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Industry and Malady: Entanglements of Power, Culture, and Disease Afflicting Breast Cancer Patients in the Bay Area

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INDUSTRY AND MALADY: ENTANGLEMENTS OF POWER, CULTURE, AND
DISEASE AFFLICTING BREAST CANCER PATIENTS IN THE BAY AREA

A Thesis

Presented to

The Faculty of the Department of Anthropology
San José State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Arts

by

Brieann DeOrnellas

May 2022

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The Designated Thesis Committee Approves the Thesis Titled

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AND DISEASE AFFLICTING BREAST CANCER PATIENTS IN THE BAY
AREA

by

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APPROVED FOR THE DEPARTMENT OF ANTHROPOLOGY

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May 2022

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ABSTRACT

INDUSTRY AND MALADY: ENTANGLEMENTS OF POWER, CULTURE, AND DISEASE AFFLICTING BREAST CANCER PATIENTS IN THE BAY AREA

by Briann DeOrnellas

In 2021, the U.S Surveillance, Epidemiology, and End Results reported that approximately 281,550 women were diagnosed with, and 43,600 died of the breast cancer. About one in eight women will develop breast cancer in her lifetime, and breast cancer has the highest cancer death rate for women, excluding lung cancer. Moreover, breast cancer incidence rates in industrialized nations have risen over time, and women who emigrate from developed countries with low breast cancer incidence to localities in the U.S. with high breast cancer incidence have a dramatically increased lifetime risk of developing breast cancer.

Despite the seeming ubiquity of the disease, in the U.S., breast cancer is culturally understood as a disease that afflicts the individual; breast cancer is something that "just happens." However, when situated diachronically and alongside the historical context of war, agrochemical use, petrochemicals, plastics, and nuclear weapons use, as well as notions of American industrial and technoscientific "progress," these pockets of the country with higher rates of women's cancers become suspect. As industries ebb and flow over time, and humans and chemical carcinogens move across space, these situated maps become increasingly complex, obscuring links between breast cancer causation and affliction.

This master's thesis explores whether prevailing discussions of "lifestyle choices" or "genetic risk" are rhetorical controlling processes that divert attention from corporate, governmental, or other institutional accountability, and whether or not these discursive diversions shift culpability onto women who are at risk of—or living with—breast cancer.

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*We all play a part in creating the paradigms of love, support, and empowerment for one
another and ourselves. We do not do this work alone.*

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CHAPTER ONE

**INTRODUCTION AND ANTHROPOLOGICAL FRAMEWORKS FOR A
BIOMEDICAL EPIDEMIC**

Introduction

Throughout my life, I have seen breast cancer and its treatments devastate the bodies and lives of women very close to me. The disease is so pervasive; everyone I know has known someone impacted by the disease. I've seen my mother weep over the loss of a friend, whose breast cancer had already metastasized—or spread to other organs—by the time it was diagnosed. I remember returning home on any given day of 6th grade and seeing the piles of long hair on the floor next to where my mother was sitting on the couch. She was going through chemotherapy. Her skin grew pale and her eyes were sunken and dark. Her breasts had been surgically removed, limiting the mobility of her upper body for months.

Then, at the age of 29 and 30, I received *my* diagnoses. My second cancer diagnosis was breast cancer, and it has forever changed the trajectory of my life, my relationship with my body, and how I navigate through the world. Following my diagnosis, I listened with grave attentiveness to all of the information about the disease that was constant and plentiful in popular discourse. *Early detection as prevention! Eat right and exercise to prevent breast cancer. Eat tofu. No, wait, don't eat tofu. If you have a child, breastfeed. Be young...young people don't really get breast cancer.* All of it seemed to be related to what I did wrong or needed to do to avoid breast cancer.

After my breast cancer diagnosis, I was also diagnosed with a BRCA-2 mutation, which is a mutation of a cancer-fighting gene that sometimes causes the gene to act in opposition to

its regular function: it suddenly decides to *make* cancer. Once this happened, my oncology team decided this was the sole reason for my tumor. I had a defective body. However, I scoured online medical libraries and found that having a BRCA mutation is not an absolute predisposition for carcinogenesis, and many people with the mutation never get the disease. Furthermore, studies have shown that people with the mutation need additional protection from environmental exposures (Bennett et al. 2000; Gorani, Farid, and Mazhari 2014; King, Marks, and Mandell 2003; Venkitaraman 2002).

I began to wonder why the discussions of breast cancer causation was so limited, and seemed to focus solely on the personal or physical defects of the breast cancer patient herself.¹ I wondered about other potential causes of breast cancer that weren't regularly discussed, both among patient care providers and more widespread popular rhetoric. I began to think about how these discussions made me feel about myself and my disease, as well as all of the countless other people suffering the realities of breast cancer. So, I began to look at the United States under a microscope, and followed threads to complex tapestries of corporate manufacture, power relations, disease, and victim-blaming.

The Tapestry: Landscapes of Industry and Disease

In the United States, breasts are viewed as feminine parts of women's bodies, and are also sexualized objects of desire (Yalom 1997). Breast cancer—for similar and different reasons—is also a sexy topic of discussion. Cancer of the breast is pervasive in the United

¹ It should be noted that breast cancer is not solely a women's issue. This is also an issue for men, trans, and nonbinary people, who are often not discussed. However, I generally refer to women in this thesis because I only interviewed people who identified as women and are biologically female, and because some of the scientific studies I cited specifically devalued or dismissed the experience of women or results of chemical exposures on the biologically female body.

States and, according to the American Cancer Society, in 2016 approximately 316,120 women were newly diagnosed, and 40,610 died of the disease. It is also a disease that has become highly marketable and commodified (Ehrenreich 2009; Jain 2007) and is surrounded with associated perceptions and narratives that permeate both collective and medical understandings of the disease, as well as the experience of being a breast cancer victim. Furthermore, prevailing practices, concepts, and knowledge in science and medicine often change over time, yet these practices and bodies of knowledge are culturally sanctioned and revered as spatiotemporally unchanging bodies of Truth (Franklin 1995). Such cultural reverence of the doctor or the scientist create unequal distributions of power between scientists and the public, which can manifest as disparities in authority (Balshem 1993; Harraway 1997) and validity of knowledge (Checker 2007; Singer 2011).

Because scientific and medical knowledge is not an entity that exists free of prevailing cultural assumptions and diachronic historical processes (Franklin 1995), I consider the potential for culture and politics to manifest in the medico-scientific processes of diagnosing and treating breast cancer, as well as attempts at breast cancer prevention. These suppositions arose throughout personal experiences with the disease, and I theorize that the breast cancer epidemic and scientific knowledge, treatments, and perceptions of the disease and its causes, are shaped by these sociopolitical phenomena. Thus, I launched an ethnographic research project to explore these potential issues, as well as the possibility for prevailing cultural ideologies to reinforce power inequalities by protecting industrial and corporate interests over those of women (Balshem 1993; Brown 2013; Checker 2007). I also hoped to

understand how, if at all, these popular narratives create or exacerbate the complex suffering of breast cancer patients.

This project explores the interconnections of industry, disease production, victim-blaming, and breast cancer; the perceptions of participants who have had breast cancer, as it pertains to their disease and its cause; how ideology shapes scientific understandings of cancer causation and prevention; and how popular understandings and perceptions of breast cancer shape treatment plans and prevention. More broadly, it considers the physiological consequences of having a body in the era of the Anthropocene—which is defined as “...a geological epoch marked by human impacts on global ecosystems” (Mathews 2020, 67).

Though there are non-neoliberal economies among powerful global nations who contribute to horrific environmental pollution and suffer severely high cancer rates, I focus on the effects and trajectories of neoliberal capitalism in the United States. More specifically, my research asks the following questions:

1. How are neoliberal practices—such as the deregulation of polluting industries, fast-tracking mass manufacture of toxic products for profit, and lack of incentive to prevent or take responsibility for negative impacts to public health—linked to breast cancer?
2. How does popular victim-blaming rhetoric constrain how scientists view and discuss the causes of breast cancer?
3. How does this popular rhetoric affect the way that breast cancer patients experience the disease?

By examining these topics, I can contribute to knowledge concerning hegemonic discourse that values corporate interests over women's bodies, as well as increase an understanding of how these neoliberal values² and power imbalances manifest within women's bodies and minds, in the context of breast cancer affliction. I also hope to broaden physicians' understandings of the ways in which ideology sometimes influences science and obscures the scope of analysis. Related issues that will build a structural foundation for my own research development will be informed by a number of different sources, cutting across various scientific disciplines. The first issue involves the entanglements and biopolitics of cancer in the body. The second will involve controlling processes that create conceptual narratives which blame individuals for their diseases, while reinforcing industry and power inequalities. The third involves the ways in which these phenomena create or exacerbate the suffering of women with breast cancer.

I hope that this project will yield several benefits including a contribution to knowledge, by facilitating a qualitative public understanding of the ways in which controlling processes and power inequalities manifest within bodies—through disease epidemics, like breast cancer—due to constructed environments that are driven by capital. I also hope to broaden physician's understandings of the ways in which ideology bleeds into science and obscures the scope of analysis, and reduce the prevalence of victim-blaming rhetoric. Furthermore, this study has the ability to contribute to new knowledge within academia, as the study of

² Though examples of horrific power imbalances, toxic environments, and disease exist from other forms of government and economies where authoritarians hold similar positions of power to corporations in the U.S. (e.g., China, Soviet Union-Russia, etc.), my study takes place in the United States, so it is the U.S. power and economic structures that were of focus in this thesis.

controlling processes is still in its early stages, and there are very few ethnographic studies of breast cancer patients, despite the prevalence of the disease. A final potential benefit of this project is that it can allow participants to find some sort of satisfaction or catharsis in having a platform to share their experiences from a position of anonymity, all while contributing to generalizable knowledge.

In this chapter, I will explore the historical context and theoretical approaches to this research by tracing the trajectories of the development and widespread use of industrial chemicals in the United States alongside cancer prevalence. Then, I discuss what I refer to as “lifestyle rhetoric,” and the ways in which it is used to offset corporate accountability for toxifying environments and bodies. Next, I examine trajectories and legacies of toxicity in the U.S., situated alongside disease epidemics. After, I discuss “pinkwashing,” or the corporate marketing of pink ribbon “breast cancer awareness” products from companies that also profit from the manufacture of commodities that cause the disease (Breast Cancer Action (BCAction 2002), as a corporate approach to making breast cancer marketable. And finally, I examine political and socioeconomic forces that create suffering and biologize the effects of poverty and inequality.

Historical Context and Theoretical Approaches to Disease, Industry, and Power

The sources that have provided a structural framework for my research cut across various scientific disciplines and include—but are not limited to—anthropology, medical science, ecology, public health, and regional industrial history. In the following, I provide a literature review of interdisciplinary topics and recurring themes that pertain to my ongoing research of the breast cancer epidemic, perceptions of the disease, and the entanglements of cancer and

the environment. Within this research, I have chosen to recognize “environment” in the context of the era of the Anthropocene (Mathews 2020), rapid industrial development, and human-produced risk that is local, global, and diachronic (Fortun 2001; Harraway 1997; Morton 2013). I also include a primary emphasis on the entanglements and biopolitics (Foucault 1976) of cancer in the body, as well as the controlling processes (Nader 1997) that create conceptual narratives which blame cancer victims for their disease (Singer 2011). Laura Nader’s (1997) discussions of controlling processes have shown that controlling mechanisms are disseminated through various mediums and become naturalized, tacitly shaping the perception of individuals into a mass-consciousness. Furthermore, these controlling processes tend to reinforce industry in ways that generally benefit the elite members of society, perpetuating power inequalities (Balshem 1993; Checker 2007). In the context of breast cancer, this also contributes to the creation of the patient-consumer and a commodified patient/disease (Jain 2007).

There are several theoretical concepts and empirical data from secondary literature sources that are thematically relevant to this topic of research. One theme that arose in such studies exemplified the ways in which social forces can become embodied within individuals (Checker 2007; Farmer 2005; Scheper-Hughes 1992; Singer 2011; Steingraber 2010). Such studies show how individuals’ biographies of illness, struggle, and premature death indicated social and economic powers that perpetuated certain epidemics and forms of suffering—while additionally constraining the agency of individuals’ ability to prevent or ameliorate such suffering (Checker 2007; Farmer 2005; Scheper-Hughes 1992; Singer 2011).

Another recurring theme appears in research that describes how medical communities and experts can be active participants in the medicalization of needs, and how that can obscure the social causes of sickness (Balshem 1993; Farmer 2005; Nader 1997; Scheper-Hughes 1992; Singer 2011; Steingraber 2010). In other words, these experts engaged in diagnoses or rhetoric that individualized both public health issues and social inequality, through the process of medicalization. Such research shows that culturally influenced scientific understandings function as a hegemonic apparatus, which is internalized by affected communities. In these cases, medical communities and popular rhetoric are able to reshape perceptions and obscure the systematic denial of the resources or protection that marginalized communities need—serving an ideological function that obfuscates systemic, socio-political issues that create this form of mass suffering, because “Sickness falls into the moral category of bad things that “just happen” to people,” (Scheper-Hughes 1992, 174).

Finally, others described the interconnections of public health and socioeconomic class, as it pertains to diet (Balshem 1993; Checker 2007; Steingraber 2010). This “lifestyle rhetoric” links poor diet to cancer causation, and there have recently been national strategies to direct people to make better food and beverage consumption choices; yet these platitudes ignore the structural “webs of causation” (Steingraber 2010, 152) that most often lead to poor consumption choices, as there can be little actual choice in consumption behaviors. Furthermore, the lifestyle rhetoric is a controlling mechanism that protects industries from indictment for polluting bodies and causing cancer epidemics. These are concepts that echo classist tones in which personal defects—such as irresponsibility or ignorance—perpetuate

plights of the working-poor or, in this case, the cancer patient (Balslem 1993; Steingraber 2010).

Industrial Chemicals and Cancer in the United States

Though spectacular in many ways, scientific and technological advances within the United States have created legacies of toxicity. The Atomic Age brought about the ideological promise of national superiority through nuclear deterrence (Masco 2014), the mass production of energy, and treatment for disease. Along with these potentials, this industry has produced toxic fission products, power plant meltdowns, and an accumulation of nuclear waste; all of which have led to the poisoning of environments and bodies. What has perhaps caused more pervasive damage in the U.S. are the agrochemical industries, which can also be linked to wartime manufacturing. Sandra Steingraber (2010) tracked the historical developments of the use of such industrial chemicals—as well as the introduction of these chemicals for personal use in the home—and situated their commodification alongside burgeoning cancer clusters.

