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# Green in a Sea of Pink: Environmental Reframing of Mainstream Breast Cancer

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To the Graduate Council:

I am submitting herewith a thesis written by Amy Elizabeth Scanzillo entitled "Green in a Sea of Pink: Environmental Reframing of Mainstream Breast Cancer." I have examined the final electronic copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Arts, with a major in Anthropology.

Gregory V. Button, Major Professor

We have read this thesis and recommend its acceptance:

Tricia Hepner, Rebecca Klenk

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Vice Provost and Dean of the Graduate School

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GREEN IN A SEA OF PINK: ENVIRONMENTAL REFRAMING OF  
MAINSTREAM BREAST CANCER

A Thesis Presented for  
The Master of Arts  
Degree  
The University of Tennessee, Knoxville

Amy Elizabeth Scanzillo  
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## ABSTRACT

As a contested illness, breast cancer has mainstream and alternate narratives that vie to shape related scientific research and legislative policy. The mainstream breast cancer movement (MBCM) shapes the dominant discourse of breast cancer risk, prevention, and cure through the utilization of the conventional biomedical model of knowledge. The environmental breast cancer movement (EBCM) contests the mainstream breast cancer narrative because EBCM activists argue that it supports an unequal power dynamic and does not adequately reflect breast cancer risk and prevention. Through the incorporation of citizen science and the precautionary principle into breast cancer research and policy, EBCM activists reframe the mainstream breast cancer narrative. This thesis illustrates how the EBCM uses citizen science and the precautionary principle to reframe the risk narrative and the power dynamic found in the MBCM. Citizen science offers EBCM activists a method to collaborate with the scientific community and reframe the power dynamic found in the traditional biomedical model through the inclusion of lay knowledge. The precautionary principle provides EBCM activists with a model to redefine the role of uncertainty as a call to action for further scientific research and legislative regulation of toxic chemicals linked to breast cancer. The research findings demonstrate how alternate narratives like the EBCM reconstruct the power dynamic found in dominant illness narratives through the incorporation of public knowledge and the

involvement of lay activists in scientific research and legislative policy. Phone interviews, archival materials, and scholarly literature were used in the research process.

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## CHAPTER 1: INTRODUCTION

According to the American Cancer Society, 1 in 8 women in the United States, or around 12%, will develop breast cancer at some point in their lives (American Cancer Society 2011a). The mainstream breast cancer movement (MBCM) uses statistics such the one above to advocate for and fund programs and scientific research that support mainstream perceptions of breast cancer risk and cure (King 2006:xix). Mainstream breast cancer advocacy has shaped the dominant discourse in relation to prevention and cure, as well as making breast cancer the best funded type of cancer. In 2006, the National Cancer Institute put over half a billion of its \$6 billion cancer research budget towards breast cancer (New York Times Well Blog 2008). Of all the cancer types funded by the National Cancer Institute, breast cancer received the most funding per individual with the disease. Although it is the most funded type of cancer, breast cancer is actually not the leading cause of death in women. According to the Mayo Clinic, more women die of heart disease than breast cancer (Mayo Clinic 2011). Despite significant funding and advocacy, women are still becoming ill with and dying of breast cancer at a significant rate. There is debate over what causes breast cancer, as well as how to end the disease. In response to this situation, the environmental breast cancer movement (EBCM) contests the dominant breast cancer narrative by reframing mainstream breast cancer research and advocacy.

The research for this thesis was performed in order to understand the methods that EBCM employs to bring transparency and environmentally

centered research to breast cancer advocacy. The goal of this thesis will be to demonstrate how the EBCM contests the dominant or mainstream narrative through the process of reframing mainstream breast cancer risk and the power dynamic found in mainstream scientific research and advocacy. This thesis will start by addressing the contested narrative found in EBCM. It will look at how the EBCM contests personal risk factors as well as power dynamic in mainstream breast cancer science. Then it will examine how the EBCM reframes mainstream breast cancer through lay involvement in breast cancer science and advocacy that focuses on environmental links to breast cancer. The role of the precautionary principle in shaping breast cancer research and legislation will be addressed. I will also analyze the role of scientific uncertainty in shaping precautionary environmental science and policy. Lastly the role of the lay community in shaping what aspects of breast cancer are studied, and how they are studied, as well as in the applications of research findings, will be addressed. Community programs looking into the racial and socioeconomic ties to the scientific research process will also be explored. The role of the lay community in deciding further research and the use of current research findings in local and national legislation will be analyzed.

Breast cancer is a contested illness because risk and ways to reduce risk are disputed within the larger breast cancer movement (Ley 2009). Like other contested illnesses, scientific and social aspects of breast cancer are influenced by a dominant paradigm (Brown 2007). The dominant paradigm offers the official

narrative in a contested illness. In response, alternative paradigms contest the official narrative and assert alternate narratives to explain an illness. Often the alternative paradigm uses narratives found in the dominant paradigm to reframe and assert alternative views of the illness.

Contested illnesses that have an alternative paradigm asserting environmental links to a particular illness have to contend with conventional science's inability to definitively prove connections between environmental causes and risk (Brown 2007). The dominant narrative often uses this inability to illustrate uncertainty in environmental links to an illness and thus maintain the authority of the dominant narrative. Contested illnesses such as Mesothelioma (Brown et al 2000:10) and Asthma (Brown 2007) illustrate how dominant paradigms often use scientific certainty to undermine the authority of alternative environmental paradigms that do not operate within the realm of certainty (Button 2010).

In terms of the contestation over breast cancer, the dominant breast cancer paradigm's claim of certainty maintains its position of authority within the larger illness narrative. The ability to claim certainty is linked to gaining and maintaining legitimacy in illness narratives. By claiming certainty, the dominant breast cancer paradigm asserts its legitimacy in the breast cancer narrative and also uses uncertainty as a way to contest the legitimacy of alternative breast cancer paradigms. The EBCM uses a public paradigm to contest the dominant paradigm and its authority within the larger illness narrative (Brown 2007). The

public paradigm challenges the dominant breast cancer paradigm by advocating the reduction of breast cancer risk through using precaution in chemical regulation and advocating for more and better scientific research focused on the environmental links to breast cancer.

