer as equated with death or alternatively, as manageable and survivable; (2) treatment for breast cancer as compromising to a women's identity, femininity, and self-worth; and (3) breast cancer as an experience that should not be openly discussed. These categories seem to offer assistance to some patients of breast cancer, but in looking to interviews conducted Marcy E. Rosenbaum, Ph.D., and Gun M. Roos, Ph.D., I found that sometimes it was more beneficial for women to reject rather than accept pervasive cultural models regarding breast cancer. The pair conducted individual, semi-structured, open-ended interviews, with 40 women ranging in age from 32 to 70 years old. Beginning interviews from within a few weeks of patients' diagnosis, the researchers periodically met with patients at six weeks, three months, and six months following surgical treatment. Out of the initial forty, thirty of returned for interviews four to five years after their initial diagnosis. One of the participants, Claire, received her diagnosis at age 32 and subsequently underwent a lumpectomy and chemotherapy. A year and a half later, she was diagnosed with a recurrence and decided to receive a modified radical mastectomy with immediate breast reconstruction. When reflecting on her two engagements with cancer and their meaning to her, Claire offered the following:

I have felt this bout of cancer much more deeply than I felt the other one. In a way, I think it had really changed me quite a bit. Before, it just washed right away. And this time there was the shock of having the cancer to deal with and then there was the shock of the changes in my body. I'm just very glad that the surgery worked. I'm beginning to feel like a whole person. I compare it to being raped, actually. You go through the process of trying to escape, trying to deny it. And then you say, "My God, I really have this. This is really

happening to me. And then there is a lot of depression. And you see a changed life. But being the optimist that I am, I think that it will continue to get better.<sup>109</sup>

From Claire's interviews it was evident that she was conscious of the dominant cultural models of breast cancer that surrounded her. In reading her responses, I gleaned a brewing conflict between ascribing to more of the Reach to Recovery philosophy in believing it was possible to move past cancer and the theme of cancer as equated with death. Instead of engaging with either of those socially constructed models, Claire alternatively relies on her own experience. But even with such a decision, a great deal of ambivalence pervaded throughout Claire's statements, especially one shared six months after her recurrence:

How do I describe this experience? In some ways, like any tragedy...its had some good points like bringing me closer to my dad. [However], the good that came wasn't worth the price. So, it has really been an awful thing in my life. I guess in my coping I try to see the good and the bad. But this has been really bad. I don't care that I learned that beauty isn't important. So I was shown that lesson. And it is true that beauty isn't important. But I would rather not have learned that lesson and not have my body mutilated, my health threatened. Some of the cares of the world have left me. I've lost some of the carefreeness of youth, I feel older. There's some regret. There's also a lot of peace. Bittersweet.<sup>110</sup>

Claire's experience, as well as those of the other women who participated in the interviews are further example of the need for discourse that better reflect the diversity of women's experiences with illness. Much of the basis for alternative feminist discourse, including that of the three artists, comes from the desire to give a revision of ill bodies, which are frequently represented as: medicalized, leaky,

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<sup>109</sup> Susan Ferguson, *Breast Cancer: Society Shapes an Epidemic* (New York: St. Martin's Press, 2000) 164.

<sup>110</sup> Susan Ferguson, *Breast Cancer: Society Shapes an Epidemic* (New York: St. Martin's Press, 2000) 178.



amputated, prosthetic and (not) dying. These categories identify the most common ways of framing the experience of living with cancer and are featured in varying forms in the work of the artists.

All of the artists featured in this project engage with the idea of the medicalized body, as each underwent invasive surgery and experienced both possible and partial recovery. As they seek to speak for themselves through their photography, the unseen specter of medical intervention and authority was ever-present. The artists collectively shared the burden of posing and answering questions of appropriation and agency in the midst of biomedical cancer diagnosis and treatment. The next theme of the “leaky body” was one that Wilke most explicitly addressed. In her *Intra Venus* series, the loss of control and contamination of her body by illness spoke of instability and exposed the precarious nature of femaleness and femininity. The significant absence that characterized the “amputated body” was one that all of the artists experienced but was embodied most prominently by Metzger. The removal of her breast following mastectomy and the subsequent relationship she developed with her body was deeply influenced by the loss of an organ deemed essential to femininity. Initially the “prosthetic body” merely prompted the image of surgical reconstruction but as described by David Willis, such a body was more complicated and in actuality represented the norm, as “all bodies are deficient in that materiality proves variable, vulnerable, and inscribable.”<sup>111</sup> Both Metzger and Spence underwent mastectomy as part of their cancer treatment and both refused to pursue reconstructive options. Their understanding of the mastectomized chest as respectively