The combination of two phenoxy chemicals—2,4,5-trichlorophenoxyacetic acid (2,4,5-T) with 2,4-dichlorophenoxyacetic acid (2,4-D)—occurred in the context of war. This combination, which is widely known as Agent Orange, was deployed in Vietnam by the U.S. military, in efforts to kill crops, underbrush, and rainforests (Steingraber 2010). Likewise, the mass production and use of dichlorodiphenyltrichloroethane (DDT) also occurred during wartime. During World War II, it was used in the devastated region of Naples, as typhus had begun to rampantly spread via insect carriers such as fleas, lice, and mites (Steingraber 2010). These insecticidal and herbicidal industries flourished during the wars but, when the

wars ended, there was a concerted effort to maintain the production and consumption of these chemical commodities.

Although the chemical combination that comprised Agent Orange was eventually banned, its phenoxy herbicide relative 2,4-D became the primary ingredient in weed-killing products marketed for golf courses, farming, and lawns of private residences. With the newfound pervasive use of 2,4-D both commercially and privately, came a rise in lymph cancers of people working in specific occupations, children, and pet dogs (Steingraber 2010). As with phenoxy herbicides, the use of DDT was marketed for commercial and private consumption. Clever marketers used propagandic advertisements to convince the general public that insects and humans could not cohabitate; facilitating the loss of knowledge that such cohabitation had previously occurred for the duration of human existence, and simultaneously increased the risk of home maintenance practices. Essentially, after World War II, children were born into greater amounts and assortments of chemical refuse than ever (Steingraber 2010). Along with these children—and the generations thereafter—the military and chemical industries grew, exponentially.

“Lifestyle Rhetoric” and Ideologies of Optimism and Illness

In the context of this study, “lifestyle rhetoric” is essentially defined as the widespread discourse about individual behavioral patterns—including poor diet, lack of exercise, and alcohol consumption—as a main causal factor of public health issues, like cancer. For the purpose of this research, the lifestyle rhetoric is a significant concept because it is one that has arisen repeatedly in discourse among the interviewed participants for this research. Furthermore, it is a recurring theme among other researchers who have directed their gaze

towards communities affected by disproportionately high rates of disease (Balshem 1993; Checker 2007; Singer 2011; Steingraber 2010).

Martha Balshem (1993) discussed the relationships between a Philadelphia community (given the pseudonym Tannerstown) with a high cancer incidence rate, local industrial pollution, perceptions of cancer causation, and the implicit forms of medical authority that exist within these relationships, especially in the forms of legitimacy and power. Balshem (1993) began her research as a member of an interdisciplinary team of scientists, which aimed to reduce cancer incidence in the community, through education and awareness that could motivate community members to change their cancer-causing lifestyles.

As with Steingraber's (2010) connections of the military industrial complex to the proliferation of domestic chemical industries, Balshem (1993) described the influx of chemical industrial production, jobs, and wealth in Tannerstown after World War I. However, decades later, these industries steadily declined, and unemployment and lower wages became commonplace. Not unlike many other industrial regions, this left Tannerstown with an inheritance of ongoing toxicity, while no longer offering economic stability. Nonetheless, these industries were still responsible for a considerable amount of Tannerstown employment, as well as a constant chemical odor in the air and a white film that would build up on the windows of homes. These realities were scrutinized by Tannerstown residents. Despite the industrial history of the region, the cancer-prevention team of scientists (including Balshem) that was employed to reduce local cancer rates advised residents to change their "improper" consumption habits: such as smoking, drinking alcohol, and eating the "wrong" foods (Balshem 1993). However, Tannerstown residents perceived the claims of

the scientific community to be infantilizing and laced with moral judgement. The community also decried the hypocrisy underlying the scientists' recommendations: residents were essentially being told that they themselves should work on cleaning up their living habits, rather than bothering polluting industries to utilize mindful modes of operation and clean-up efforts.

The community generally rejected the blame-the-victim concepts implicit within the lifestyle rhetoric presented to them by scientists, and many openly shifted blame toward the toxic industries in which they worked and neighbored. Furthermore, most of them seemed to know, even if scientists did not, that eating the "wrong" foods, smoking, or drinking alcohol are not risk categories that exist within a vacuum, nor are they decisions that are made free of history and circumstance. Likewise, Steingraber (2010) also described the flawed results of scientific studies that measure a singular life factor (such as diet or exposure to a single chemical), as their analyses were predicated upon the assumption that no other chemical exposures or dietary factors are present within a lifetime and, furthermore, that such combinations of factors do not create new sets of risks.

Additionally, Merrill Singer (2011) discussed environmental racism, risk perception, and the concepts of "lifestyle choices" as they pertain to diet. Singer's study examined the experiences and perceptions of environmental risk within a low-income, predominantly African American community in Ascension Parish, Louisiana, which is located in an anonymous neighborhood along a stretch of the Mississippi River. Unfortunately for this community, a number of chemical, plastics, and nitrogenous fertilizer manufacturing companies are also rooted along this stretch of riverside land.

People in Ascension Parish had been experiencing a number of health issues (including skin sloughing off after a bath, respiratory disease, and high rates of cancer), and also noted the smell of ammonia in the air and the stinking, foul tasting water from their taps. The residents in Singer's study attributed many of these experiences to pollution from the industries that surrounded their community, but most were impoverished and depended on the institutions that were poisoning them to survive. Meanwhile, spokespeople for these industries would greenwash their work, by presenting their careful attempts to relocate at-risk species (not humans, of course) away from their production sites, while reminding locals to maintain their individual health by "eating right," exercising, and not smoking. As some community members began to believe they were complicit in their own developments of health ailments, it became clear that this hegemonic rhetoric had successfully altered some public perception of the causes of poor health in Ascension Parish (Singer 2011), and effectively broke down institutional accountability and communal suffering by individualizing illness.

Steingraber also presented counter arguments to lifestyle rhetoric. At an international environmental convention, she described an attendee who was discussing an outbreak of liver cancers among the St. Lawrence beluga whale, whom fed off of a type of fish that were contaminated by waterside chemical industries. This individual asked if the beluga whales were drinking too much alcohol, smoking too much, or subsisting off of junk food (Steingraber 2010). These questions combatted the idea that cancers in humans are merely caused by poor consumption choices of individuals.

Furthermore, Steingraber also described the interconnections of public health and socioeconomic class, as it pertains to diet. Lifestyle rhetoric links poor diet to cancer causation, and there have recently been national strategies to direct people to make better food and beverage consumption choices; yet these platitudes ignore the structural “webs of causation” (Steingraber 2010, 152) that most often lead to poor consumption choices, as there can be little actual choice in consumption behaviors. In other words, even in the incidence where individuals predominantly consume junk food, the pricing disparities, and lack of time, energy, and geographic accessibility to healthy foods are phenomena that can prevent the poor from making different consumption “choices”.

The lifestyle rhetoric is a controlling mechanism that protects industries from indictment for polluting bodies and causing cancer epidemics. The American reverence for rugged individualism and morality are also woven throughout the lifestyle rhetoric, echoing classist tones in which personal defects—such as irresponsibility or ignorance—perpetuate plights of the working-poor or, in this case, the cancer patient. The pervasiveness of relating cancer to lifestyle choices in scientist-community discourse is evidence that the controlling processes (Nader 1997) which uphold an economic and social structure have permeated medico-scientific understandings of cancer (Balshem 1993; Singer 2011; Steingraber 2010;). These insidious ideologies can create myopia concerning scientific efforts to prevent or treat cancer, and can exacerbate the suffering of people living with, or at risk of, the disease.

Along with the victim-blaming undertones of lifestyle rhetoric, there has also been an American ideological shift towards “positive thinking,” which is entangled with propaganda, politics, and American capitalism and consumerism (Ehrenreich 2009). In Barbara

Ehrenreich's (2009) *Bright Sided*, she discussed the ways positive thinking can be used as a medium to dismiss troubling news, and also highlighted the contradictions within the idea that positive thinking is indicative of individual happiness, as she links it rather to a sign of distress. Furthermore, the repression of emotions is psychologically damaging, and the American trend towards positive-thinking—and its manifest function of emotional repression and a seemingly benign way to dismiss suffering—is likely a contributing factor to Americans consuming more than two-thirds of the global production of antidepressant psychopharmaceuticals (Ehrenreich 2009).

The Revolving Door Between Industry and Disease

In her book, Gayle Sulik (2011) described the ways in which corporations embed themselves within advocacy movements regarding breast cancer awareness and treatment. They do this by creating strategic relationships with consumers and their target audience—breast cancer patients—through multimedia propaganda which seeks to paint specific portraits of how the corporations are involved in breast cancer activism or treatments. One of such companies is Zeneca. In 1985, Zeneca sponsored the National Breast Cancer Awareness Month through the American Cancer Society. Into the 2000s, the company (now AstraZeneca) bombards the public with “early detection” rhetoric and statistics, that exaggerate the benefits of mammography and entirely omits the risks of this form of breast cancer screening. Moreover, Zeneca once made 49 percent of its profits from pesticides and insecticides—some of which are known or probable carcinogens (Donna et al. 1981)—while also profiting from their widely-prescribed breast cancer drug, Tamoxifen. The company continued this dualistic and arguably unethical production and profit pattern until enough

pressure from activists resulted in the sale of their insecticide and pesticide company, in 2000.

Sulik (2011) also discussed how General Electric (GE) marketed some of their products with their logo in pink, to market solidarity with breast cancer patients and survivors. Akin to AstraZeneca, GE spokespeople have made public statements about the efficacy of “early detection [through mammography] saving lives,” touting a 91 percent survival rate for women who detected their cancers in early stages (Sulik 2011). Unfortunately, this statement has been skewed in such a way that it renders the actual data invisible. The actual cure rate that they based this statement upon was a *five-year* survival rate for women who had early stage breast cancer. This means that 91 percent of women were still alive during the fifth year after their treatments—it does not in any way reflect that women in this circumstance would have a normal life span. These examples show how powerful industries can cloak their marketing strategies in purported breast cancer advocacy, while disseminating misleading information about prevention and concealing industrial contributions to, and profits from, cancer.

Big pharmaceutical companies like Novartis market their breast cancer treatment medications with cultural undertones of individualism, and the themes that are embedded within breast cancer culture: fear, hope, and goodness (Sulik 2011). A Novartis advertisement that Sulik (2011) discussed encouraged patients to ask themselves what else they could—or should—be doing to reduce their risk of recurrence; in this case, what was being peddled were additional Novartis medications. Ultimately, Sulik’s (2011) discussion illustrates the complex entanglements of the breast cancer pharmaceutical industry, which

promote unrealistic cultural perceptions and expectations that do not match biophysical reality. Furthermore, Sulik's (2011) work makes evident that the big pharmaceutical companies who produce and profit from breast cancer screenings and treatments also heavily control information that is disseminated to at-risk women and what options are available to them (Steingraber 2010).

Breast Cancer, Capitalism, and "Pinkwashing"

Many breast cancer patients have come to realize that their disease has become a sexy tool for marketing. This is exemplified through the slightly higher price of commodities that are color-coated in pink, with the promise to donate some of their profits to fund research for a cure for breast cancer. In 2002, BCAction—a grassroots activist group based out of San Francisco—created the neologism "pinkwashing" and defined it as the corporate marketing of pink ribbon products to create the façade that the corporation cares about breast cancer, when in fact they are profiting from the manufacture of commodities that cause the disease (BCAction 2002). The consumer is attracted to the noble cause of spending money on products to "find a cure," and moved to purchase pink. Besides the ways in which pinkwashing is used to boost consumption and corporate profit, it is also a machine that disassembles collective activism, and reassembles the power of grassroots mobilization into collective into commercialized pink ribbon marathons. There is an extensive history of controlling the bodies of women (Ehrenreich 2009; Ehrenreich and English 1978), as they have been systematically infantilized in their life roles, decisions, and suffering. In the context of pink-ribbon products and events, breast cancer is exploited to sell commodities,

and pinkwashing is a hegemonic apparatus that mutates the focus of collective efforts from activist demands for research and regulatory protection, to cute and superficial city walks.

In the late 19th century, experts had decided that women's bodies and minds were intrinsically pathological—menstruation and menopause, the occasional inability to be exceedingly submissive³ and, as in *The Yellow Wallpaper* (Gilman 1892), the desire to do more than be a housewife, were all considered to be indicative of madness. Women have often been understood to know little, if anything, about what they needed, including their own medical decisions. Up until the 1970s women were given radical mastectomies,⁴ which was debilitating on the treated side of the body (Ehrenreich 2009). It was also common practice to conduct biopsies, diagnoses, and mastectomies, all during the same procedure while the patients were anesthetized; stripping from them the right to consent to the amputation of their body parts. In the 1990s, women with metastasized cancers were given extremely potent forms of chemotherapy that destroyed their bone marrow, which was then replaced with transplants; this often hastened their death, and increased the agony they experienced during the remainder of their lives (Ehrenreich 2009). It took activism and outcries from women to bring these practices to an end.

In 1991, Charlotte Haley was inspired by AIDS activists and initiated her own efforts to convince the U.S. government to allocate more funding to cancer research aimed more heavily at disease prevention and breast cancer causation. She did so by mailing out

3 A woman's lack of submission was linked to enjoyment of clitoral stimulation, rather than penetration alone (Ehrenreich and English 1978).

4 Radical mastectomies are extreme mastectomies in which the breast, underlying chest muscles, and lymph nodes in the arm pit are all removed.

postcards to get others involved, including legislators. Affixed to those postcards was a pastel orange ribbon. As Haley's grassroots movement gained momentum, Estee Lauder and *Self* magazine became interested in the marketability of the ribbon, and they approached her to inquire about rights to the ribbon (BCAction 2017). Admirably, Haley refused their offers. So, the corporations consulted with their attorneys and changed the color of the ribbon to pink, because a think tank decided that the color of pink was "happy, warm, and reassuring" (BCAction 2017), and everything that masks the realities of the tragic disease. To the benefit of corporations rather than breast cancer patients, breast cancer—which is the number one cause of cancer deaths in women—and pink ribbon products can both be marketed for profit. Although the *cause* of breast cancer has not been adequately researched and is likely multidimensional, pink ribbon products promise to donate proceeds to the *cure*. And with that, hope is sold as a side order with pink products that make a life-threatening disease cute and pretty.