The EBCM contests the dominant narrative of risk that consists of lifestyle, reproductive, and genetic factors. It also contests the focus on risk management through the use of technologies such as mammography and pharmaceuticals such as tamoxifen found in mainstream breast cancer science and advocacy (Ley 2009). Instead of viewing risk through individual factors like lifestyle, reproductive health and genetics, the EBCM contests the mainstream narrative of breast cancer risk by asserting that environmental toxins are associated with a collective breast cancer risk. The dominant breast cancer narrative focuses on individual risk because it is easier to argue scientific certainty for individual risk factors, which are easier to scientifically represent. Since individual risk is the dominant narrative, it is the “objective frame used by experts and mirrored by the media” (Button 2010:168). Because the dominant narrative can claim certainty using individual risk, the dominant paradigm asserts individual risk as the sole breast cancer narrative. Therefore, the EBCM contests the objective frame of breast cancer risk asserted by the MBCM. The EBCM also contests the dominant narrative of technological and pharmaceutical prevention and cure. While the dominant narrative uses the term “prevention” to refer to preventing late stage breast cancer and reducing the risk of dying from the disease, the EBCM argues

that prevention can only occur before a person gets breast cancer. The EBCM contests the dominant narrative's claim of technological and pharmaceutical prevention and cure through the assertion that understanding the environmental links to breast cancer reduces the collective risk.

The EBCM also contests the conventional scientific model which claims science is expert knowledge, and is more valid than personal experience and lay knowledge, through the active participation of the lay community in scientific research (Morello-Frosch et al 2006:249). By prioritizing validity in scientific knowledge over lay knowledge, the conventional scientific model creates an uneven power structure between the science and lay community. This uneven power structure keeps lay knowledge out of the scientific discourse (Button 2010:168). Because lay knowledge is not in scientific discourse, science ends up perpetuating the dominant discourse related to mainstream views of risk and cure, while keeping out alternative views of breast cancer risk and prevention. Since the mainstream breast cancer movement (MBCM) relies on the conventional scientific model, the EBCM contests the mainstream breast cancer narrative by developing a "citizen's science," where the lay community is actively involved in breast cancer research and "become experts in their own right" (Button 2010:169). An example of citizen science can be found in the Long Island Breast Cancer Study Project, which later became the Huntington Breast Cancer Action Coalition. During the Long Island Breast Cancer Study Project, lay activists collaborated with scientists to determine whether polychlorinated

biphenyls (PCBs) and organochlorines caused increased cancer rates in local communities (Brown 2007:79). The project represents how citizen science includes lay communities in science and scientific decisions related to breast cancer research. The environmental breast cancer movement (EBCM) contests the mainstream narrative of breast cancer risk by reconstructing scientific research related to the public perception of environmental links to breast cancer. While the EBCM uses the same biomedical knowledge as the MBCM, the main difference between the two movements are the way they interpret and participate in scientific research. Drawing largely from the environmental movement, as well as feminist and social justice movements, the EBCM challenges mainstream constructions of breast cancer (Ley 2009:12). The EBCM came about as a way to redefine mainstream constructions of breast cancer and bring awareness to environmental links to breast cancer. The EBCM redefines the MBCM's focuses on prevention through the technology of mammograms and scientific research related to finding a medical cure for breast cancer by advocating lay involvement in science related to finding environmental links to breast cancer (Ley 2009:4). While mainstream breast cancer advocacy centers around the individual understanding her own breast cancer risk, the EBCM focuses on assessing breast cancer risk by looking at how environmental toxins may put communities at risk for breast cancer.

As a counter movement, the EBCM not only challenges facets of mainstream constructions of breast cancer causation, but also the social

structures, like funding, science and political spheres, that influence mainstream perceptions of breast cancer risk. Environmental breast cancer activists base their work on the model used by environmental justice groups, which demonstrates connections between environmental factors and social factors like gender, race, and class (Baralt 2006:5). The EBCM's reframing of mainstream perceptions and research of breast cancer illustrates that rather than one "objective" construction of breast cancer as a social problem, there are multiple collective definitions of the causes of and cures for breast cancer (Blumer 1971:298; Schneider 1985). The key distinctions between the MBCM and the EBCM are in their perceptions of causal and political responsibility (Gusfield 1984). The EBCM's primary goal is to provide women with knowledge of the potential causes of breast cancer, calling for further testing of causes of breast cancer, and political involvement in policy and laws that would protect women from potential and known causes of breast cancer.

The EBCM reframes mainstream discourses of power through the involvement of lay communities in breast cancer science and legislation. The goal of lay involvement is creating transparency in the science and legislation related to breast cancer. The need for scientific and governmental transparency comes from the "personal is political" framework, which highlights "the political and economic issues in breast cancer causation, research, and treatment" (Brown 2007:88). Women's experiences of breast cancer are not just personal; they are also imbedded in the politics related to the science and

legislation of breast cancer. The EBCM asserts the claim that since women are affected by the politics of breast cancer science and legislation, they should be involved in the decision making process, in order for their perspective to be incorporated into the science and legislative outcomes (Bogard 2003:212). The EBCM claims that balancing out the power dynamic through incorporating lay community members in decisions is the only way that the needs of the lay community will be adequately addressed. In terms of governmental transparency, the EBCM promotes collaborating between the lay community and environmentally focused politicians to create chemical regulatory policy and other environmental/precautionary principle centered policies. As for scientific transparency, the EBCM involves the lay community in collaboration with the scientific community about environmental research related to breast cancer (Anglin 1997).