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<sup>111</sup> David Willis, *Prosthesis* (Stanford: Stanford University Press, 1995) 137.

beautiful and defiant appears in line with another feminist of the period, Lorde, who believed, “when other one-breasted women hide behind the mask of prosthesis or the dangerous fantasy of reconstruction, I find little support in the broader female environment for my rejection of what feels like a cosmetic sham.”<sup>112</sup>

### **Existing in “Cancerland”**

The five tropes used to conceptualize ill bodies emphasized how stigmatization could remove the sick women’s subjectivity. This relationship was crucial as women during the 1970s and 1980s pushed to receive recognition and support for those living with breast cancer. After the adoption of Reach to Recovery by the American Cancer Society, Rose Kushner made a substantial push for the organization to modify its philosophy and focus on the long term physical and emotional consequences of cancer treatment. Her suggestions went unheeded. In 1975 Kushner founded the Breast Cancer Advisory Center which utilized a hotline and mail service to educate men and women alike about breast cancer. In between the years of 1975 to 1982 the center responded to over 20,000 callers.<sup>113</sup> A catalyst for the creation of other support groups, a year later in 1976, the Post Mastectomy Discussion Group was established in New York. The discussion group eventually evolved into the Self-Help Action Rap Experience (SHARE) which was a organization committed to allowing women to support one another through their own experiences with cancer. As breast cancer moved into the mid to late 1980s the forms of assistance available to patients expanded from support groups to a more political

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<sup>112</sup> Audre Lorde, *The Cancer Journals* (Argyle: Spinster, 1980) 16.

<sup>113</sup> Roberta Altman, *Waking Up/Fighting Back: The Politics of Breast Cancer* (Boston: Little, Brown and Company, 1996) 295.

orientation. In her book *A Darker Ribbon: Breast Cancer, Women, and Their Doctors in the Twentieth Century*, Ellen Leopold spent time reflecting on the conflict between women and the medical establishment that was intrinsic to the breast cancer movement, “When the battle joined patriarchy with pathology, a different dynamic arose. Where male authority and expertise were believed to be tied up with life-saving skills, the habitual female response of total surrender was much harder to dislodge. If the physician was all that stood between a newly diagnosed woman and death, it would be not just foolish but possible suicidal to put sexism over survival. Who would risk it, for the sake of principle?”<sup>114</sup> Despite such a tension breast cancer activists took the lead from the women’s health and AIDS movements, setting about the task of becoming active participants and decision makers in their own treatment. The AIDS movement in particular represented a comparable model of a single-disease, consumer based groups, whose activists had garnered public acknowledgment and proven that alternatives to becoming a compliant patient were possible. At the Surgeon General’s Conference on Self-Help in 1987, Lee Miller, the president of SHARE discussed the most pressing issues that support groups faced and indicated the trajectory that both individuals and the movement must take, “We need to feel in control again, even if we know it is an illusion in the grand scheme of things. We need to feel we can take charge of our own bodies, be informed medical

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<sup>114</sup> Ellen Leopold, *A Darker Ribbon: Breast Cancer, Women, and their Doctors in the Twentieth Century* (Boston: Beacon Press, 1999) 249.

customers, and participate fully in decisions regarding our health. An uninformed choice is not a real choice.”<sup>115</sup>

The work of the artists, Wilke, Spence, and Metzger inspired my interest in this research as they offered conversations I had not previously engaged in. With that in mind it felt fitting to conclude this section on the consumption of breast cancer with at least one of their own reflections about the impact breast cancer on their lives. By no means all encompassing, the artists’ musings over the course of this project highlight the difficulties in maintaining the identity of a breast cancer patient, and a patient in general. In this chapter there was a disconnect between the image of breast cancer constructed for the public and the actual experience of the disease by patients. My aim has not been to conclude whether or not such differences are reconcilable but to maintain that such a difference need not exist in the first place. In my eyes Spence’s retelling of her experience read just like a script, meaning that the words and actions of doctors and patients were so routinized as to become inherent.