As with fair trade coffee consumers in Paige West's (2012) "Neoliberal Coffee," pink ribbon products appeal to the "politically-minded" or self-identified philanthropic consumer. I have no doubt about the well-meaning motives of people who consume pink ribbon products, and many of these consumers are likely the loved ones of women who have been afflicted with the disease. In the hierarchy of consumers, pink product purchasers are ostensibly superior in their consumption choices. However, these consumers are misguided. Corporations predicate upon the controlling mechanisms inherent in the compulsion to consume, and they produce consumer identities that are woven with charitable, sympathetic narratives. This reinforces the insatiable urge to buy, while simultaneously creating the

imagined possibility for individualism and consumption to replace political action and negate the need for knowledge about environmental injustice and exploitative capitalism. All you need to do is buy this pink product for yourself to help someone else! It seems so simple. Unfortunately, the breeding ground for contradiction begins with being misinformed. When these pink ribbon products (*e.g.*, vacuum cleaners, cars, and license plate frames) promise a percentage of proceeds from each purchase to fund the cure for breast cancer, consumers may believe that scientists are on the verge of creating a cure (Jain 2007). What is also unknown to pink ribbon product consumers is that companies put a cap on how much funding they will donate; so if, for example, the Eureka vacuum cleaner reached its cap of \$150,000 in donations, the entirety of all other proceeds of pink ribbon products are merely corporate profit (Jain 2007). Meanwhile, their pink products remain on the shelves signaling corporate “caring” and soliciting money from the charitable consumer.

You can find these pink ribbon products everywhere during the month of October, which has been deemed “Breast Cancer Awareness Month.” You can also find an abundance of these products at breast cancer fundraisers, which usually take the form of marathons. These marathons are corporate-sponsored races for “the cure,” which in a darkly ironic way, resemble a celebratory disease parade: hundreds of women dressed in whacky costumes, with layers of precious pink in various textures—fluffy, sparkly, shiny—flocking together in a mass migration to raise money for an elusive cure. There is a beautiful amount of community support and ‘sisterhood’ on display at these marathons, but this perception of collectivity is misguided and misdirected. The activist model that inspired people like Charlotte Haley, which has been disemboweled by the controlling processes discussed here, is the model that

worked for the AIDS Coalition to Unleash Power. The thousands of breast cancer marathon participants who have raised millions of dollars over the years and walked hundreds of miles could instead be focusing their efforts on “acting up.” They could be marching in the streets and to legislators’ offices to demand health care and screenings. They could be emptying the ashes of those who died from metastasized breast cancer onto the White House lawn, to demand more than 5% of cancer research funding to be allocated towards understanding the *cause* of the disease, and to demand that regulatory legislation be passed to protect consumers and workers from carcinogenic chemicals in products. Instead, pink ribbon products and pink ribbon marches commodify breast cancer, and romanticize and de-politicize the breast cancer epidemic (Pool 2012). My suffering, and the suffering of other breast cancer patients, has been appropriated to boost corporate profit.

Industry, Corruption, and Disease

Barbara Ehrenreich (2009) and Lochlan Jain (2007) described the corporate commodification of breast cancer in the United States. Gayle Sulik (2011) delineates the ways in which some corporations create a revolving door between chemical production, the creation of the patient through diseases caused by industrial chemicals, and the manufacture of the patient-consumer by producing and profiting from treatments used to remedy the diseases caused by industrial chemicals. Tangentially related, Kate Brown (2013) described American industries that profit from the refining and enrichment of radioactive elements for weapons production in the context of war, and discussed the blatant lack of protection of neighboring communities who were exposed to related radioactive and chemical agents, as well as the corruption and ideological fallacies that forged a gap between scientific “experts”

and members of the public who were seeking aid and restitution for their ongoing physical maladies created by this industry.

In Kate Brown's (2013) *Plutopia*, she examines communities in Washington state, Oregon, and Idaho that were affected by contamination produced at the Hanford Nuclear Site in the Columbia Basin of Washington. Forty years earlier, this site had been used to enrich plutonium and prepare the bomb that the U.S. dropped on Nagasaki. During its years of operation, the nuclear production complex released 700,000 curies of radioactive iodine into the air, and millions of curies into the water and ground, and epidemiological studies were never conducted by the U.S. government, nor the Department of Energy (DOE). Furthermore, local residents were not informed of the toxic operations, and new community members and subsequent generations were not notified until much later. Over time, these communities developed high rates of a variety of different types of cancers and diseases. In the 1980s, a journalist published an article which informed members of the communities of the invisible contaminants in their environment and homes, but the DOE manager at the time denied these toxic practices and the contamination of the environment. Ultimately, the stories Brown (2013) presented demonstrated the tragic realities of government protection of industrial power, and the marginalization of poor farming communities that disproportionately suffered as a result of this industry.

When the public was informed by the newspaper article, people started connecting the clusters of "individual" illnesses in their communities to the Hanford site. They became enraged. This public outcry eventually inspired the Center for Disease Control and Prevention to put pressure on the DOE to fund a study of exposed populations around the

site. Unfortunately, the imbalance of power came into play again, when the DOE was able to hire its subsidiary contract laboratory to conduct the investigations. The biased nature of the contractor's relationship with industries that produce cancer-causing waste corrupted the scientific scope of analysis, as the DOE essentially was allowed to control the investigation of itself. Furthermore, the U.S. district judge that presided over the slew of lawsuits that were brought against the DOE had a vested interest in Columbia Basin land, and decided to place rigid qualifiers for claimant participation in the case: plaintiffs were required to prove that they had been exposed to radiation high enough to cause double the number of cancers as would occur in a general population. The bulk of these exposures had taken place decades ago—or in increments over long periods of time—with no timely studies on the health effects of neighboring communities, so such criteria were generally impossible to obtain. While the judge obstructed and delayed the case for more than a decade, the laboratory associated with the DOE published their findings determining that the cancers and illnesses that were so prevalent in the region had nothing to do with Hanford's past activities (or ongoing contaminant leaks). Following these events, disputes between scientific "experts" and local knowledge of afflictions caused by operations at Hanford continued. Local experiences with high rates of disease and suffering were simply viewed by experts as anecdotal.

Sociopolitical Links to Epidemics and Suffering

The trajectories of human-produced toxic environments have complex and interwoven histories which unequally distribute benefits and loss across time and space (Cernea 1997). Such is the case with the communities of focus in most of the aforementioned studies. Unpacking the interconnection between burgeoning chemical industries, deregulation,

victim-blaming rhetoric, and controlling processes (Nader 1997) in the region provides a more holistic and fittingly polemical examination of the causes and responses to disease epidemics like breast cancer. However, there are other issues that are implicated in this discussion as well, such as the glaring issue of institutionalized socioeconomic inequity as a major factor in the production and distribution of risk and disease, and the associated dismissive, individualistic, and, frankly, eugenicist attitudes of scientific and elite communities.

Paul Farmer (2005) described general agreements on what constitutes extreme suffering; this included “premature and painful illness...[and] more insidious assaults on dignity, such as institutionalized racism and gender inequality” (29). Beyond this, Farmer (2005) shifted his anthropological gaze to when and how social forces become embodied within individuals. Specifically, he applied these foci to his fieldwork in Haiti, in the context of AIDS, tuberculosis, and other infectious or parasitic diseases. During this research, it became apparent that individual biographies of illness, struggle, and premature death indicated social and economic powers that perpetuated the AIDS epidemic, and constrained the agency of individuals to prevent or ameliorate such suffering. Though Haiti was the location of his fieldwork, Farmer (2005) often expanded his discussion of “suffering” and “the poor” to a global scale, and described the ways in which the suffering of the poor is rendered invisible to the wealthy, even when the wealthy are directly involved in producing that suffering.

Although these forms of analysis may be unprecedented, Farmer (2005) calls for action to conceptualize analytical models for understanding suffering in a global context. Furthermore, he calls for this analysis to be “historically deep” (42), moving beyond the immediate

circumstances of the poor, and including decades or more of histories that shaped suffering in the present. This means understanding not only that poverty is a health risk, but what the *structural causes* of poverty are. It means remembering that, in a patriarchal society, women's rights are consistently violated in innumerable ways, even by scientific communities. It means that, when noting that infant mortality rates are higher for black populations, that this likely indicates structural racism. Because, to conclude that black infants are more likely to die than whites simply because they are black, is to biologize structural violence, making concrete the ways that ideology and historical erasure impact health outcomes; race cannot be substituted for class in discussions about disparities in health and mortality. In other words, discussion of race in this context is a lazy—and racist in and of itself—attempt at explaining the “distribution of misery” (Farmer 2005, 48), and conveniently ignores the implications of neoliberal systems in the distributions of disease risk. Ultimately, Farmer (2005) presented narratives and analyses which demand attention to power imbalances and inequalities that create and perpetuate suffering. In the context of breast cancer, Farmer's (2005) work points to the possibility that the experiences, needs, and risks of women are often dismissed or overlooked by medical communities and the government as a regulatory entity. Farmer's (2005) discussion can also be applied to the likelihood that the breast cancer epidemic could be considered an embodiment of socioeconomic forces, and that communities that are at higher risk for poor disease outcomes are situated within bodies and geographic areas with complex race, sex, and class histories that produce suffering in the present.

There are also international studies that have been conducted, linking historic trajectories and socioeconomic inequity to embodied suffering and, moreover, the ways in which medical and local communities internalize displaced blame for this suffering. One such study was produced by Nancy Scheper-Hughes (1992) during her research among impoverished communities in Brazil. Scheper-Hughes (1992) found that existential insecurities like hunger, starvation, grinding poverty, illness, and death were issues that permeated much of the discourse with her participants. Among her participants' conversations about these concerns was the constant repetition of an ailment dubbed with the folk taxonomic term *Nervos* or *Nervoso*. *Nervos* was a term that essentially described a variety of ontological and physiological symptoms of hunger and poverty. However, the term became adopted by medical communities and served another function: it medicalized and "othered" the needs of the poor, obscuring the social causes of sickness. In other words, *Nervos* was embedded with concepts that individualized poverty as a physical affliction in the realms of both public health issues and social inequality. Thus, the term *Nervos* and its collective cultural understanding functioned as a hegemonic apparatus, which was internalized by the marginalized communities in which Scheper-Hughes worked. Framing *Nervos* as a medical condition suffered by individuals effectively denied the resources that the poor truly needed in a systematic way. It was an ideological function that perpetuated false consciousness.

Scheper-Hughes (1992) also showed that when doctors, intellectuals, and other experts who "misidentify" symptoms of starvation and poverty, they become contributors to this hegemonic process and, ultimately, perpetuate human suffering. This is done when the psychological and physiological effects of hunger are ignored, or recategorized as a

romanticized folk concept of *Nervos*, which is a sickness. In this way, “misidentification” operates to obfuscate systemic, socio-political processes that create mass suffering, because “sickness falls into the moral category of bad things that “just happen” to people,” (Scheper-Hughes 1992, 174). Similarly, applying Scheper-Hughes’ work to breast cancer in the U.S., we can see how the disease is a public health issue that has been reduced to a disease of the individual. Furthermore, the individualization of breast cancer and reductive conversations of the disease’s causes to lifestyle rhetoric or randomness, obscure the roles of historic trajectories of chemical industries and sociopolitical issues in the creation of disease and suffering.

Comparative History

Understanding the causes of breast cancer and its cure both depend on science. However, the extent to which political or economic ideologies are ensconced in supposedly objective “scientific” theory are well documented, and have occurred globally. For example, in the USSR during the mid-twentieth century, the Soviet government sponsored pseudoscientific theories of agronomist and biologist Trofim Lysenko (Graham 2006). In the wake of the forced collectivization of farms and resultant famine under the authoritarian regime, Lysenko’s rejection of Mendelian genetics, and his emphasis on Lamarckian concepts of soft inheritance and promises of improved crop yields were well-received by Stalin (Gordin 2012; Sterling 2004). Furthermore, Lysenko came from a background of the working poor, and Stalin believed his support of Lysenko could make the authoritarian leader appear to be a friend of the proletariat (Krementsov 1996). Lysenko’s work was so heavily supported by the USSR, that dissenting Soviet scientists risked being ousted from their positions, imprisoned,

or even executed. Unfortunately, Lysenko's misguided work exacerbated the extent and duration of famine in the region.

While Lysenkoism is an overt case of political influence on scientific theory and the institutional enforcement of a particular scientific epistemology, many U.S. institutions are increasingly politicizing science in more implicit ways. This includes funding mechanisms for academic sciences provided by "special interests" which produces knowledge that is ideologically situated. Department of Defense funding awards for research reflect a political agenda, but are still imbued with a façade of objectivity (Price 2008). In the United States, elite corporate interests are the primary decision-makers in the context of production, consumption, and legislation that enable industrial practices, as well as dissemination of ideological information that justify certain forms of development. Unfortunately, such operations have unequal distributions of benefits and loss (Cernea 1997), and the communities that are disproportionately faced with increased disease rates due to industrial production tend to not be communities in which elites are likely to face direct consequences. Moreover, lifestyle rhetoric can be seen as an example in which one scientific theory is embraced and widely disseminated; this theory is one that blames cancer victims for their disease, ignores anthropogenic links to cancer, and serves as a mechanism to deliver a hegemonic discourse that aligns with the goals of the elite.

Breast cancer is tightly entangled with controlling processes (Nader 1997), cultural narratives, discrepancies in power and authority, and defies dominant Western spatiotemporal concepts. Steingraber (2010) described the historical context of the pervasive use of chemical carcinogens in the United States, as well as the controlling mechanisms that

were utilized in motivating consumers to purchase toxic products and acquiesce to a constant and endless exposure to chemical cocktails. As Steingraber (2010), Singer (2011), and Balshem (1993) have shown, these controlling mechanisms extend beyond encouraging the widespread personal use of chemicals, and bleed into the fallacies within discourses concerning the causes of—and death from—cancer. These cultural ideologies are cloaked in the shroud of scientific truth, which actively produces disparities in the valuation and validation of varying epistemologies (Balshem 1993; Checker 2007; Singer 2011; Steingraber 2010). Furthermore, the medico-scientific community is both self-consciously authoritative in delivering health messaging and scientific findings, but conveniently unaware of how this authority is derived (Balshem 1993; Harraway 1997, 2016). This myopia includes the inability to recognize the ways in which culture constrains the capacities of the scientific scope (Franklin 1995; Harraway 1997, 2016; Martin 1991). This dynamic often causes outliers who refute these issues to be viewed as having problems of non-compliance or ignorance (Besley, McComas, and Trumbo 2008; Lyon-Callo 2004; Thun and Sinks 2004), and community outcries or defectors are often dismissed. These disparities in authority and power simultaneously nurture fallacies within the dominant cultural narrative and deflect accountability away from toxic industries and the government as a protective agency. Ultimately, the anthropogenic hazards and other realities produced by neoliberal industries and empowered by plutocratic culture do not articulate kindly with bodies of the living in the Anthropocene (Morton 2013), or more specifically with women's breasts.