The primary way EBCM challenges discourses of power is through the challenge to the Dominant Epidemiological Paradigm (DEP) and mainstream science (Brown 2007). The DEP rests authority on the voices of the scientific community. Conventional science holds that authority in research and results lies in the scientific or expert community. The EBCM contests the dominant scientific paradigm by creating a “new public paradigm” which demonstrates that the lay community, particularly women with breast cancer, have an important perspective to bring to scientific research related to breast cancer (Benford and Hunt 2003:160; Brown 2007:87-89). In this “community-based participatory research,”

lay and science communities collaborate to research environmental links to breast cancer, and to explore the geographic patterns related to breast cancer risk (Davis 2002:188; (Brown 2007:13). Through collaboration with lay and science communities, the EBCM hopes to "...broaden scope of what [traditional science considers] to be environmental problems." (Brown 2007:87). The EBCM also works towards a "democratization of science" where there is a public discourse and involvement in science (Brown 2007:13). Scientific research, particularly when peer reviewed, is ostensibly democratic because it is reviewed objectively within the scientific community (Davis 2002:126). However, the EBCM argues that in reality there are political pressures, such as corporate lobbying, that drive the design, interpretation, and use of scientific research. The EBCM wants to change the way science is performed, interpreted and used politically, as well as future scientific research (Brown 2007:51).

The precautionary principle plays an important role in the EBCM's reframing of science related to breast cancer. According to the precautionary principle, "the indication of harm, rather than the proof of harm, should be the trigger for action" (Steingraber 1997:270). The EBCM uses the precautionary principle to challenge mainstream views that dictate chemicals must be proven to cause harm before they are regulated by claiming that chemicals should be regulated until they can be scientifically proven to not cause breast cancer (Loseke 1999:40). The precautionary principle plays an important role not only in science, but in legislative advocacy as well. In terms of science, the EBCM uses

the precautionary principle to focus scientific research on the environmental causes of breast cancer. In terms of legislation, the EBCM uses the precautionary principle to advocate regulating chemicals, like BPA (Karen Miller, interview, December 2, 2010), that are linked to causing breast cancer.

Central to the precautionary principle model, and the reason it is favored by the EBCM, is the “concept of uncertainty” (Aven 2006:199). Although links to environmental toxins and breast cancer risk are apparent, there is still uncertainty and debate related to what chemicals actually increase breast cancer risk. While uncertainty is harder to analyze and does not necessarily fit in with scientific ways of knowing that value certainty, the EBCM claims that the underdevelopment of knowledge about what chemicals are linked to breast cancer makes precaution imperative to preserving human life (Button 2010:15). The EBCM uses the precautionary principle because it “advocates preemptive action in the face of uncertainty, whether scientific evidence is conclusive or not” (Mayer et. al 2002:575). The precautionary principle provides the EBCM a way to demonstrate uncertainty related to breast cancer risk and to advocate for more regulation of, and scientific research on, chemicals that may cause breast cancer.

Past literature has discussed the environmental risk factors that the EBCM links to breast cancer, as well as how lay women have shaped the environmental discourse. In *When Smoke Ran Like Water*, Devra Davis (2002:170) writes about chemicals like DDT and their link to breast cancer. Davis also talks about how

women affected by breast cancer formed various organizations that have challenged science and legislation surrounding the disease. In *No Family History: The Environmental Links to Breast Cancer*, Sabrina McCormick (2009) looks into the way the EBCM challenges mainstream ideas about risk related to family history in order to demonstrate the environmental breast cancer risk. McCormick also explores how women living in communities affected by high cancer rates employ “cancer clusters” and collaborate with the scientific community to demonstrate the link between environment and breast cancer (2009:90).

In “Mapping out a Search for Environmental Causes of Breast Cancer” (with Ruthann A. Rudel 2003) and “Environmental Pollutants and Breast Cancer” (et. al. 2005), Julia Brody looks into the chemicals linked to environmental risk, as well as the challenges of studying and coming up with conclusive population based data linking environmental toxins with breast cancer. In *From Pink to Green: Disease Prevention and the Environmental Breast Cancer Movement*, Barbara Ley looks at the how disease kinships, or the social and biological connections between different diseases, shape how the EBCM collaborates with scientific community and other disease movements (2009:13). In “The Social Context of Science: Cancer and the Environment,” Devra Davis and Pamela Webster (2002) address how social factors like socioeconomic status and the structure of traditional science affect breast cancer research and treatment. Davis and Webster promote the use of the precautionary principle

and the understanding of environmental risk as effective methods to reduce breast cancer.

The precautionary principle and community involvement in breast cancer science and advocacy are also addressed in the literature. In “Community-Initiated Breast Cancer and Environmental Studies and the Precautionary Principle,” Brody et al (2005) explore studies in Long Island, New York and Cape Cod, Massachusetts, as well as studies by the National Institute of Environmental Health Sciences breast cancer and environment centers. They look at how women activists in all three cases started their own research on the links between breast cancer and the environment. In “Rethinking Breast Cancer Risk and the Environment: The Case of the Precautionary Principle,” Davis et al (2002) look at how scientific research on environmental breast cancer risk can shape public policy and reduce breast cancer rates. Phil Brown (2007) looks at how lay communities are reshaping the DEP in order to affect science and policy that reduces the environmental risk of breast cancer in *Toxic Exposures: Contested Illnesses and the Environmental Health Movement*. Throughout “The Personal Is Scientific, the Scientific Is Political: The Public Paradigm of the Environmental Breast Cancer Movement,” McCormick (2009) also uses the idea of the public paradigm to demonstrate how lay communities get involved in the science and legislation related to the environmental links to breast cancer.

Research on the EBCM has addressed how the movement encourages lay involvement in science and advocacy, and emphasizes the role of the

precautionary principle in the science and regulation of known and potential toxic chemicals. While past research has looked at the EBCM through the lens of social movement theory, and some researchers have also looked at contested narratives, there has been little research that uses social problems theory and contested narratives to demonstrate how the EBCM contests and reframes the dominant narrative found in the MBCM. Social problems theory aims at understanding “the activities of groups making assertions of grievances and claims with respect to some putative conditions” (Kituse and Spector 1973:415). Research employing social problems theory and contested narratives is needed in the EBCM literature because it demonstrates the dynamic social and political meaning attached to breast cancer science and advocacy. A focus on contested narratives is needed because they offer a way to demonstrate what the EBCM argues in order to challenge the dominant narrative of breast cancer risk and the role of scientific research found in the MBCM. Social problems theory is also needed because it demonstrates how the EBCM reframes science and advocacy in relation to the dominant frame found in the MBCM. Social problems theory provides a way to analyze how the EBCM uses citizen science and the precautionary principle to contest the dominant narrative found in the MBCM.