If I were to ask myself the one thing that I have learned as a result of having cancer it is just simply that I never realized how powerless I really was, and how few rights in the world I had, until a young man in a white coat whom I had never seen before surrounded by others similarly clad, stopped at my bedside in a provincial English hospital, ruffled through some notes clamped to a board, leaned over me and drew a large black cross above my breast, uttering those memorable words, “That’s the one that is coming off!” From that moment on I was on total alert. I began to search for a treatment which could recognize me as a whole human being, and not as parts to be disposed of; one that would take account of my physical, psychic, social and spiritual

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<sup>115</sup> Roberta Altman, *Waking Up/Fighting Back: The Politics of Breast Cancer* (Boston: Little, Brown and Company, 1996) 300.

self. I even investigated my legal position in relation to suicide and euthanasia.<sup>116</sup>

The development and operation of support groups like that of the Reach to Recovery program and subsequent breast cancer activism, served to further confuse the distinction between socially constructed and inherent, making the statement of “That’s the one that is coming off!” something to be expected. My take on the artists was that they intended to emphasize and critique the consumption of socially constructed notions of what it means to be a woman living with breast cancer.

The safe images of breast cancer presented by the breast cancer movement and through the functioning of Reach to Recovery brought to mind the Mastuschka image from the chapter “Meanings of Metaphor and Fetish in Breast Cancer Discourse” as a point of contrast. Just as Mastuschka’s magazine cover was offset by other more “acceptable” portrayals of cancer, the corporatization of breast cancer in the twentieth first century has produced a whole new crop of “proper” cancer actions and identities. The pink ribbon culture that dominates discussion about breast cancer today has allowed companies to capitalize on the popularity of the disease. Creating an environment where cancer can be “cured” through the purchase of a lipstick or a vacuum cleaner, has very real consequences for women both living and not living with cancer. In looking to the type of products sold under the guise of curing cancer, it is possible to see the perpetual feminization of the disease, as most of the goods are marketed towards women. In a document drafted by the group, Breast Cancer Action, a list of corporations benefitting from the product placement permitted by the status of breast cancer as a feel-good cause. The list included: “...Cartier’s Roadster Watch

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<sup>116</sup> Camerawork Ltd, *Silent Health: Women, Health, and Representation* (New York: Hyperion Books, 1990)

(\$3,800), Breast Cancer Awareness Tweezers (\$20), Pink Ribbon Tic Tacs (\$0.79), an Estee Lauder lipstick named Elizabeth Pink (\$22), Essie Pink Ribbon nail polish (\$7), 3M Pink Ribbon Post-it Notes (\$1.99-\$4.95), an assortment of Ralph Lauren Pink Pony Products (\$10-\$498), Playtex Passion for Living pink gloves (\$2.99), Pink M&Ms (\$2.99), Qwest and Sanyo pink cell phones (from \$79.99), and Everlast pink boxing gloves (from \$30).”<sup>117</sup> In addition to contributing to the further feminizing of breast cancer, such tactics also have led to the definition of “pinkwasher”, defined as: “A company that purports to care about breast cancer by promoting a pink ribboned product, but manufactures products that are linked to the disease.” With the emergence of these types of business practices and the continued emphasis on “proper” ways of handling breast cancer, I am left wondering how much has actually changed since the late twentieth century and what direction we should continue in.

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<sup>117</sup> Maren Klawiter, *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (Minneapolis: University of Minnesota Press, 2008) 254.

## **CONCLUSION**

### **Thinking Through Today**

What is relatively recent is that now, at the tip of the fingers, there lies a gateway to knowledge that is constantly being regenerated and supplemented. This means that all decisions are subject to continual reassessment because the risk role never ends--not prior to, not during, and not even after treatment is completed. (Maren Klawiter 2008: 272)

Spence and Wilke were never able to see if their beliefs in the prominent display and engagement with the one-breasted women were realized as they both died from cancer in the early 1990s. Metzger is still with us and creating art. In reflecting back on the circumstances at the time of the artists' cancer diagnoses, I wonder what their reaction would be to discourse of breast cancer today.

The framework of this project has truly been the lifework of Metzger, Wilke, and Spence. Their engagement with medicine and their subsequent renderings of self influenced the organization of each chapter, as I built the argument that the experience of living with breast cancer during the late twentieth century was highly fragmentizing. A unifying theme in the photography of the artists was the event of breast cancer diagnosis followed by disjunction in identity. The artists' unique means of addressing such a change in self-perception underscore the infinite identities available to patients of chronic illness. However, as the artists showed, this infiniteness is heavily inhibited by forces such as biomedical discourse and the metaphors implicit in popular cancer discourse.