Methodology

Along with the review and analysis of secondary literature sources, my research included qualitative ethnographic methodologies, such as participant observation and semi-formal interviews. Due to ethical concerns of privacy within a medical space, all participant observation aspects of my work were solely autoethnographic—in other words, drawn upon my personal experiences and observations of data. Autoethnography is a form of introspective storytelling that is situated within historical and cultural context, and can be connected to the experiences of others. In this study, I use autoethnography to focus primarily on my own personal stories that relate to (or juxtapose) the experiences of other participants, as well as overarching themes within the research (Brettell 1997; Chang 2008; Ellis 2004). These observations began in 2016, after my diagnosis and initial induction into the world of “*the breast cancer patient*,” and continues to the present. The primary observation locations were a respected Bay Area cancer research center and an affiliate women’s cancer center. They also include personal communications and my own experience related to the way that others have perceived my disease. While I recognize such experiences and observations are a contribution to my data and methodology—with myself as a subject—I directed greater focus on the other women in my study as subjects.

During the participant interview process, I had arranged for eleven open-ended interviews with breast cancer patients in the greater Bay Area to occur over a three-month period beginning in November of 2017. Locations for the interviews were chosen by the interviewees and the interviews were audio-recorded for later transcription. The informants I interviewed were women from ages 30 to 64 in age and were from diverse backgrounds.

These women had been diagnosed with different stages of breast cancer and, at the time of the interviews, each of the women were in different phases of treatment; two were recently diagnosed with little or no treatment, two had already undergone some of their recommended surgeries and treatments, and the remaining seven were two-or-more years post-treatment.

I also distributed and collected 50 questionnaires (containing yes/no, Likert scale, and open-ended questions), and drew upon peer-reviewed articles, public records, and other literature about breast cancer from interdisciplinary origins. These studies, statistics, and historical and ethnographic data provided a structural framework for my research and discussion about breast cancer as a disease that is situated within the Anthropocene, ideology, power relations, and controlling processes (Nader 1997). The literature review also includes themes that articulate with those in my primary data, and thus can serve as quantifiable, secondary data.

Because this project involved data collection from communities of people scattered across a large area—current and former breast cancer patients in Northern to Central California—and due to the fact that many were private about their afflictions, the best sampling strategy for ethnographic interviews in my study was network sampling. As a former breast cancer patient and activist, I participated in grassroots organizations and support groups, which situated me in the unique position to reach out to identify potential interview participants through my own social network. I reached out to members of a large breast cancer support group through an anonymous email listserv. When doing so, I informed members about my research project, providing them a timeframe during which I would conduct interviews, logistical information including how long the interviews would take, and

invited anyone interested in participating to contact me to schedule an interview. Nine women responded and scheduled interviews with me in their place of choice. Some chose to be interviewed in their homes, while others chose restaurants or coffee shops. Two additional participants were women I knew personally who were interested in contributing to my project. Over a five-month period—from December of 2017 to April of 2018—I completed the interviews using digital audio-recordings supplemented with written notes.

Summary and Implications

In this chapter, I discussed the historical context and trajectories of chemical industries and the widespread commercialization of war-time chemical products in the United States, while situating this industrial expansion alongside increased cancer incidence (Steingraber 2010). I also examined the ways in which medical communities and popular discourse reshape perceptions of disease epidemics by individualizing broad public health concerns and the social inequalities that erode resources and protections that are critically needed by vulnerable communities (Balshem 1993; Farmer 2005; Nader 1997; Scheper-Hughes 1992; Singer 2011; Steingraber 2010).

What I refer to as “lifestyle rhetoric” is a part of this hegemonic apparatus that functions to protect corporations that contaminate these entire communities, while circumventing corporate accountability for toxifying environments and bodies. Furthermore, some big pharmaceutical companies produce and profit from breast cancer screenings and treatments, and control a great deal of information that is disseminated to at-risk women (Sulik 2011). Worse, some corporations who profit heavily from carcinogenic pesticides and herbicides are

engaged in an unethical cycle of production and profit, benefitting from the manufacture of both carcinogenic chemicals and cancer treatments (Sulik 2011).

In this chapter, I also discussed pinkwashing (BCAction 2002), and the ways in which pink ribbon merchandise and pink ribbon marathons have commodified breast cancer, boost revenues for corporations who also produce carcinogenic products, and have romanticized and de-politicized the breast cancer epidemic. Lastly, I explored the ways in which political and socioeconomic forces create suffering and vulnerability in communities with complex socioeconomic histories (Farmer 2005) that cause or perpetuate disease epidemics, like cancer. Phenomena like pinkwashing and lifestyle rhetoric obscure systemic, socio-political dynamics that create mass suffering caused by breast cancer by depoliticizing the epidemic and reducing a public health crisis to a random or self-inflicted disease of the individual.

CHAPTER TWO

JOURNAL ARTICLE: TRAJECTORIES OF MALIGNANCY: INTERCONNECTIONS OF BREAST CANCER, INDUSTRY, AND VICTIM- BLAMING RHETORIC AS SOCIAL CONTROL

Imagine a scenario that perhaps is not too far-fetched: After a refreshingly intense workout at the local gym, you feel a tension in your chest and try to massage the tissues to dissipate the pain. But then you detect something beneath your fingertips—palpable, hard, and persistent. You realize as pangs of anxiety reverberate through your body: that’s not a pulled muscle. That’s a *lump*. Could it be cancer? *How?*

This article explores the interconnections of industry, disease production, and treatment; the perceptions of participants who have had breast cancer, as it pertains to their disease and its cause; and how ideology shapes scientific understandings of cancer causation and prevention; how popular understandings and perceptions of breast cancer shape treatment plans and prevention. More broadly, it considers the physiological consequences of having a body in the era of the Anthropocene, by which I mean, a period marked by human impacts on global ecosystems—particularly the impacts of fossil fuels and nuclear radiation. More specifically, my research asks the following questions:

1. How are neoliberal practices—such as the profit-driven lack of adequate regulation of chemical industries or protections for the public and environment—linked to breast cancer?
2. How does popular victim-blaming rhetoric constrain how scientists view and discuss the causes of breast cancer?

3. How does this popular rhetoric effect the way that breast cancer patients experience the disease?

By examining these questions, I contribute to the body of knowledge about how hegemonic discourse that values corporate interests over women's bodies as well as increase an understanding of how these power imbalances and neoliberal values—such as privatization, deregulation, and cuts to public services—manifest within women's bodies and minds, in the context of breast cancer affliction. My work also broadens anthropological understandings of the ways in which ideology can influence science and obscures the scope of analysis.

Related studies that built a structural foundation for my own research development was informed by a number of different sources, cutting across various scientific disciplines. The first involves the entanglements and biopolitics of cancer in the body. The second will involve controlling processes that create conceptual narratives which blame individuals for their diseases, while reinforcing industry and power inequalities. The third involves the corporate creation of the patient-consumer and a commodified patient/disease through Pink Ribbon culture.

Because scientific and medical knowledge do not exist free of prevailing cultural assumptions and diachronic historical processes (Franklin 1995), I considered the potential for culture and politics to manifest in the medico-scientific processes of diagnosing and treating breast cancer, as well as attempts at breast cancer prevention. My thoughts on this issue arose through personal experiences with the disease, and I began to theorize that the breast cancer epidemic and scientific knowledge, treatments, and perceptions of the disease

and its causes, are shaped by these sociopolitical phenomena. Thus, I launched an ethnographic research article to explore these potential issues, as well as the possibility for prevailing cultural ideologies to reinforce power inequalities by protecting industrial and corporate interests over those of women. I also hoped to understand how, if at all, these popular narratives create or exacerbate the complex suffering of breast cancer patients.

This article demonstrates how a qualitative public understanding of the ways in which controlling processes and power inequalities manifest within bodies—through disease epidemics, like breast cancer—due to constructed environments that are linked to global processes that prioritize capital and resource accumulation over public health. It also points to the various ways in which ideological beliefs can bleed into scientific discourse and obscures the scope of analysis, and reduce the prevalence of victim-blaming rhetoric.

Stories

My curiosity about this topic began with my own experiences with cervical and breast cancer, broader observations about pinkwashing (BCAction 2002), “pink ribbon culture” (Sulik 2011), and dialogue about lifestyle, prevention, and causality in cancer epidemiology. At the time of my first diagnosis, I was a single mother, part-time worker, and full-time undergraduate student. Suddenly, my struggles were exacerbated by the physical and emotional suffering of surgeries, cancer treatments, and the severe anxiety of recurrence during my recovery periods, so I looked to a breast cancer support group in the Bay Area of Northern California. Joining the support group gave me exposure to other women who personally understood all of the ways in which cancer complicated many aspects of my life. In addition, as I was exposed to the thoughts and experiences of other breast cancer patients,

curiosities and questions solidified in my mind about the far-reaching effects of the interconnections of industry, victim-blaming, blind positivity, and breast cancer. In this article, I discuss my initial experience with cancer diagnoses, and contextualize the internalized complications of this experience that were caused by cultural propensities regarding the therapeutic benefits of positive-thinking and body-shaming, the damaging nature of rigid beauty standards, and the impact of binary gender systems. Following, I share the stories of the eleven women I interviewed to understand their experiences and perceptions of their disease. Next, I describe my participation in lobbying Sacramento politicians to pass the Toxic-Free Cosmetics Act with multiple activist groups. And finally, I reflect on my experiences during the undertaking of this research, and conclude my discussion by situating the experiences of my participants and myself within the context of the broader issues of industry, victim-blaming, and breast cancer.

Autoethnography: “Likely Benign” Diagnoses

The examination room had the faint odor of sanitizer and bandage adhesive. I waited anxiously until the doctor suddenly knocked on the door and entered the room. We went over my health history and what to expect with my annual examination, until the doctor got to the crux of the visit. “Have you ever had an abnormal pap smear?” she asked. “No,” I answered confidently, as over the years I had never had an issue. Although outwardly self-assured in that moment, I also had a quiet realization that I did not actually know what an “abnormal pap” meant. When I heard it, I associated it with something generally wrong. But what?

Abnormal, like the brain of “Abby Normal” in Mel Brook’s (1974) *Young Frankenstein*, that, when inserted into a body, was suddenly strong, desperate, and rampant. Perhaps it was some

zombie-like extension of the body, devouring as it decayed. Was it really any of those things in *my* body? It couldn't possibly be, had never been, and it didn't matter anyhow because "abnormal" was a word that could only describe me socially, at best. And, once again, I knew I could rest assured because at the end of my exam my doctor said, "I would say you're doing very well. This was a pristine pap!" I laughed in response, "Good! Can you give me a bumper sticker that says that? I'll put it on my car: *Pristine Pap...*"

The doctor and I had been so prematurely positive about the potential outcome, you could imagine my surprise when I got the phone call from her suggesting a very different reality after school, just as I sat down to dinner with my family. The pap was abnormal. She went on to say that it was most likely benign, but it could be cancer. Further tests confirmed the latter. My cancer was an early stage, and I underwent the surgical removal of most of my cervix, but later had a total hysterectomy—the removal of my cervix, uterus, and fallopian tubes—as the mutating cells kept reappearing.

Less than five months after my first surgery, I underwent a new series of tests, starting with the mammogram. Again, I thought nothing of it. Although the process was *very* strange; a kind woman kneading my breast into the flat, plastic jaws of a monstrous machine. Despite the very uncomfortable sensation, it was not as horrid or painful for me as others had warned. Once again, the results were in and I heard foreign words describing my "likely safe" biological state: I had microcalcifications that were "probably benign." The nurse also assured me that my youth decreased the likelihood of a breast cancer diagnosis (I had just turned 30 years old). I had hoped that the nurse's optimistic statements were solely grounded in statistics, but realized that perhaps they were also delivered with an authentically

American optimism. In response to her confidence in my physical health, I informed her that the last time I heard I was “probably okay,” I found out I had cancer.

The next thing I knew, I was informed that I needed a biopsy, and this time I did not allow myself to glom onto the same optimism that I did before my first diagnosis. I had learned that such optimism did not prepare me for less favorable possibilities. I laid atop a table with a hole, which my breast hung through. Once again, it was clamped into plastic jaws, but this time the mammography experience was accompanied with needles of lidocaine—sharp, painful, deep, and burning as the anesthetic was injected into my tissue. Once my breast was numb and they located the area of concern via x-ray, they removed tissue for pathological analysis. After my biopsy, I did my best to ignore what was happening. I washed the dishes, did my homework, and played Minecraft with my son. But, despite my efforts at distractedness, a blanket of anxiety weighed on my consciousness.

Two days after the biopsy, I was diagnosed with cancer. Again.

My Body Parts Make Me Feminine

In the United States, gender and biological sex traits are ideologically sutured to one another. This leads to a wealth of issues for those who are gender nonconforming, intersexual, transsexual, and more. But what about those who gender themselves “accordingly” with their biological sex traits, and face the surgical amputation of the telling body parts?

When I underwent the surgical removal of most of my cervix, I experienced a surprising sense of loss. It struck me that such an “invisible” amputation would make me feel sad and, somehow, like less of a woman. When I thought further about it, I realized that this feeling of

diminished “womanness” could have something to do with the pervasive and sexist assumption that the purpose of women being sexually active is to become pregnant, and I was told that after this operation I would miscarry if I became pregnant again. I also realized that the procedure had been an assault on a part of my body that science and culture associate as female and feminine. But there was a part of me that thought I was overreacting, and that these feelings were occurring in me, personally. However, during a conversation with my mother’s best friend who had also had cervical cancer, she told me that after her operation “[she] was devastated, and didn’t feel like a woman anymore.” This gave greater validity to my initial thoughts of the role of sexist, patriarchal ideologies as it pertains to the loss of womanness after surgery for gynecological cancer.

As Laura Nader (1997) and Linda Coco (2005) have described, U.S. media, marketing, and ideologies enforce and disseminate ideas of “Official Beauty.” Every day, American women are inundated with presentations of specific—thus exclusionary—types of beauty, and are sold products that can ease women’s deformative inability to resemble those images, so that they can attempt to perform to that standard. In the American context, these forms of hegemonic advertising help to transform and strengthen capitalism (Ewen 1976) by molding women into lifelong, needy, insecure, and anxious consumers (Coco 2005).

Again, such damaging controlling processes that affect the lives of healthy women become even more unbearable to those whose illness leads to actual (not socially imagined) disfigurement. And these mechanisms that create insecure, insatiable consumers out of women had indeed sutured themselves into my mind since I was a child. Fortunately, I stumbled across anthropology and began my process of “unlearning” many of the cultural

assumptions that had been naturalized throughout my lifetime. I allowed myself to be proud of my strengths, confident in my abilities, and to love and appreciate the body that I have, whether or not I fit the standards of “Official Beauty.” I wear what I like, and adorn and gender myself in a way that makes me happy. But, suddenly, with the diagnosis of breast cancer, I had to imagine the amputation of a more visible part of my body. This body that I had finally allowed myself to love was conspiring to kill me, and the only way to stop it was through mutilation and sickening treatment. “I like my breasts! And I’m pretty sure this world is a better place with them in it!” I told one of my friends, in a frustrated and facetious tone. Once again, I found myself experiencing a culturally produced fear of diminishing womanhood and femininity. With the destruction of these culturally fetishized biological markers, what am I?