## CHAPTER 2: LITERATURE REVIEW

The environmental breast cancer movement (EBCM) demonstrates the contestation of risk and precautionary measures found within the breast cancer movement (Brown 2009:229). The EBCM “functions as a ‘culture of action’...within the broader breast cancer movement” by advocating for a change in the type of science and the way science is conducted in relation to breast cancer risk and prevention (Kalawiter 1999; Ley 2009:7). Activists contest the broader movement’s focus on individual risk and reliance on conventional science that does not value lay knowledge. Instead, they argue that breast cancer affects communities or populations (Ley 2009:8). Looking at environmental risk factors not only demonstrates community risk but also offers a way to reduce risk through reducing environmental risk. The EBCM contests the dominant paradigm through a public paradigm that focuses on citizens actively engaged in transforming how science looks at breast cancer risk, as well as the tools it uses to understand and prevent risk.

This chapter will begin by discussing both how the EBCM contests the mainstream view of risk and how it redefines breast cancer risk based on environmental factors and social inequalities. Next, this chapter will discuss the EBCM’s contestation of conventional scientific narrative in terms of risk management. The mainstream focus on technology and prevention drugs to mitigate risk will be discussed. The role of corporations and pharmaceutical

companies in using and shaping mainstream breast cancer dialogue related to risk and prevention will also be addressed. Then this chapter will explore how the precautionary principle is used to redefine risk. The role of uncertainty in environmental links to breast cancer, and the ways in which the precautionary principle offers a way to deal with uncertainty will be addressed. Lastly, this chapter will examine how citizen science uses the precautionary principle to reshape mainstream dialogues of risk, as well as the way science understands and prevents breast cancer.

### *2.1: Risk and Risk Assessment*

Perhaps one of the most important factors in preventing breast cancer is risk assessment, because knowing what factors lead to breast cancer can help create methods to mitigate or remove the disease (Potts 2000:131; Yadon 1997). In the mainstream breast cancer dialogue, understanding and reducing personal risk factors are key to breast cancer prevention. Personal risk factors, which include family history and genetics, affect an individual's likelihood of developing breast cancer (Ley 2009:7). The EBCM argues that personal risk factors, particularly family history, account for only a small portion of women who develop breast cancer. As a result, the EBCM argues that understanding community risk, rather than individual risk, is an important part of breast cancer prevention. Community risk examines how groups of people are affected by toxic chemicals,

as well as how social inequalities related to race and socioeconomics increase breast cancer risk.

One personal risk factor the EBCM challenges is family history. It is often cited by the mainstream as an important risk factor for developing breast cancer (Bellenir 2009:118). While family history includes potential genetic links, it also encompasses shared lifestyle risk factors (American Cancer Society 2011b). Although genetic risk is highly publicized as a major risk factor for developing breast cancer, the EBCM argues that women with a family history of breast cancer account for a small portion of women with the disease, and many women with breast cancer have no family history (McCormick 2009). Women with breast cancer in their family history only account for 5 to 7 percent of women diagnosed with breast cancer (Cornell University Program on Breast Cancer and Environmental Risk Factors in Hew York State 2003:1). While people with a family history of breast cancer are at a greater risk of developing the disease, when examining the overall percentage of women with breast cancer genetics plays a small role in the likelihood of developing the disease.

Furthermore, the EBCM argues that the mainstream's focus on genetic risk factors like the BRCA1 and BRCA2 genes misses the broader picture of breast cancer risk. According to the National Cancer Institute at the National Institutes of Health (2009), BRCA1 and BRCA2 belong to a class of genes known as tumor suppressors. Mutations of these genes have been linked to the development of hereditary breast and ovarian cancer. In fact, the National Cancer Institute's

research shows that “a woman who has inherited a harmful mutation in BRCA1 or BRCA2 is about five times more likely to develop breast cancer than a woman who does not have such a mutation” (National Cancer Institute at the National Institutes of Health 2009). Despite the likelihood of a woman with BRCA1 or BRCA2 developing breast cancer, EBCM asserts that most women do not have the genetic link to breast cancer. (McCormick 2009:22). In reality, BRCA1 and BRCA2 account for only about 5 to 10 percent of the total percentage of women with breast cancer (National Cancer Institute at the National Institutes of Health 2009). As in regard to general family history of breast cancer, the EBCM argues that breast cancer among those with the BRCA1 and BRCA2 genes is much higher than those without the faulty genes, while the number of breast cancer cases linked to the BRCA1 and BRCA2 genes are relatively small.

EBCM activists also argue that women do not experience breast cancer the same way. Social inequalities related to ethnicity and socioeconomic class put poor and minority women at greater risk for breast cancer and for later stage breast cancer because they have less access to quality healthcare than white women and women of higher socioeconomic status (Zambrana 1988:115-56). The difference in breast cancer risk among ethnicities and socioeconomic classes demonstrates the social meaning embedded within the disease and how this meaning affects risk and risk management (Anglin 1997:1404). Like other aspects of social inequalities, patterns of breast cancer risk correlate with race/ethnicity and social class. Often structural issues, elaborated below, create a

climate in which poor and minority women face more aggressive forms of breast cancer and, therefore, higher morbidity.

While access to quality health care accounts for white women having a greater chance of being diagnosed with breast cancer (Ley 2009:139), the lack of access among minority populations is a major reason why women of color are more likely to die from the disease. The connection between ethnicity and diagnosis illustrates the connection between social inequality and access to healthcare. One reason for the increase in morbidity can be attributed to “lack of health insurance; lower levels of personal income; and disparities in health care resulting from racism, classism, and language and other cultural barriers” which contribute to women of color receiving a late stage diagnosis. The later the stage in diagnosis, the more likely it is that a person will die from the disease.