Over the course of this project I recognized my own limitedness in how I had conceptualized the identity of breast cancer patients. I became aware of my unquestionable reliance on biomedicine as a source of treatment and the localization of risk and responsibility into my sense of personhood. I wondered what my own

response to mastectomy would be and if I would feel represented by and connected to any sector of the breast cancer movement. While I found the work of the artists to be helpful in elucidating the issues inherent in discourse on breast cancer, I by no means meant them to serve as prescriptive or totalizing forces. Reading the art of Spence, Wilke, and Metzger as the “right” way to deal with cancer would only reify the norms of the breast cancer experience that I attempted to challenge.

As I look around at the current state of breast cancer as a disease and social movement, I wonder what the artists would think. Would they feel better supported in the 21st century or is breast cancer still as fragmentizing an experience as it was in the 1980s? The silencing of breast cancer and the patient’s experience, both in public discourse and institutions of medicine, was often alluded in the artists’ pieces. Currently, breast cancer has spurred new media campaigns, as the disease has transformed into a powerful means of product promotion. It also calls to attention to a prominent issue of the 21st century: environmental health. The new images and representations of women with breast cancer have expanded the social spaces where cancer is discussed, allowing many groups to engage with the issues raised by these artists. One organization, the Breast Cancer Fund, developed an “Obsessed with Breasts Educational Campaign” in January 2000. Reminiscent of the photograph of Matuschka on the *New York Times Magazine*, the group printed a number of images, including one that “spliced the nude torso of a woman with a double mastectomy (Andrea Martin, the executive director of the BCF) onto the body of a model on the cover of a magazine that looked like *Mademoiselle*, *Glamour*, or *Cosmopolitan*.”<sup>118</sup>

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<sup>118</sup> Maren Klawiter, *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (Minneapolis: University of Minnesota Press, 2008) 249.



The difference between the campaign by the BCF and the Matuschka image was the content of the written pieces that accompanied the BCF visuals. The posters made by the group all featured rhetorical questions and statements such as: “Your Breasts: Not Just for Looks” and “Breast Cancer Epidemic: What’s behind It?” These were all meant to push the audience to think about what was actually being done about cancer. The general audience, however, had a negative response to what was termed “offending images” and the public outcry that followed the posters' unveiling forced the BCF to remove them from public spaces.

On, February 22, 2011 the *New York Times* ran the article, “A Familiar Canvas, Seen Anew in Diagnosis’ Glare” by a physician from Memorial Sloan-Kettering Cancer Center in New York. The author, Peter Bach, M.D. wrote about his wife, Ruth and her diagnosis with breast cancer. As Bach experienced the initial moments of feeling the lump in his wife’s breast and accompanying her for a biopsy, he expressed a sense of displacement from his position as a doctor:

I was hyperaware of my surroundings, as if I were a first-time visitor in my own hospital. Things that were around me every day of the week were suddenly new: the type and volume of forms Ruth was asked to complete; the conduct of the first secretary we met; whether the staff members introduced themselves by name.

As I read the article, I was conscious of the shift in perspective experienced by Bach. Here a medical professional caught a glimpse at what it was like to be a patient, going from a position of control and authority to one of mercy and uncertainty. The article, in tandem with the artists of this project, caused me to question the strict boundaries we set, not only between patient and doctor but also of proper and improper treatment, and individual and shared experiences. Perhaps these distinctions are not as

concrete as previously thought. I wish to end by reiterating that this work has been about broadening perspectives and acknowledging the ability of the featured artists to challenge and redefine our understandings of experiencing illness. Through their self expressed discomfort, rejection of “good” recovery and patienthood, and the issues they presented for physicians and the breast cancer movement to reconsider, the artists constructed narratives beyond the available model and demanded recognition of alternate identities.

I entered this work with unrealistic expectations of Wilke, Spence, and Metzger, wanting them to alter my way of thinking. When I began this project, I hoped that the lens through which I thought about representations of illness experience would become drastically transformed and startlingly clear. This is not the case. If anything, this research has taught me to obscure my own lens and to continuously question anything that claims one- or even two- dimensionality. As I articulated the importance of patients having a space to define their own experiences, where they could adopt any number of identities, I discovered that I wanted the same space for myself and others.

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