There are many other ways that the value of a woman is reduced to her body, and whether or not it mimics the arbitrarily constructed ideas of Western sexiness and beauty. Apart from other negative impacts, these conceptualizations inevitably devalue women who have the “sexy” parts of their bodies removed for medical reasons. Rell Sunn, one of the world’s most skilled female surfers in the 1970s and 1980s was diagnosed with breast cancer and underwent a double mastectomy—the surgical amputation of her breasts. Shortly thereafter, she was dropped from her sponsorship. As Krista Comer (2010) wrote, “Without breasts, she was no longer the surf industry’s Polynesian goddess...” (212).

Regardless of what I know about controlling processes and the ways in which I work to exercise a counter hegemony to these processes, I know that I will be treated differently by members of the public if I am visibly “maimed” and therefore do not conform to ideals of

beauty and anticipated shapes and functions. Beauty ideologies that create insecure customers to boost consumption and increase profit for plutocrats have also created a public that is unaccepting of physical deviation from the official beauty narrative.

Ideological Indoctrination: The Stuff Your Body Does is Gross

Through the marketing of products that mask natural bodily processes and enable the denial of the existence of these “disgusting” byproducts of the living body, Americans learn that the things our bodies do are socially unacceptable. Women, especially, should not sweat or fart; we should remove body and facial hair and keep our backs straight; we should not belch, and women should certainly act as if they do not defecate. If our bodies expel any of these signs of life, we must purchase products that will extinguish or conceal their existence.

When I went through biopsy procedures, as well as my first surgery, I found the generalized list of expected healing processes that had been provided to me by my surgeon was inadequate in describing the symptoms I was experiencing. This illustrates the censorship of medical descriptions of physical processes experienced by women. I was alarmed something was wrong with me when I experienced phenomena that were not included on the list of post-operative symptoms and complications, which included infections due to surgery-induced imbalance of vaginal flora, severe odor, discharge with gobs of coagulated blood and dead tissue, pain and bleeding from granulated tissue formation, and more. Late at night, I scoured the internet for gynecological cancer blogs, to see if anyone else had experienced the same. I found the stories of many women whom had similar post-surgery experiences, although, many of the women overly censored themselves, trying to depict their experiences as “neatly” and non-specifically as possible.

Because I have a knack for thick description and realized that many women were as alarmed as I was by the symptoms that they had not been prepared for by their physicians, I decided I would write up a very specific and detailed blog post about my experiences, and post it on several women's cancer blogs. I wanted to do this to help the many other women who, like me, were worriedly reading through the experiences of others to establish some normalcy in a situation where the security of every day expectations of our bodies had been inverted. In retrospect, this blog post was an applied form of radical public anthropology, as I used my autoethnographic methods and activist sensibilities to help provide insight and inform others in need.

So, I wrote up my personal accounts, and expanded on even the most gruesome details, including peeling tissue, discharge, strange bloody odor, and pain. Before posting my account on a gynecological cancer blog, I read what I had written to my mother. She had been a breast cancer patient years ago, and I had helped her through that time, so I knew she had experienced the gamut of horrifying biological processes involved—surely she would empathize. Or, so I thought. When I read her my account, she told me with palpable disgust, “*Nobody* wants to know all *that*.” I was hurt by her reaction, but I was also angry. “Yes, there ARE people who want to know all that,” I replied, “People like me and the thousands of other women who have posted on these blogs!”

Her reaction is a result of the fact that we have been taught to pathologize bodily functions, and to be embarrassed by them. These attitudes become as toxic as disease that afflicts us because we become disgusted with ourselves and subsequently fear reaching out to others fearing potential social repercussions. To be sure, these ideologies concerning body

image and bodily functions can be linked to hegemonic processes that lead the masses to consume. Often times, these ideologies are harmful, and create some extent of psychological suffering.

As I navigated these issues, I myself was plagued by depression and crippling anxiety. When the psychological suffering became unbearable, I found a breast cancer support group for women who had been diagnosed under the age of 40. Within the safety of the anonymous support group, I found that the other women shared many similar experiences. Some of the women volunteered to be interviewed, and I used pseudonyms to protect their anonymity, and included four of their stories in the following sections.

Stories from the North Bay

Naomi Jones

I met Naomi Jones in a coffee shop in her San Francisco neighborhood. She was petite, bore a large, warm smile, and had fluffy, long black hair. She currently had breast cancer, and was shockingly thin, to an extent that I was concerned her cancer had metastasized (or spread to other organs in her body). She was 41 years old, and had grown up in Struthers, Ohio, but had been residing in different states since 1998, when she'd fallen in love and moved in with a woman. Her family and town locals did not approve of her homosexuality, and in 2001 she finally moved to San Francisco. As a child, she spent a lot of time with her mother and grandmother, who were two strong female figures in Naomi's life that feared Western medicine and greatly influenced her perception of disease treatment.

Naomi had worked in a variety of occupations. She'd been a waitress, a real estate agent, an exotic dancer, and had worked a number of other odd jobs. But when she was a child,

steel mills were the predominant industry near her Ohio home, one of which was where her father was employed. Upon further research into this industry, I learned that steel mills utilize pollution-producing processes that create toxic emissions (Cecil 1997). Some of the predominant contaminants released into the environment during steel production process are polycyclic aromatic hydrocarbons (PAHs). Many PAHs bioaccumulate, are carcinogenic, and are known to contaminate the air, watersheds, and soil in the Mahoning Valley region (Cecil 1997) where Naomi spent her childhood and early adulthood.

Five years prior to Naomi's diagnosis, her mother had died of cancer, which had metastasized to her brain. Naomi had struggled with her mother's death, especially because it had happened so suddenly—she was diagnosed in December 2012 and died March of 2013. "I was so lost after my mother passed away...I couldn't work, I couldn't do anything. I was literally a mess." Naomi's maternal aunt also had a cancer diagnosis; she had been treated for ovarian cancer, from which she was in remission thanks to what Naomi referred to as the "standard of care," which she mentioned often, and with antagonism. "I thought that we were being lied to by the medical industry about a lot of things," Naomi said. "I didn't want to go to the 'standard of care,' [i.e. a Western doctor] so I began seeing a naturopath, and trying to shrink [my cancer] that way, rather than going to like UCSF [University of California San Francisco Medical Center] or something." When I inquired about her own distrust in the standard of care for breast cancer treatment in the U.S., she cited her reasons as involving articles she had read online which stated that healthcare providers receive financial incentives for prescribing surgery, chemotherapies, and radiation, and that treatments like chemotherapy can spread cancer cells.

Taking in this information had disastrous effects on her treatment decision-making: “I’m just getting all of this information and I don’t know what’s right and what’s wrong, so I feel like I’m paralyzed to a degree...I don’t know what to do!” Though Naomi had expressed her difficulty deciphering disinformation from “real” information, she also embraced and delved into conspiracy beliefs, including one about elite members of the medical industry and how they arranged for the murders of naturopaths that found cures for diseases.

The literature Naomi found on the internet regarding naturopathic and magical approaches to cancer treatment—coupled with her fear of the Western medical approach—led her to delay ‘standard of care’ treatments for months following her diagnosis. She found online information about Rife Machines and a concept called *bioresonance*. According to Naomi’s online sources, the Rife Machine could find the frequency of her tumor’s vibration, match that vibration, and destroy her cancer. She reported she’d noticed a “major shift in [her] tumor,” thanks to the Rife Machine. She spent a huge amount of money on these treatments and supernatural methods of diagnosis, none of which were covered by her health insurance. Furthermore, her bioresonance treatments led to more diagnoses: she was told she had spirochetes, Lyme Disease, fungus in her body, and Chlamydia—all of which she would continue treating using expensive, fraudulent, pseudo “natural” and supernatural methods. Naomi admitted to being in severe debt as a result of seeking out these treatments—ironically, something that is potentially contemptable to some but not unlike what would happen if she were to seek out Western cancer treatments if she did not have medical insurance. The naturopathic and supernatural specialists who administered Naomi’s tests and treatments talked to her extensively—sometimes for hours—during her appointments, all of

which fueled her belief in conspiracy theories as well as her emotional and physical needs for the alternative therapies they provided for a fee. She expressed her frustration and suspicion concerning a lack of a cure for cancer in Western medicine: “It pisses me off, and it just makes me think they are lying to us...because with all this technology that we have—I mean, a bioresonance machine exists, and this could be at every hospital in the United States, and they could be helping to cure cancer!” One of her bioresonance therapists did a “cancer search” of her body after several treatments and told Naomi that her cancer was gone.

After months of exploring an array of alternative and magical therapies, Naomi was referred to Dr. Anderson, an oncology surgeon who specialized in the combination of “standard of care” cancer treatments and integrative wellness approaches. It was Dr. Anderson who was able to address Naomi’s concerns about Western medicine in a respectful manner, while simultaneously encouraging Naomi to try standard strategies for breast cancer treatment combined with complementary therapies and holistic approaches to wellness. Naomi’s first experience with a Western medical approach to her cancer treatment was Lupron injections, which helped stop production of hormones that fed her tumor.

When I asked Naomi whether or not her oncology team had discussed with her what may have caused her cancer, she said they inquired about her alcohol consumption, and Naomi admitted to drinking a lot, especially after the loss of her mother. Even though her healthcare providers did not specifically mention diet and exercise, Naomi expressed a strong belief that diet and cancer are linked. She experimented with cutting out sugar from her diet entirely. She was surprised that her zero-sugar diet did not shrink her tumor, but surmised it was because she had Lyme Disease and spirochetes in her system. In a comment with an

overwhelming sense of self-blame, Naomi also expressed her belief that her cancer could also have emotional links: “I’m a big proponent of cancer coming from emotions, and I’ve been dealing with a lot of emotions since I was a child from being gay. And I think that might have contributed to my cancer. And just the depression, and the struggle, and all the negative thoughts that come with that.” She continued delving into her perceptions of cancer causation, “So, what is the reason for my cancer? Um, negative thoughts, negative emotions, diet, alcohol, lack of exercise...” Naomi had deeply internalized victim-blaming rhetoric regarding her breast cancer in the context of structural violence that punishes gender nonconformity.

Stories from the South Bay

Jennifer Aimes

When I interviewed Jennifer Aimes, she invited me into her home in Campbell, California. She was nestled into her deep, brown, textured couch, and I sat across from her in a reclining chair. Jennifer was 65 years old and cared for her elderly father who was slowly dying of heart failure. She also spent much of her time in her garden, babysitting her grandson, and spending time with her dog and cat—a task she laughingly referred to as “zookeeping.”

Jennifer grew up in the San Jose area, which comprises what was formerly known as the Santa Clara Valley and is now the heart of what is widely known as the Silicon Valley. During her childhood, long before tech innovation industries took over, the valley floor was lined with lush orchards that bore apricots, cherries, prunes, almonds, and walnuts. Because the valley had soils, weather, and topography that favored the farming of fruit, it became the

largest fruit production and packing region in the world until the 1960s, when the technology industry began to dominate the region (Wikipedia 2021b). Jennifer reminisced playing in the orchards, building tunnels in the grass and weeds, and getting hired by local farmers to pick fruit, bringing back full crates of fruit and getting paid by the crate. But, little did she know, these were fruits of wrath.

Unfortunately, the valley that once produced such a sunny, tree-lined, fruit sweetened playground for Jennifer was also treated with a number of agricultural chemicals. Having personally grown up in the region, I was aware of some of the environmental contaminants. But further reviews of literature revealed that Santa Clara County, now with more toxic cleanup sites than any other county in California, has poisonous soil and water contamination from lead, arsenic, DDT, and other legacy pesticides (Lynch 2007; Young et al. 2005). To make matters worse, long before local fruit industries proliferated, the southern San Jose area sprouted around quicksilver mines which extracted cinnabar—mercury ore—from the earth and became one of the U.S.’s largest mercury distributors (Wikipedia 2021a). Unfortunately, mining operations polluted the Guadalupe River and South San Francisco Bay, impacting a number of native terrestrial and aquatic species—an environmental issue that continues to this day.

In Jennifer’s early 20s, Santa Clara County experienced its first tech boom, stimulating local economies and creating new work opportunities. So, Jennifer found herself working at a number of different tech companies, including National Semiconductor, Los Gatos Circuits, and Raytheon. At Raytheon, Jennifer did solder work on chips and circuit boards, and cleaned them in a chemical etch, which she referred to as an “acid bath.” Trichloroethylene

(TCE) was a common chemical used in this process. Today, the Silicon Valley is home to 23 Superfund⁵ sites, with TCE listed as one of the main chemical contaminants at these sites.

TCE has been found by the Environmental Protection Agency (EPA) to be a human carcinogen through mutagenic means (EPA 2011), and has also been linked to liver, kidney, and brain damage, as well as heart malformations in fetuses, and other effects (Nieves 2018).

“There are companies that are dumping toxic chemicals into the water, into the ground—washing out their cold traps and stuff like that that they’ve used to etch semiconductors with, and that’s in the ground,” Jennifer said, with disgust. “The time I saw this happen I was, what, almost 30? And it was happening then, and the companies I saw doing it weren’t the only ones. And there were much bigger companies doing that.”

Jennifer was 43 years old when she noticed a lump in her breast and was diagnosed with breast cancer. She felt like her diagnosis was a death sentence, and underwent a double mastectomy and chemotherapy. Going through breast cancer treatment strained some of Jennifer’s relationships. She recalled people who treated her like she was “catching.” Although people were kind, Jennifer felt a distance created by others, as if her cancer and its related struggles were contagious. Jennifer’s mother and daughter were very saddened and concerned for her, but her husband remained unsympathetic and unsupportive. “He would use me as an excuse to get out of work, if he wanted to get out of work...but I drove myself to all my chemo treatments.” She considered her husband—a step father to her daughter—to be untrustworthy and unfit to raise her daughter and, fearing she may die from her disease,

⁵ A superfund, also known as Comprehensive Environmental Response, Compensation, and Liability Act is a federal law which was implemented in 1980, allotting funds to clean up sites that are contaminated with hazardous substances.

she began planning to select someone else to care for her little girl. Jennifer's younger brother and his family expressed their belief that she had contracted cancer as punishment for a sin—perhaps having been a single mother. “You know, they were brutal towards me...it was like I had done something wrong in my life and I'd deserved [cancer]. My other brother and sister-in-law didn't really come around much either. Nope. No one really came around a lot.”

Jennifer's body image had also been radically altered; she felt as if her womanness and attractiveness had been severed and discarded with her breasts. “Not being attractive, that stays with you...that doesn't go,” she said with a furrowed brow as she stroked the fluffy brown fur on the bag of her dog's neck. “Because all I have are scars across my chest and I got a couple of implants that are just lumps—it's just something that's under by skin and uncomfortable, and I don't want people seeing it because I don't think it's attractive. It's *not* attractive.” Her disparaging image of herself was nurtured by a deep depression she experienced during her treatment. Within this maelstrom of emotional turmoil, she also felt shame for being unable to keep a tidy home. She internalized cultural standards and expectations of gendered productivity, namely self and home care. “...I didn't want people to come visit me if my house wasn't clean. You know, I felt that I still had to maintain that normalcy and I couldn't do it.”