Geographic location and occupational risk are also linked to high rates of breast cancer in minority women (McCormick 2009:76). Asian women provide perhaps the most compelling example of how changing location can influence breast cancer risk. Women living in East Asian countries have the lowest breast cancer rates worldwide, however, when they move to the West, their breast cancer risk rises to 80 percent for the first generation and their daughters’ breast cancer rates reach those of other women born in the United States (Stellman and Wang 1994).

The EBCM also argues that a woman’s socioeconomic background affects breast cancer diagnosis. Poverty is a “powerful predictor of late diagnosis, poor

treatment, and high mortality” (Hardisty and Leopold 1996:1). Poverty is also connected to minority women’s risk of developing late stage breast cancer and not receiving adequate treatment because minority women with a late-stage diagnosis often come from lower socioeconomic brackets. Perhaps more influential than race or ethnicity alone, socioeconomic status (SES), affects an individual’s exposure to toxins in the environment because low economic status is often linked with lack of “access to education, certain occupations, health insurance and living conditions...all of which are associated with the risk of developing and surviving cancer” (Bellenir 2009:82). Economic hardship and ethnic discrimination increases breast cancer mortality and late stage diagnosis, due to limited emotional and financial resources available to poor and minority women (Kasper 2000:183).

According to EBCM activists, corporate and government spheres influence how social inequalities as well as the environment affects breast cancer. To understand how this takes place, EBCM activists argue that it is important to study the structural framework influencing corporate and government spheres. Although the government is involved in reducing breast cancer through legislation which increases research and programs that focus on biomedical prevention and cure, it also encourages corporate support of breast cancer programs. Instead of attempting to end cancer through understanding potential origins in industrial chemicals, Sheldon Krimsky argues that “a number of government officials made the decision that it would be more economically

beneficial to cure cancer than to prevent it” (McCormick 2009:182). As a result, the scientific research and prevention programs found in the mainstream movement reflect the focus on finding a cure for breast cancer.

### *2.2: Science and Technology in Risk Management*

The EBCM contests the risk management and breast cancer treatment narrative found in the dominant paradigm adopted by the MBCM. The dominant paradigm guides “biomedical and research centers, government agencies, health organizations, pharmaceutical companies” and mainstream advocacy that focuses on prevention through screening measures like self-breast exams and mammograms, “diagnostic techniques such as surgical and needle biopsies,” and “treatment modalities such as mastectomies, lumpectomies, radiation, chemotherapy, and other therapies to remove cancer from the body” (Ley 2009:4). The dominant paradigm also focuses on understanding personal risk factors like genetic and reproductive health in order to reduce risk (Ley 2009:5). EBCM activists contests the dominant model because it places conventional science above knowledge based on experience of the disease. Since conventional science is valued more than lay knowledge of breast cancer, activists also argue that the dominant paradigm does not adequately understand or reflect the lay communities’ needs in terms of breast cancer prevention and treatment.

The EBCM contests the dominant narrative of breast cancer prevention through a public paradigm that uses public or lay knowledge of breast cancer as an important component of understanding the disease (Brown et al. 2006). The EBCM created the public paradigm based on the idea of a “public hypothesis” in which the public demands to participate in science and scientific decisions because they want to be part of the decisions affecting their health (Krimsky 2000; McCormick and Brown 2003). Since the public understands that scientific decisions influence their lives, they actively participate in science and critique the conventional science model found in the dominant paradigm through active collaboration with scientists. Through the public paradigm, lay activists go “from recipients of expert knowledge to critics of such knowledge” (Ley 2009:6). By critiquing the conventional science model, the EBCM acts as a boundary movement. The public paradigm found in the EBCM acts as a boundary movement because organizations and activists “move between social worlds and realms of knowledge” through lay and professional collaboration (McCormick and Brown 2003:547). Moving between lay and scientific spheres, activists are able to inform science with their personal knowledge of breast cancer while having a say in medical and scientific decisions that affect their experience of the disease.

One example of EBCM’s contestation of the dominant paradigm can be found in the EBCM’s critique of the conventional focus on prevention through mammograms. The dominant paradigm asserts that mammograms are essential to breast cancer prevention because they are able to detect breast cancer before

it reaches later stages of growth (Davis 2007:270). Embedded in the social and political narrative of the “war on cancer” (Davis 2007), mammography provides a way for the dominant paradigm to assert its ability to save lives through technology. However, the EBCM contests the dominant narrative of mammography in breast cancer prevention and, similar to their contestation of personal risk, uses scientific evidence to support their argument that mammography does not offer true breast cancer prevention. Since it is harder to detect breast cancer in the dense breast tissue of younger women, the EBCM argues that mammography is not an effective form of prevention for them (Davis 2007:270). While mammography can detect early stages of breast cancer in older women, younger women are left out of this form of prevention. The EBCM also contests the idea that mammography is a good tool for preventing breast cancer because they argue that if a tumor exists, breast cancer has not been prevented (Brown 2007:46). The EBCM claims that true prevention exists if you prevent the tumor before it forms.

Prevention drugs like tamoxifen are another way EBCM claims that pharmaceutical companies construct breast cancer prevention. Tamoxifen is a medication that is used to reduce the risk of breast cancer. Tamoxifen is usually prescribed as a preventative measure for women with a high risk of breast cancer, particularly if they test positive for BRCA1 or BRCA2 (National Human Genome Research Institute 2011). Despite the use of tamoxifen to decrease breast cancer risk, the EBCM uses conventional scientific research to argue that

in some cases it can actually increase the risk of other cancers (Ley 2009:94). The EBCM turns to research from organizations like the National Cancer Institute at the National Institutes of Health (2008) to illustrate that tamoxifen can increase risk of blood clots, stroke, and endometrial cancer and uterine sarcoma. If a person is at an increased risk for cancer, due to genetic or environmental causes, taking tamoxifen could increase their risk of getting other types of cancers. The EBCM argues that prevention pills like tamoxifen are not an adequate form of prevention because they can actually put women at risk for developing other diseases (A1). Although the EBCM differs from the MBCM in its approach to mitigating risk, both movements use conventional biomedical knowledge to support their claims.

Looking at the role of the pharmaceutical industry, particularly in the area of organizational funding and government lobbying, illustrates the EBCM's claim that the dominant narrative focuses on prevention rather than finding the cause of breast cancer. The focus on medication and medical breast cancer prevention has a clear connection to pharmaceutical companies like AstraZeneca, the manufacturer of tamoxifen (Ley 2009:39). The role of AstraZeneca in shaping the dominant narrative of breast cancer prevention can be seen in their creation of Breast Cancer Awareness Month. The National Breast Cancer Month (NBAM) was founded in 1985 by Zeneca (now AstraZeneca), a multinational pharmaceutical corporation and then-subsubsidiary of Imperial Chemical Industries (Brown 2007:86). Breast Cancer Awareness Month shapes the dominant breast

cancer narrative because it focuses on technological prevention through mammograms (Brown 2007:44). NBAM helps generate awareness and funding for mainstream breast cancer programs that support the dominant narrative of technological prevention. The EBCM claims that pharmaceutical companies focus on medical and technological prevention rather than understanding the causes of breast cancer because they can make a larger profit from mammograms and prevention pharmaceuticals than curing breast cancer (Ley 2009). Pharmaceutical companies use lobbying as well as donations to fund organizations and support legislation that correlate with their agenda of prevention through mammograms and prevention pharmaceuticals.

### *2.3: The Precautionary Principle*

EBCM activists base their public paradigm on the precautionary principle, which places the burden of proof regarding the health effects of chemicals on the producers rather than the consumers and declares that proof of safety should exist before chemicals are utilized (McCormick et al. 2003:546; Raffensperger and Tickner 1999):

In order to do this, the environmental breast cancer movement works toward four goals: (1) to broaden public awareness of potential environmental causes of breast cancer; (2) to increase research into environmental causes of breast cancer; (3) to create policy that could prevent environmental causes of breast cancer; and (4) to increase activist participation in research.

Since the precautionary principle challenges traditional science's need for certainty, the concept of uncertainty is an important part of the precautionary principle. Through the precautionary principle, activists challenge the dominant scientific paradigm's claim that chemicals must be proven to cause harm before they can be regulated. EBCM activists argue that "tens of thousands of chemicals already on the market, and dozens more are developed every year" all without scientific proof of their safety (Ley 2009:82). Proving whether or not all these chemicals are safe could take years, and science is also limited in what it can prove. Because of the time and scientific restrictions, activists turn to the precautionary principle to advocate for chemical regulations. Their argument rests on the idea that proof of harm should not come after people are already affected by toxic chemicals. Regulating chemicals should occur until science can prove that certain chemicals are safe for the public. Although there are scientific challenges to proving the connections between toxins and breast cancer, activists argue that there is enough research to be able to show a link and to prevent disease through regulation (Ley 2009:82). Activists use the precautionary principle to not only demand that science focus more on environmental causes of breast cancer, but also to advocate for a better scientific framework and better scientific methods. Since the precautionary principle acts more as a "conceptual framework...it can be implemented to meet the specific needs of the particular problem at hand" (Ley 2009:88).

The precautionary principle does not get much attention in the United States, mostly because the concept of regulation without exhaustive testing and viable alternatives does not really exist. Current U.S. chemical regulations require substantial evidence of harm before regulatory action is taken, regardless of the availability of alternatives (Brody et al 2005:921). Since corporate involvement is prevalent in government legislation and regulation laws, methods like the precautionary principle are not in line with a legal system that is generally conservative when it comes to change. In order to include the precautionary principle in the legislation, activists must try to change the legislative process, particularly in terms of corporate lobbying. EBCM activists argue that corporate lobbyists, especially trade associations, have “a disproportionate influence in the regulatory process” (Davis and Webster 2002:25). Not only do trade organizations have millions of dollars to use in lobbying efforts, but they also have the ability to hire scientists that generate uncertainty related to toxic chemicals and use this information to help them lobby against regulation of chemicals (Davis and Webster 2002:25). The uncertainty created by scientists hired by trade organizations not only influences legislation through lobbying, but it also effects how the general public perceives the role of toxic chemicals in breast cancer risk. The EBCM argues that generating uncertainty illustrates the power placed on certainty in the dominant framework. In order for environmental risk to have a place in scientific research and legislation, the EBCM challenges the dominant scientific framework through contesting scientific certainty.

The EBCM uses the precautionary principle to illustrate the power in the claim of scientific certainty found in the dominant science and social frameworks. Focusing on individual risk factors (Davis et al 1998) and risk management through technology and pharmaceuticals allows the dominant scientific framework to claim certainty because individual risk and prevention technologies like mammograms are easier to scientifically demonstrate than community risk and prevention techniques. The power science places on certainty and the ability to gain more certainty from looking at risk and risk management at an individual level allows the dominant framework to exist in a position of power. Since looking at risk at a community level does not offer the same level of certainty, EBCM activists do not have authority and power in conventional science. Through the use of the precautionary principle, the EBCM challenges the dominant framework that emphasizes certainty, while at the same time working with science to create better research and research methods. Since communities are at risk and have knowledge related to their experience with breast cancer, EBCM argues that communities should challenge the dominant framework. Community experiences and knowledge offer a way to contest the certainty asserted by the dominant paradigm. Although the dominant scientific framework maintains power through the assertion of certainty, the EBCM contests this power by focusing on citizen science and collaborating with scientists to change the research process (Brody et. al. 2005).