Though Jennifer couldn't recall her doctors extensively discussing with her what may have caused her cancer once she was diagnosed, she recollected a brief discussion with her healthcare providers when she had her fine-needle biopsy. First, she was asked if she had a family history of breast cancer, indicating that inherited genetic causes were the only possible

factor on their medico-scientific radar. To their credit, three of Jennifer's paternal aunts had been diagnosed with breast cancer—simultaneously, Jennifer's aunts had also grown up in the Santa Clara Valley. Furthermore, her doctors honed in on Jennifer's maternal grandmother, who had had cervical cancer. Her doctors emphasized that genetic breast cancer must come from the matrilineal line, and that Jennifer's breast cancer therefore was likely a mutation of the gene that caused her grandmother's cervical cancer. Jennifer also recalled one of her healthcare providers asking her if she had injured her breast prior to diagnosis, "It was almost like they thought it could be brought on by injuries sometimes."

Once she received her diagnosis, however, the discussions about breast cancer causation ceased. When I asked Jennifer what *she* thought caused cancer cells to proliferate in her breasts, she expressed her belief that she inherited a mutated gene from both her maternal and paternal bloodlines. Due to her belief that genetics was the leading or sole factor in her breast cancer diagnosis, she was perplexed as to why neither of her two brothers developed cancerous tumors. "I don't understand why my brothers didn't end up with cancer. But my great niece got cancer when she was a baby. An infant."

My questions about breast cancer prevention yielded oscillating and sometimes contradictory answers from Jennifer, most of which involved self-blame, but some of which involved more mystical concepts like "luck" or "sin." She explained her perceptions of genetic risk: "How can someone *avoid* cancer? You get what you get when you're born, number one. Number two, if you don't have the genetic exposure, you would have to start from the beginning of your mother's life. Maybe it didn't start from the day *you're* born but whatever your mother's indulged in will be passed on to you. So—looking at it from a

biblical sense—it is the sins of the mother or the father that is what you carry forward.”

Although Jennifer chose a biblical platitude to illustrate her point, it became clear that she was not only referring to poor lifestyle choices, but also went on to unknowingly describe concepts of epigenetics: “...what the [mother and father’s] occupations were, if they worked in an industry where they were exposed to carcinogens, and then it would be in their systems and get passed on to you.”

Jennifer also discussed alcohol consumption, saying that some may get cancer from drinking too much, but then immediately compared this possibility to individuals who consume alcohol very often but live a long and healthy life. She went on to describe areas with lower breast cancer rates, “...I think Japan is one of them? And that has something to do with...its gotta have something to do with their diet.” Jennifer did eventually discuss some environmental contaminants as an issue, but throughout her interview it was clear that her and her healthcare providers’ perceptions of breast cancer causation and risk were tightly bound to genetics and lifestyle choices.

Though Jennifer was somewhat aware of environmental exposure in her youth and early adulthood, her lack of attention to intergenerational and personal exposure to environmental carcinogens may be undergirded by mainstream discussions about the causes of breast cancer, as well as her doctors’ intense focus on genetics. It was of interest to me that her healthcare providers assumed that genetic breast cancer solely came from the maternal bloodline. It rang a familiar tone of the long-term and ongoing sexism that exists within science. Whether Jennifer, her doctors, or her family attributed her cancer to genetic

mutations, life choices, or injuries, the underlying thread that weaves through it all is defect of the individual.

From the East Bay: Isabella and Mary

Isabella Perez

God, I'm really angry. I asked you to heal my arm, and you sent me cancer. I asked you for children and you gave me infertility. I asked you to get along with my husband, and you sent me a death sentence. You know, I pray for many things, but you know better. I don't even know what I want or what I need, or why you know better. So, I just put it in your hands and I try to do my best, and I let you do whatever you want to. And it's weird and I don't get it, but just help me... (Isabella Perez, personal communication, 2017)

I met Isabella Perez at her in-laws' home in Santa Rosa, California. We sat in the backyard at a patio table, underneath the lush canopy of a tree that was filled with singing birds. Isabella had beautiful dark eyes, tightly coiled curly hair, and a thick Jalisco accent. Isabella was a 34-year-old nurse practitioner from Tequila, Mexico. Tequila is city in the state of Jalisco, and is not surprisingly known for tequila production. Isabella's hometown of Tequila had many large, industrial farms containing seemingly endless rows of massive, blue-green pineapple-shaped agave plants. Along with the agave fields were a number of tequila distilleries, which have multiplied in the area due to international demand for the liquor they produce. An aspect of this industry that Isabella did not discuss, and possibly was unaware of, was the massive use of agrochemicals and the volume of highly toxic waste from the distilling process that is often dumped into local waterways (Tetreault, McCulligh, and Lucio 2020). Additionally, distillery wastewater often contains organic and inorganic pollutants as well as heavy metals, most of which are carcinogenic, mutagenic, and

endocrine-disrupting (Chowdhary, Raj, and Bharagava 2018). Isabella lived in Tequila until she was 16 when she moved to live with family in Texas and began her secondary education.

At the time of my interview with Isabella, she had just been diagnosed with grade 3 invasive ductal carcinoma, and had undergone a unilateral mastectomy. She said it had all started when she noticed a lump in her breast. However, it was not an irregular occurrence for her to have painful, dense breasts, especially when she was menstruating. But this time was different; the lumps did not go away, and the pain continued to intensify. Isabella had been desperately trying to have a baby with her husband, and was hopeful that the persistence of the pain in her breast meant that she was finally pregnant. Her hopes dwindled over time, especially when she noticed that the lump was very hard and only in her left breast, so she decided to have an ultrasound. She got her first ultrasound in Mexico, where it was cheap and she was able to have the screening immediately and biopsy immediately. She appreciated that she didn't have to wait a period of weeks before all of the screenings, biopsies, diagnoses, and care discussions, as she would in the U.S. By the time she returned to the U.S. two weeks later to be tested again, her tumor had already grown.

Upon her diagnoses, like many other women, Isabella experienced emotional turmoil—a plethora of complex feelings; she was angry, sad, scared, and in denial. She reflected on her paternal grandmother's fate. Her grandmother had been diagnosed with breast cancer when she was 59 years old, and died a year later at age 60—the cancer had metastasized. Isabella feared she would die before even turning 40. Along with that fear of dying from her disease, she countered her fear of death by contemplating suicide. As she lay in the hospital, recovering from the surgical removal of her left breast, she told her nurse, “If I go home, I'm

going to hang myself in the garage.” As a result, her care team decided to keep her in recovery at the hospital for an extra night. She told me she had many depressive episodes since she was a child. During the interview, Isabella expressed an unrelenting oscillation between suicidal thoughts and the drive to live a fulfilling life. On one hand, she believed her cancer may have been caused from her lifelong struggle with depression and suicidality: “Sometimes I feel like this is all a punishment, for wanting to die so many times.” But in a following statement, she said “I am wanting to live. I know I will die of something else one day, but I don’t want it to be cancer, so I’m doing treatment.”

Isabella’s self-image was also deeply impacted by her diagnosis and treatments. Her internalization of mainstream Western beauty standards had always had a hold on her. She remembered telling her breast oncology surgeon, “All my life all I’ve been trying is to look normal [sic]...I don’t want to lose my nipple, I don’t want to lose my breast...I’m going to take your advice, but maybe if you don’t need to do the mastectomy then I’ll do the lumpectomy.” Ultimately, Isabella felt that her doctor had written off the possibility of a lumpectomy. Isabella also had conflict with her surgeon when she requested to have a copy of her pathology report. She had been recovering from her surgery and was not fully lucid due to pain medications and anesthesia, and she could not fully comprehend what her surgeon was telling her about her procedure and the results they found after removing and analyzing her tumor in the laboratory. Isabella requested to see her pathology report, and her doctor refused. Isabella believed that the doctor was defensive about this request, but she advocated for herself and insisted that she would contact the medical records department and get the report herself if her surgeon refused to supply it. The surgeon eventually agreed.

One of the hardest aspects of the disease that Isabella was contending with at the time of the interview was the possibility that she would be infertile after treatments. She felt cancer was taking everything from her. Because her embryos would likely be damaged from chemotherapy, she might not be able to carry a child. She cried as she told me that her care team had been monitoring her fertility, and that the previous month none of her ovarian follicles were released, which happens when a woman is fertile. She also reflected on the risk that long-term therapies like Tamoxifen will essentially throw her into menopause prematurely. "...menopause will affect the way I feel, like vaginal dryness, sex drive—which I already have problems with my sex drive because of my [childhood sex abuse]—and I know these problems and I just get really mad." She sobbed in frustration and sadness and continued, "Why didn't [cancer] happen when I was 50, or 60, or 70? Why does it have to be right now?!"

None of Isabella's healthcare providers ever discussed with her what may have caused her breast cancer, though others in her life, including Isabella herself, had ideas about what caused her tumors—not one of which were related to the abundance of toxic chemicals surrounding her in her hometown as the lobes and ducts in her breasts formed. Her husband firmly believed that her stress was what led to her cancer and, though she agreed that he may be right, that theory tacitly blames Isabella for her disease. Isabella also attributed her cancer to genetics, referring back to her grandmother who'd died of the disease. Other people Isabella knew had briefly mentioned the potential for other causes of her breast cancer; one of her friends signed her up for a Meal Train program, to help provide her with healthier meals for a few days, to try to help mitigate her cancer.

Mary Williams

I met Mary Williams at her home in Lafayette, California. It was by far one of the nicest homes I had been to in years. The house had two stories, a wine cellar, a basketball court, and a lovely view of rolling oak grassland hillsides. Mary was petite with bright eyes and shiny strawberry blonde hair that delicately rested upon her shoulders. She offered me a cup of tea, and I obliged. It gave me the caffeine boost I sorely needed.

Mary was 42 at the time of our interview, a retired attorney, and her husband was a law professor in San Francisco who was able to financially support her early retirement. Mary was also a self-proclaimed “stay-at-home mom and a full-time volunteer.” She had two children, a son and a daughter, and was volunteer who served on the Board of Directors for a regional nonprofit cancer organization, as well as a volunteer for a regional refugee resettlement program. After the election of President Donald Trump, Mary had felt the need to help people who were fleeing from violence in the Middle East, sometimes for individuals who had aided the U.S. military, and were now being hunted by domestic terrorists. The structure of the U.S. refugee program often left such individuals waiting in hiding for up to two years after reporting to the government that terrorist organizations were looking to murder them and their families.

Mary grew up in Portland, Oregon, and met her husband when she was in graduate school in North Carolina. The predominant industries in Mary’s hometown were logging companies and Intel, a semiconductor corporation that has been connected to emissions of an abundance of toxic pollutants in the region (Rogoway 2019). Breast cancer was not Mary’s first cancer diagnosis. Mary had first been diagnosed with Hodgkin’s lymphoma when she

was 20 years old while attending college in Connecticut. She had noticed swollen lymph nodes on the left side of her neck, so she visited the clinic at her college. The doctor at the clinic misdiagnosed her: he said she had mononucleosis. Though she felt there was something worse going on in her lymph nodes, the doctor brushed her off. As the lumps in her neck got larger and became painful, she visited the college clinic doctor again. He ignored her concerns once more, telling her that the semester was almost over, and that she should wait until it ended and see her family doctor back home. When she finally saw her family physician back in Portland, he took one look at her and wanted to run tests. The tests confirmed she had Hodgkin's lymphoma. Fifteen years later, she was diagnosed with breast cancer.

Unsurprisingly, Mary had been traumatized by her first cancer, so facing her first mammogram brought about much anxiety. She recalled Hodgkin's lymphoma being a difficult life experience, but also knew that she got her life back on track fairly quickly. Likewise, Mary knew breast cancer would be inconvenient and uncomfortable, but because of her previous experience had assumed that she would soon enough be back to normal. Only after her surgeries, treatments, and long-term health problems did she realize her new diagnosis would be much more traumatic: "There's no getting back to normal after breast cancer. There's a *new* normal but not your old life. It's always me, plus the breast cancer. It just never goes away. You learn to live with it but it's always there." She explained this experience as being the primary reason for being so active in the Bay Area breast cancer support group.

After Mary's second cancer diagnosis, she was tested and diagnosed with a mutation of the BRCA-2 gene. Such a mutation increases the risk of breast, ovarian, and a number of other cancers. Her experience with Hodgkin's lymphoma, breast cancer, and a BRCA-2 mutation has increased the severity of her anxiety about her health. She is tremendously concerned whenever she detects something abnormal in her body. She had hoped to have a third child, but gave up that dream to have a full hysterectomy and oophorectomy, leaving her with no uterus or ovaries as a prophylactic measure to prevent a new cancer from forming (and dying from it). The prophylactic removal of ovaries, fallopian tubes, uteri, and breasts is now a common medical prescription for women who have mutations of the BRCA-1 and BRCA-2 gene. Mary suffered permanent alopecia (a condition that causes baldness) from chemotherapy, and has also had a litany of skin biopsies, leaving numerous scars from the removal of moles that may have become melanoma. Mary still feels tremendously anxious every time she has to go to the doctor.

Mary's doctors attributed her breast cancer to a number of things, namely her BRCA-2 mutation and her Hodgkin's lymphoma and associated radiation therapy. Mary's belief about her breast cancer generally fell in line with the explanations presented by her healthcare providers, though she sometimes oscillated between blaming her genetics and discounting her genetics: "Like, there's someone that has the BRCA-2 mutation that never develops cancer, and there's someone who is exposed to the [Epstein-Barr] virus that never gets Hodgkin's lymphoma, it's just—something in *my* body, in my DNA, it goes to cancer." Mary concluded this thought by expressing that having cancer DNA feels like a death

sentence; she believes that she will die of cancer one day, she just hopes to be elderly when that time comes.

Considerations

Though these stories only reflect four of the eleven interviews I conducted, there were many themes and patterns across all of the interviews that were glaringly evident. All of the women experienced fear—fear of death, recurrence, shifts in family dynamics as a result of their disease, and more. Guilt and self-blame were also quite prevalent in their discussions, and was most commonly related to perceived spiritual, nutritional, or substance abuse flaws. Furthermore, *none* of the eleven women I interviewed blatantly incriminated corporations or regulatory institutions as being to blame for the breast cancer epidemic, nor their personal cancers. Nonetheless, some of them implied possible connections to the ubiquitousness of contamination in water, air, soil, and food. Even when interviewees briefly expressed these implications, they always oscillated back to personal mistakes or the “randomness” of breast cancer. These phenomena of depression, guilt, fear, and more, can be considered the psychological fallout not only of breast cancer itself, but of lifestyle rhetoric and the social discounting of environmental factors.