#### *2.4: Citizen Science*

In order to contest the dominant epidemiological paradigm that influences narratives about mainstream breast cancer risk and prevention, the EBCM uses citizen science to actively work with the scientific community. Citizen science consists of “lay-professional collaborations in which citizens and scientists work together on issues identified by laypeople” (Brown 2007:33). The precautionary principle is an integral part of citizen science because it fosters public participation and understanding of environmental breast cancer risk (Brody et. al. 2006). Through the employment of the precautionary principle, citizen science challenges conventional science to prove the safety of chemicals before they are used in public products. Citizen scientists are lay individuals who collaborate with the scientific community on scientific research. Although they are not scientific experts, collaborating with the scientific community gives citizen scientists the scientific legitimacy in scientific and legislative communities. Environmental breast cancer organizations often bring the lay and scientific communities together in research process. Citizen scientists actively participate with conventional scientists to define what should be researched, how it should be researched, and how to use research findings to affect local and national legislation (Brown 2007).

According to the citizen science model, lay observations are key to understanding the environmental factors that are linked to breast cancer risk

(Brown 2007:50). The citizen science model is about “interjecting lay knowledge into traditional scientific ways of generating explanations” (Brown 2007:71). Since the lay community is affected by environmental factors, their perspective allows science to more adequately reflect the needs of communities at risk. A fundamental focus of the EBCM is on the ways in which breast cancer impacts a woman’s understanding of her body, and how this knowledge can inform breast cancer research. Through collaboration with the scientific community, citizen science counteracts the “inadequacy of the patriarchal medical profession to understand a breast cancer illness experience that is deeply rooted in being a woman” (Morello-Frosch et al 2006:258). Citizen science allows activists to regain power over lay bodies that are directly affected by breast cancer, and use lay experience with breast cancer to inform research. Unlike individual risk factors, looking at environmental risk demonstrates how populations are at risk because environmental toxins affect risk at a community level (Ley 2009:8). By looking at environmental risk, citizen science also places importance upon understanding community risk rather than individual risk.

An example of how citizen science looks at community risk is through mapping breast cancer clusters (DaiKwon 2004). Long Island activists in Suffolk County noticed that there were a number of women who had breast cancer in their area. Through mapping the location of women with breast cancer, the activists were able to see a pattern that suggested a connection between women

with breast cancer and living near water contaminated by pesticides (Ley 2009:59). Cancer clusters like the one in Suffolk County to demonstrate a pattern in breast cancer causation. Illustrating a pattern in risk connects individual women together to illustrate that they share environmental risk at the community level. EBCM activists claim that elevated breast cancer rates found in cancer clusters also fit into “part of a larger international puzzle about patterns of breast cancer incidence and mortality” (Brody et al 1996:497). Understanding cancer clusters and the chemicals that cause them offer science a way to understand how environmental toxins effect breast cancer risk. Much like the example of Suffolk county, women in the community are the ones who bring the issue of high breast cancer rates to the attention of local government and scientific communities. With support of politicians like New York Republican Senator Al D’Amato and research organizations like the National Cancer Institute and the National Institute of Environmental Health Sciences, the women of Suffolk county long island were able to get Public Law 103-43 passed (McCormick 2009:93). The law mandated research into the possible environmental factors linked to breast cancer in their area. The case in Suffolk county illustrates how the lay community reaches out and is able to garner support from political and scientific communities to understand cancer clusters. The example of cancer clusters also represents the importance the lay community places on conventional science to understand the environmental links to breast cancer.

Citizen science influences scientific decisions through representation on advisory boards. Advisory boards offer lay activists a way to engage with scientists as part of a research team (Brown 2007:146). Through engaging with scientists, activists have transparency and influence on the decisions that are made. An example of citizen science representation on advisory boards can be seen in the founding of the Silent Spring Institute. Originally the Cape Cod Breast Cancer and the Environment Study, the Massachusetts Breast Cancer Coalition (MBCC) used state granted money to form the Silent Spring Institute (Brody 2005:921). As in Long Island, residents in Cape Cod noticed increased rates of breast cancer in their community, and through mapping the clusters they were able to get a legislative mandate in order to fund further research on the causes of the high rates of breast cancer in their community. The Silent Spring Institute was created by the MBCC as a way to “transcend ‘science as usual’ and [give] activists governance roles on the scientific team” (Brody 2005:921). Advisory boards, like the one created by the Silent Spring Institute, demonstrate the EBCM’s goal in bringing transparency to the scientific process by incorporating the lay community in scientific decisions related to breast cancer research.

The key component of citizen science is to increase transparency in the scientific process through a “democratization of science” (Brown 2007). Increasing transparency in the scientific process means that lay activists are actively involved in science and scientific decisions related to breast cancer

research. While experts within the dominant scientific paradigm are not generally receptive to lay involvement in science, there are a growing number of scientists who engage in critical epidemiology. In the context of citizen science, critical epidemiologists combine their expert knowledge with social justice issues through collaboration with the lay community in the scientific process (Brown 2007:37). Along with critical epidemiologists, citizen science contests power placed on expert knowledge in the dominant scientific paradigm by placing value on lay knowledge. Collaborating with scientists and having positions of power in the scientific process allows lay knowledge to permeate and change the scientific process. The research problems that are studied and the methods used to study these problems are colored by lay knowledge and experience with breast cancer.

## CHAPTER 3: METHODOLOGY

### *3.1 Methods*

Archival research was analyzed and consisted of electronic documents, journals, books, and websites. Web based materials from The Collaborative on Health and the Environment's Breast Cancer Working Group (CHE) were used. A podcast of CHE's conference call entitled, "Breast Cancer and the Environment: A Life Course Approach: A New Report from the IOM," which took place on December 16, 2011, was also used. In addition to archival research, interviews were conducted. Interviews took place during November and December of 2010 by telephone. Participants located in the East Tennessee area were originally sought, but due to lack of environmental organizations in the area, participants could not be found. However, participants from New England and California were found through internet research. Due to distance restrictions, phone interviews were used. Participants were chosen based on their involvement in various non- pink breast cancer organizations. Since these organizations challenge mainstream views that are associated with pink ribbon campaigns, they are non-pink organizations. Although most focus on environmental causes related to breast cancer, not all organizations chosen solely focused on environmental links to breast cancer. Participating organizations had varied ideas related to environmental causes of breast cancer,

collaboration with mainstream breast cancer groups and funding policies.