Following the interviews with participants, I ventured into another realm of radical anthropology: cancer activism. I became involved with a number of political groups, grassroots organizations, and individuals who, like myself, had been impacted by the disease in some capacity and saw patterns of corporate practices that were increasing cancer risk for the public. My participation in cancer activism began with volunteering for the grassroots activist organization BCAction.

Over the few months of my volunteer work with BCAction, I came into contact with other individuals and entities who were involved in cancer activism in other capacities. Like BCAction, these groups were aimed at public education, providing access to resources, and work with politicians to protect the public—though the concerns of the other groups were geared towards many types of cancer and other physical maladies caused by environmental exposures to toxic substances. The first time I ever connected with some of these groups was when we lobbied politicians to pass California Assemblyman Al Muratsuchi’s Toxic-Free Cosmetics Act.

Cancer Activism: The Toxic-Free Cosmetics Act

On January 8, 2020, I arrived at a cafeteria inside the state Capitol building in Sacramento, California. Walking around the building was both disorienting and fascinating. It was a maze, and none of the elevators were alike, as they granted or blocked access to different areas of the massive building. Some elevators were reserved for assembly members only, others required worker badges to operate, and finally there were those for visitors. It took me a few wrong attempts to find the visitor elevators, and an elevator that would get me to the wing I was looking for. The building was phantasmagoric: giant wooden doors adorning the conference rooms; the wood-detailed, etched, and painted ceilings, the ornate chandeliers and wall sconces; the brass and marble statues; the elaborately carved wooden bannisters, and more. The intricacy of every inch of the building was awe-inspiring and overwhelming.

I was there to meet with various representatives and board members from environmental and women’s health activist organizations and cosmetic companies—all with the same goal:

to lobby politicians to pass the Toxic-Free Cosmetics Act (AB 495). In 2019, Bill AB 495 was introduced by Assemblyman Al Muratsuchi, and was designed to ban 13 highly toxic chemicals from cosmetics and personal care products in California. These chemicals are known to be carcinogenic, or cause a slew of other health issues, and included formaldehyde, mercury, asbestos, two parabens, Polyfluoroalkyl substances (PFASs), two phthalates, and two phenylenediamines. Muratsuchi reached out to his personnel, who contacted organizations that would be interested in helping to persuade other assembly members to pass the bill. I was made aware of these efforts when I received an email through the listserv of my support group.

This was my first experience participating in lobbying efforts, and my mind was a crucible of happy excitement and horrific nervousness. Once all of the participating women had arrived, Jenna, the event organizer, informed us that corporate lobbyists were also present that day to implore assembly members to reject the bill. Then, Jenna arranged us into groups of four-to-five women. Every woman in the group had a different title and background; some work at toxin-free makeup and child cosmetic companies, others—like myself—were breast cancer survivors, and some represented organizations like Black Women for Wellness, Breast Cancer Prevention Partners, California Public Interests Research Group, and Environmental Working Group. Though it occurred to me that the women who represented toxic-free cosmetic companies may be looking to negatively impact big cosmetic industries for their own gain, I had the impression that most—if not all—of the women shared the same motives for lobbying in favor of this law: we wanted government agencies to be accountable for protecting the public from being involuntarily exposed to

hazardous chemicals by using care products. We wanted to create a space where the detriments of toxic chemicals in these products are actually discussed. Also, in recognizing that California is an economic superpower in the U.S., we wanted our state to be a trend-setter in demanding changes in the practices of industries that inundate our products with toxic ingredients. The assumption was, and is, that if California enacts this ban, the economic impact on such industries would be so great that they would likely have to make their product lines safer. These chemicals have already been banned in the European Union and other countries (Eur-Lex 2009).

Once we split up into our groups, we set out to meet with assembly members with whom we had scheduled meetings. Though we often got to speak directly with assembly members themselves, there were quite a few instances when we spoke with their legal aides. Each of the members in the group discussed their relevant experiences and perspectives pertaining to the importance of the bill. Mine, like a few of the other women's, was quite personal. I introduced myself as a student, a mother, and an archaeologist. Then I told them why it was so crucial to me that they pass AB 495:

I am a breast cancer survivor and have a BRCA-2 genetic mutation. Having a BRCA mutation means my lifetime risk of breast and other cancers is dramatically increased by exposures to the carcinogens and hormone disruptors in this bill, specifically asbestos, formaldehyde, and the two phenylenediamines, parabens, and phthalates. People like me with the BRCA gene mutation—and all women at risk of breast cancer—need protection from the toxic ingredients found in cosmetics and personal care products that we use every day.

It is not right or fair that companies are knowingly—and legally—increasing my risk of cancer. As a young woman who has had the disease, I can tell you that I have suffered enough. Having breast cancer should not be a rite of passage that women go through because we are not protected from the toxic practices of corporate giants. It is a disease whose effects and treatments are disfiguring, sickening, and emotionally traumatic—and I can attest that some of these effects are lifelong.

As an individual, a survivor, and a mother, it is unfortunately impossible for me to screen the ingredients of all products my child and I come into contact with, and we know that some companies will not voluntarily do what is right to protect consumers—which is why we need you to support AB 495, which will ban these toxic chemicals from the products that I and many other people use every day. (Briann DeOrnellas, personal communication from the author to California legislators, January 8, 2020)

Ultimately, AB 495 did not pass. It had gotten enough votes to advance to the Assembly Health Committee, but some committee members required the removal of two of the toxic chemicals—lead and asbestos—from the bill, essentially causing it to have to be re-written. Because lead and asbestos can be found in natural substances like talc, it is considered a contaminant and not an intentionally added ingredient, some committee members were not interested in banning them from our products. Fortunately, the bill was re-written and introduced as AB 2762, and by September of 2020, it had passed the legislature and was signed into law by Governor Gavin Newsom.

Conclusion: Inherent or Constructed Vulnerability?

Although power relations shape what is possible for and what is expected of citizens, the unequal distributions of power can be broken down, so that what is possible is not degrading (to say the least), and what is humane is possible. Merrill Singer (2012), Janet Page-Reeves et al. (2013), and BCAction (2002) provided excellent arguments that such shifts can—and likely should—begin through grassroots community organizing, statewide advocacy education campaigns, and applied anthropological research. In this vein, anthropology can be applied through advocacy while informing interdisciplinary communities. Research, such as the project I began for this thesis, can be used to make connections between individuals, their

maladies, and industries across space and time, helping to de-individualize public health issues, and bring to the forefront systemic flaws that create epidemics like breast cancer.

Recognizing breast cancer in terms of a temporary life event suffered by the individual is ultimately ahistoric, ignoring trajectories of corporate interests, victim-blaming ideologies, and power inequalities that create or perpetuate epidemics and the experience of being diseased. Epidemiologists and public health officials render this history invisible as they are often “more skeptical of the scientific value of cancer cluster investigations than the general public” (Thun and Sinks 2004, 273). In this context, scientific communities are overtly denying community members’ capacity to recognize patterns of cancer development, much to the benefit of the corporations responsible for polluting such communities.

Furthermore, we can look to studies in disaster anthropology to better understand vulnerability not as an adjective, but as a concept that pulls our gaze towards historic and contemporary political, economic, and social forces that distribute risk disproportionately to specific communities and bodies (Faas 2016; Oliver-Smith 1999). This discussion of vulnerability leads to a question: Are breasts vulnerable because they are breasts, or are they vulnerable because of the toxic conditions imposed upon them? Evidence suggests that vulnerability of the breast is imposed. Yes, breasts are naturally fatty, and are filled with intricate ducts and glands for the production of breast milk, and these complex, lipid-filled areas of the body have been shown to be especially susceptible to the accumulation of carcinogens and other toxic chemicals, that can lead to the development of breast cancer (Nelson 2006; Wang et al. 1996).

Power differentials must also be considered in these contexts. When medico-scientific communities exercise their authority to decide what conversations are being had with patients about their cancers, they tacitly shape how victims perceive their disease and the questions they themselves ask about it. Manipulating perceptions of breast cancer causes often creates false assumptions of safety. However, working to instead expand knowledge and limited understandings of the disease has the potential to enable women to be more informed about their actual risk, and bring to light the legacies that produce vulnerability.

CHAPTER THREE

DISCUSSION, REFLECTIONS, AND CONCLUSION

Pervasive ideologies pertaining to lifestyle rhetoric and breast cancer, and the internalization of these blame-the-victim concepts or ideas of “randomness,” permeate both medico-scientific and popular understandings of the disease’s origins, and consequently compound the suffering of breast cancer patients. Similar to the phenomenon of hard-stance global warming denial (Morton 2013), I argue that the cultural or politico-scientific dismissiveness or silence—in the context of discussing most cancers as being human-environmentally produced—is compelled by similar ideological beliefs. Addressing breast cancer as an anthropogenic epidemic and demanding change to facilitate its prevention is a threat to neoliberalism, chemical industries, and their accompanying belief systems. Like the extensive implications of an oil spill—but far less visibly—the legacies of carcinogenic chemicals in the air, water, soil, and bodies shatter Western conceptualizations of time, space, and centrality of things in relation to time. Like global warming, the “action at a distance” (Morton 2013, 39) across space and time that leads to cancer obscures direct, causal links and their aesthetic symptoms, making them difficult to prove (Morton 2013), and the element of cultural/ideological threat makes the concept even more readily deniable. Moreover, the fact that there is extensive scientific data showing the susceptibility of the human breast to chemicals and endocrine disruptors as catalysts to the development of malignant breast tumors—yet half of the population is incessantly put at risk of contracting the disease—displays the structural devaluation of women.

A primary goal of this research has been to qualitatively contribute to knowledge, by facilitating public understanding of the ways in which controlling processes and power inequalities physically manifest within bodies—through disease epidemics, like breast cancer—and result from constructed environments that are driven by capital or sociopolitical notions of progress. I also intend to broaden physician’s understandings of the ways in which ideology can, and sometimes does, influence science and constrains the scope of analysis. Finally, the results of this study will shift prevailing discussions about breast cancer causation, so that it is possible to reduce breast cancer incidence as well as the complex suffering of breast cancer victims everywhere.

My research demonstrates disturbing commonalities concerning internalization of lifestyle rhetoric in breast cancer patients’ perceptions of what caused their breast tumors. Specifically, many described their cancer as being potentially linked to their problematic life and lifestyle choices. Emilia Albrecht was diagnosed at age 38, shortly after giving birth to her second daughter. Like many others I interviewed, she initially feared that her diagnosis was a death sentence. Emilia’s oncologists suggested that she developed breast cancer because she gave birth and breastfed too late in her life. Seven years after her diagnosis and treatment, Emilia still believes that her waiting to have children is what caused her cancer, the loss of her breasts, and long-term onco-anxiety. Other participants also noted at least one of the following as having possibly caused their breast cancers: drinking alcohol, smoking cigarettes, eating the “wrong” diet, consuming too much caffeine, not consuming enough vitamins, or being too stressed. Naomi Jones, who was haunted by past traumatic experiences and relationships, believed her breast tumor was a manifestation of negative emotions that

she failed to let go of. Others blamed their biology, indicating that having cystic breasts or “bad genes” was the cause of their disease. Some described these factors one moment, then dismissed them by describing the “randomness” of breast cancer later on.

None that I have interviewed overtly perceived industry or regulatory institutions as being responsible for the breast cancer epidemic—nor their personal cancers—though some hinted at the “inescapability” of water, air, soil, and food toxicity. Anahita Murphy mentioned that her husband attributed her breast cancer to growing up near a Chevron refinery, which left a layer of a white substance over the porch of her childhood home. None of her doctors entertained this possibility, so she dismissed his idea. Jennifer Aimes, who had been diagnosed with breast cancer at age 42, was also diagnosed as a BRCA-2 mutation carrier and blamed her genetic mutation for her disease. Though research does indicate that BRCA-1 and BRCA-2 mutations dramatically increase the lifetime risk of breast cancer, mutations of the BRCA genes have been found to *not* be predispositions for carcinogenesis, and cancers in BRCA mutation carriers have been linked to exposures to chemical carcinogens, hormone disruptors, and other non-genetic risk factors (Bennett et al. 2000; Falck et al. 1992; Gorani, Farid, and Mazhari 2014; King, Marks, and Mandell 2003; Li et al. 1996; Venkitaraman 2002). Furthermore, upon my inquiry into Jennifer’s personal history, she discussed the work she did as a child, picking fruit from orchards in the Santa Clara Valley, and getting paid by the crate. My further research into the history of the region showed that these orchards were routinely sprayed with DDT (Lynch 2007), which is a currently banned toxic insecticide that has been linked to aggressive breast tumors (Comer 2010; Demers et al. 2000; EPA 2017; Woolcott et al. 2001).

Jackie Brennan was 40 years old when she was diagnosed with breast cancer. She grew up in Reedley, California, a town not too far from the Bay Area, in which one can *see* the air. Upon a recent drive with her through Fresno and Reedley, I noted the brownish-grey mist that hovered high and wide over the vast, flat land, tightly hugging the crops and orchards that it cloaked in the promise of insect or weed death. The atmosphere was dense and felt more like it was displacing the air in my lungs, rather than filling them. Jackie grew up working and playing in these local orchards that were bathed in human carcinogens and, though she did recognize the abundance of chemicals in the region and the associated respiratory health problems suffered by others, she did not attribute her cancer to these exposures, and imagined her disease as unavoidable. However, she has also chosen to dramatically alter her diet to reduce her cancer risk.

In one of my own experiences, I had asked my breast oncology surgeon if she was aware of any current research involving testing extracted breast tumors for chemical carcinogens, and about the possibility of submitting my tissue for such testing after it had been analyzed in the lab for clear margins. I wanted to investigate potential causes of my cancer. She denied knowing of any ongoing research and informed me that trying to fund such testing on my own would cost tens of thousands of dollars. She assured me that my tumor was likely due to a defect in my body, and referenced the existence of “bad neighborhoods” in society as analogous to my breast cancer: “Some people just have bad cellular neighborhoods.”

Medical Anthropology and Social Justice

Merrill Singer (2012) discussed the past role of anthropology in the making of public policy, as well as the ongoing necessity of involving anthropology in the process of

addressing social issues and designing policy. Singer showed that many people ideologically acquiesce to “the world as it is,” which relieves pressure that could bring about institutional injustice. Singer also described the ways in which many who are in the position to design and implement policy are detached from the needs of the people the policies hope to serve. Singer argued that anthropologists, because of our qualitative ethnographic research methodologies—and our contextualization of histories and systems in which issues occur—offer a unique perspective and ability to bridge the gap between policy makers and the often invisible and marginalized members of the public.

Singer (2012) also examined the immense importance of community organization and situated anthropologists as excellent collaborators in such projects. Unfortunately, plutocrats do have much power to influence the minds of the masses and public policies that are implemented; as such, Singer (2012) provided examples of conservative efforts to defund or prevent the success of social programs, and the ways in which policy is governed by hegemonic fictions. However, efforts of the masses through grassroots community organizing can bring power back into the hands of the public, and Singer (2012) provided many examples of medical anthropologists applying activist strategies when working with communities, in addition to utilizing ethnographic research to develop policy recommendations.

Reflections: Inhabiting Cancer World and Breast Cancer Activism

Throughout this research, my ethnographic and autoethnographic pursuits have placed me into fluctuating stages of intense interest, excitement, struggle, sadness, anxiety and interpersonal growth. At first, I was thrilled to begin interviewing people and analyzing the

raw data I collected, but, of course, there were a number of unexpected obstacles I encountered along the way. Sometimes, as I was funneled through my personal experiences of the multiple valances of cancer care, stepping into the perspective of the ethnographer helped reduce anxieties that I otherwise would have felt in certain moments. I was able to hyper focus on many of the visual and conversational details as data—I was able to sometimes feel like a researcher and not a patient, even though I was both. It was somewhat like having an out-of-body experience in the face of a traumatic situation or immanent threat. That is not to say that turning on my anthropologist-brain helped erase the trauma of my experiences, but it certainly helped ameliorate the extent and duration of my suffering, at times.

When I interviewed the participants, the anxiety, sadness, and inspiration set in. I drove to locations all over the Bay Area and beyond to meet the participants, which sometimes landed me on the road for six hours or more in a day. As I drove, getting closer and closer to the predetermined meeting points, I would become more and more nervous about the encounter I was about to have. I never knew what to expect, and every participant was so different from one another. I wore cardigans to cover my tattoos, worried I would be judged by them or that it might make someone less comfortable sharing their experiences with me; and sometimes wearing these sweaters as cover-ups meant that I was drenching myself in sweat for the duration of the interview. I also strained to be mindful of my actions, responses, and facial expressions. I did not want to ask leading questions, nor judge a participant's answers or experiences, and all the while keep engaging enough to try to better understand her perspectives.

The hardest part of interviewing participants was experiencing the intensity of their internal pain during some points of their interviews. Their shaky voices as they described some of their deeply traumatizing experiences—some of which were still being experienced, and others who still bore the scars of the past. When Mary told me she felt her BRCA-2 genetic mutation, along with her two cancer diagnoses, was a death sentence—when she told me she knew that one day she would die from cancer—I felt that statement and sureness in every cell of my body. The hair follicles on my scalp twinged. I felt the same way she did. After my two cancer diagnoses, my prophylactic surgeries, my constant and invasive cancer screenings and biopsies, and my diagnosis with a mutation of the BRCA-2 gene, I constantly dive down the rabbit hole of pain and fear of recurrence or death by cancer. I, too, believe that I will die of cancer one day. And probably a lot younger than most. I cried with many of these women as they cried. My heart opened up, taking in their pain through that opening, and I'd wished they hadn't endured these horrors.

Those feelings did not dissipate when the interviews ended. When I listened to the interview recordings during the transcription phase, I relived it. Only this time these feelings were compounded by memories of my own related traumas. Because I was no longer in front of the participants, entirely focusing on her accounts, more of my own stories flooded my mind alongside theirs. Sometimes it was almost too much and I would become depressed. I sincerely hope that, when interviewing these women, they had a moment of catharsis. And I hope they felt less alone. I also hope that my work, along with similar studies of far more influential anthropologists, can help catalyze some change, however incremental. I don't want it to all be for nothing, and I don't want countless more people to have to suffer through

this disease when many cases can be prevented. I am tired of how frustrating and dismissive this world seems at times, and I want to help it to improve.

On Breast Cancer Action

In 2017, shortly after completing radiation therapy, one of my undergraduate professors suggested I look into an organization called BCAction, in San Francisco. BCAction is a non-profit, grassroots, watchdog breast cancer activist group. I read through articles on their website, noted multiple resources for breast cancer patients and loved ones of patients needing help understanding how to provide support. I was also immediately intrigued by their approach to the breast cancer epidemic: they viewed it as a public health issue, and wanted to address systemic failures that perpetuate the epidemic and fail to protect women. I energized by their tactics and perspectives and I wanted to participate. So, I reached out to staff members of BCAction and asked how I could help. Though I was working at the time, I arranged to spend one day a week at their office in San Francisco, helping with whatever tasks they needed to facilitate their work. Often times it was administrative support, or arranging and mailing packages to community leaders all over the U.S. who organized groups to “educate, organize, and take action” (BCAction 2021). After working with the team for a couple of months, I was asked to do various literature reviews to gather sources for new articles on the organization’s website. I also participated in BCAction-organized protests, as well as educational fundraising events, including Acting Out and Food for Thought. The people I worked with at BCAction (2021) helped connect me with resources I didn’t know existed, like their “toolkit for navigating breast cancer,” guides to supporting loved ones with cancer diagnoses, and medico-scientific institutions working on breast

cancer research. They facilitated my ability to find help, and also gave me ammunition I needed to help others and become a more effective activist.

On the Toxic-Free Cosmetics Act (AB 495)

I was extremely anxious and intimidated when I lobbied at the California state capitol for the Toxic-Free Cosmetics Act (at the time AB 495, but now AB 2762). I walked around on a broken toe that occurred the night before, when I was playfully chasing my boyfriend and smashed my toes into the bottom of his large boot. I purchased medical tape, taped my broken toe to a neighboring unbroken toe as a splint, and went on with the show.

Though my nerves were wrought, I was so grateful to observe that those who organized this lobbying effort were very familiar with the agenda, and how to implement the carefully plotted logistics of the day. Having that solid and thoughtful leadership was comforting. Nonetheless, my anxiety left my mind racing and heart pounding in my chest. One of the reasons for my anxiety was what is referred to as “imposter syndrome,” and generally refers to doubting yourself academically and professionally, not recognizing your accomplishments, or feeling like a fraud—though I should note that recent discussions (Tulshyan and Burey 2021) argue that imposter syndrome is not an affliction of the individual, but is an individualized and biologized symptom of decades of classism, racism, and sexism in elite communities.

And mine certainly bubbles up inside me in circumstances like this. I try to dress and adorn myself and behave in a way that will help me “pass.” To trick people higher than me on the political or socioeconomic ladder into thinking that I belong there...that I am one of them, or damn near close. Fortunately, all of the women who met for the event were kind and

very supportive. I had arrived with my script so that I could engage assemblymembers with the intention to motivate them to cast their vote and pass AB 495. Many of the other women who attended this lobbying effort had no personal history with cancer, but they all strongly encouraged me to tell my story, and share why this regulatory legislation was so important to me. So, I did. It was deeply personal, but if sharing my suffering might help prevent others from having the same experience, I will do it. And I would do it again.

On the Final Completion of This Thesis

As I complete this thesis, my gynecologic oncologist recently located a mass on my left ovary after two visits to the emergency room due to being in sudden and excruciating pain. It may be cancer, or a mass that will become cancer (precancerous), so it is in my best interest to have the ovary removed via partial oophorectomy. The anxiety, what-ifs, and intermittent severe abdominal pain weigh on my mind. As I write these chapters, I think of the suffering of the women I interviewed, my own suffering, and that of countless others. In my heart I hope with authentic and deep earnestness that efforts will be made to prevent cancer, and that those of us afflicted with the disease will be better cared for. But in the pit of my stomach is a heavy wretched thing that fears my hopes will never come to fruition. That same heavy pit weighs on my chest when I worry that I will die of this disease one day. I will have my next surgery shortly before I submit this work, and hope that I don't have to go through treatment again.

What Can We Do?

Unfortunately, the regions in the U.S. that I discussed in this thesis—and many more that I did not—are likely to remain contaminated by chemical carcinogens for many years to

come. However, there are ways to mitigate the effects or preclude similar issues. To prevent further damage to communities and bodies, the U.S. government could utilize tenets of the Precautionary Principle that is used by governing agencies of the European Union. The Precautionary Principle is essentially a legal approach that requires extensive scientific research into new innovations or products when scientific data is lacking and the product has the potential to cause harm to communities and natural environments. It is unethical to allow industries to use chemicals on a mass scale without first proving their safety for the public and environment. By enacting the precautionary principal as national policy in the U.S., new materials must be proven safe before entering the market, and the burden of proof is placed upon the producers, rather than the public. Furthermore, enacting legislation like the Precautionary Principle increases public awareness and involvement in development and production activities, and begins the unbinding of government from corporate interests.

Accountability and public health should also be of utmost importance. The U.S. government could provide healthcare (for all) and rigorous tracking and testing of symptoms of people in communities affected by toxic industries. This can provide relief or treatment for those already suffering effects, minimize the onset of more serious disease in the cases of those who haven't yet become ill, and help bolster scientific knowledge concerning the toxicity of certain exposures—which could then be used to ban certain materials, products, or modes of production. Additionally, poor communities and communities of color should not be disproportionately exposed to risk. Perhaps the elite individuals who benefit the most from toxic industries should have to live in the communities that are excessively exposed to the

worst aspects of those industries. Maybe then would we see an increase in regulation and investment in public health.

To reflect further on these suggestions, that elites in the U.S. are the ones who decide what constitutes risk, and those working-class communities comprised of those who work in factories or live alongside polluted riverbeds are the ones who carry an unequal distribution of suffering and loss. Furthermore, corporations and private entities should not have the ability to sway public institutions—especially those that are in place to protect the public. Such practices and relationships are corrupt and need to be dismantled. It is also important to recognize that symptoms caused by exposures to toxins can present themselves differently among different people and animals. While there can sometimes be similarities, I think it is imperative to understand that variations in disease occur in these contexts, so that we can broaden the scientific scope of what should be analyzed in concerned communities.

Finally, when we examine who constitutes “risk” in the U.S., we can also consider how public health issues are defined. The Center for Disease Control and Prevention (2019) defines a cancer cluster as a “greater-than-expected number of cancer cases that occurs within a group of people in a geographic area over a period of time.” Many communities concerned about cancer clusters are dismissed by public health officials because people do not have the same cancers, even though most chemicals that have been discovered to be human carcinogens were only realized as a result of thorough cancer cluster investigations (Thun and Sinks 2004). Furthermore, the vagueries of the official definition of cancer clusters warrants attention. There is a need to broaden specifics within the definition of cancer clusters, especially in the context of investigating how prolonged exposure to a

chemical affects the human body. Furthermore, why should it be assumed that vulnerable populations should develop the same tumors as others? Many studies (Birnbaum and Fenton 2003; National Toxicology Program 2006; Rayner and Fenton 2011; Rudel et al. 2011; Steingraber 2010) have shown that ages of exposure and stages of physiological development during exposure periods play a role in types of tumors developed; it is highly probable that at-risk community members would develop different cancers (*e.g.*, breast, bladder, and leukocyte cancers). What should also be considered and further researched is the likelihood that the amount, duration, and vector of exposure are important factors when analyzing different types of cancers in a community that are possibly afflicted with an environmental hazard leading to cancer clusters.

Limitations

One of the main limitations to this thesis was funding. I was so fortunate to have some of my equipment and travel costs covered by Beyond Pink fund—created in honor of SJSU Graduate Alumni Mary Koskovich, who had tragically died of metastatic breast cancer several years ago, while completing her thesis in Applied Anthropology at SJSU. This fund was specifically earmarked for graduate students producing research related to breast cancer. The Beyond Pink fund was of great help in allowing me to include the number of participants I had, especially because they were located so far from one another and required logistics and travel on my part. Nonetheless, and unrelated to the Beyond Pink fund, I certainly wish there was greater financial relief provided by education institutions for students conducting research for their theses. My time was also very limited, as I am a single mother, working,

and a student—not to mention the still-constant health complications, cancer scares, screenings, and procedures.

Unsurprisingly, the global Covid-19 pandemic became one of the biggest limitations of my study. I had initially planned to do a project rather than a thesis, attend some breast cancer conferences and interview healthcare providers, and perhaps produce a short film to compliment the write-up of my project. But, in March of 2020, everything in my county shut down. I am sure we all remember vividly the collective internal struggles caused by the lockdowns, as they rolled out across the U.S. one area at a time. So, I did not get to move forward and complete my initial research as planned, and instead worked with what I had already gathered to produce this thesis.

I had also hoped to include each of the interview participants' stories in great detail, but could only include four in the article section of this thesis, due to article length limits. Each of the eleven women had complex stories that were enlightening, horrific, fascinating, and moving, and I could not strip those stories to fit them into the section, as I believe it would remove too much of their voice and the human experience. However, I do hope to produce additional articles in which I can include more detailed accounts of the other participants.

Finally, there were future questions I did not delve into during this thesis, for the sake of brevity, but also limited time and looming deadlines. Several additional questions I would have liked to explore were:

1. Who decides what constitutes risk, as it pertains to breast cancer?

2. Who is disproportionately affected by said risks (i.e., are those who decide what constitutes risk the ones who are exposed to the risk, or are they making these decisions on behalf of others, without their consent)?
3. How can we use studies such as this to problematize the ways in which phenomenon like “cancer clusters” are defined and analyzed?

Future Research

Gayle Sulik’s (2011) discussion of the corporate production of the breast cancer brand that perpetuates cultural perceptions that are biophysically inaccurate will provide context for analyzing widespread misunderstandings of breast cancer that I hope to explore in the future. Sulik’s (2011) work also provides important insights into pharmaceutical companies that profit from carcinogenic products as well as breast cancer treatments. I also hope to utilize more expansive participant narratives, just as Kate Brown (2013) relayed the individual narratives of people whom had chronic or life-threatening health issues, in the historic context of a toxic site. Brown also included a more expanded discussion of which claims to truth are taken seriously—such as local versus expert knowledge and the devaluation of local knowledges—which I expect will be themes that arise during my own continued research.

Like Paul Farmer (2005), I hope to further understand and elucidate the historic, structural causes of health risks of breast cancer patients, and how past and ongoing systemic power imbalances shape suffering in the present. I also expect Nancy Scheper-Hughes’ (1992) analysis of false-consciousness and the individualization of structurally produced public health issues to continue informing my research. Farmer and Scheper-Hughes both

discussed the ways in which scientific communities can biologize structural violence through ideology, which is a concept I will look for during future data collection and analyses.

By examining these topics, I can continue to contribute to knowledge to disarm hegemonic discourse that values capitalist development over women's bodies, and also increase an understanding of how these neoliberal values and power imbalances manifest within women's bodies and minds, in the context of breast cancer affliction. This study will also provide information to broaden physicians' understandings of the ways in which ideology can influence science and obscures the scope of analysis.

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