Although they varied in their policies and advocacy, they all shared a mission to challenge mainstream views of breast cancer advocacy.

### *3.2 Challenges*

There were numerous challenges in completing this research. The most significant challenge to the research was the number and size of the organizations sought for the study. Since there was a small number of non-pink organizations and each organization had a small staff, the number of individuals available for interviews were limited. The organizations that participated were not mainstream breast cancer organizations. Non-pink organizations, particularly those that focus on environmental causes of breast cancer, generally have a small staff and there are only half a dozen or so (A2) that can be found online. Interviewees also mentioned that the environmental breast cancer movement is small. Geographic location was also a challenge because most non-pink organizations were located either in California or in the northern region of the United States.

Six e-mails were sent to individuals working on public outreach in Silent Spring Institute, Breast Cancer Fund, National Breast Cancer Coalition, Breast Cancer Action, and Zero Breast Cancer asking for their participation in the study. A brief description of research goals and benefits were included in the e-mail.

After the six e-mails were sent out and phone calls were made to all the individuals e-mailed, interviewees were selected based on responses to either form of contact. One individual from Breast Cancer Fund, two individuals from National Breast Cancer Coalition and one individual from Breast Cancer Action were interviewed. Each phone interview lasted for roughly an hour. Topics of discussion included the organization's history, collaboration with other cancer organizations, advocacy for connecting social disparities to breast cancer risk, legislative advocacy, scientific collaboration, as well as policies related to funding. The interviews were concluded with final thoughts from the interviewees and information related to any other individuals who would like to participate in the study. The real names of participants and organizations were maintained throughout the research process.

While the use of phone interviews provided a way to conduct research with organizations outside the Knoxville area, there were limits to this mode of research. Unlike methods such as participant observation, where the researcher can actively engage with the interviewee, the use of phone interviews limited the time spent with the each person who participated in the research process. Also, this type of research limited the ability to create rapport, not only by limiting the time spent with the interviewee, but also because the interviewee never saw the interviewer in person. The lack of contact inhibited the ability to pick up on facial and body language cues related to the interview process. Although the use of Skype or other video conference software could have aided in the ability to build

rapport, it could not be used because the individuals that participated in interviews did not have access to that type of technology.

## CHAPTER 4: RESULTS

### *4.1 Risk*

The EBCM contests individual risk factors that are advocated in mainstream prevention. Through the contestation of individual risk supported by the MBCM, the EBCM seeks to redefine scientific research related to breast cancer (Hilgartner and Bosk 1988: 55). According to the EBCM, the overall percentage of women who have individual risk factors like family history or reproductive history is low in comparison to the overall percentage of women with breast cancer. Miriam Hidalgo (interview, November 30, 2010) from Breast Cancer Action asserts that risk factors related to breast cancer “are present only in 30 percent of women” and “70 percent are causes that we are not aware of.” Instead of focusing on the smaller percentage of women with individual risk factors, science should look at “what exposures are linked to environmental risk that are leading to the disease” (Miriam Hidalgo, interview, November 30, 2010). Breast Cancer Action views breast cancer as a “complex group of diseases that occurs in an environmentally complex world” (Breast Cancer Action 2011a). Many different chemicals are involved in breast cancer risk. As a result of this complexity, the EBCM claims that new ways of doing science must occur to understand how different chemicals interact with the body to increase breast cancer risk (Benford and Hunt 2003: 154).

By contesting individual risk factors, the EBCM argues that family history plays a small role in breast cancer risk. In contrast, MBCM activists argue that family history increases a woman's risk of developing the disease. According to the American Cancer Society, "breast cancer risk is higher among women whose close blood relatives have this disease," and "having one first-degree relative (mother, sister, or daughter) with breast cancer approximately doubles a woman's risk" for developing breast cancer (American Cancer Society 2011). Despite mainstream activists' assertion that family history drastically increases the risk of developing breast cancer, environmental activists argue that family history only represents a small portion of women who get breast cancer. The National Breast Cancer Coalition (NBCC) claims that while "the risk for developing breast cancer does increase with increasing numbers of affected first-degree relatives compared with women who have no affected relatives," most women with family history "will never get breast cancer" (National Breast Cancer Coalition 2011b). Although family history is a significant risk factor for some women, when looking at individuals with breast cancer as a whole, family history only represents a small demographic of women. The case of family history illustrates how the EBCM and MBCM both use scientific studies of breast cancer risk but draw different conclusions from the research. The NBCC also asserts that family history, while advocated by the mainstream breast cancer movement as a major risk factor, is only one risk factor among many potential risk factors for breast cancer. The contestation of family history is used by the NBCC to illustrate that

“a risk factor doesn't cause cancer, it just affects your chance of getting cancer” (National Breast Cancer Coalition 2011b). Women who have family history do not always get breast cancer, while there are a large number of women with no family history that do develop the disease. The EBCM asserts that risk is a larger and more complex picture than personal risk factors like family history. The key to understanding complexity is through researching the environmental links to breast cancer.

Similar to family history, the EBCM asserts that genetic links like BRCA1 and BRCA2 are only a small part of a larger picture of breast cancer risk. Mainstream breast cancer activists argue that women with the BRCA1 and BRCA2 genetic mutations are more likely to get breast cancer. Because of this assertion, mainstream activists focus their efforts on educating women about BRCA1 and BRCA2. Mainstream activists also encourage women to get tested as a preventive measure. According to A.D.A.M. Medical Encyclopedia, BRCA1 and BRCA2 genetic mutations increase breast cancer risk and “women with one of these defects have up to an 80% chance of getting breast cancer sometime during their life” (PubMed Health 2011). However, environmental breast cancer activists view the mainstream’s focus on BRCA1 and BRCA2 testing as an example of how the mainstream misses the broader issue of breast cancer risk because the mutation only exists in a small number of women who develop the disease. The EBCM advocates for women to educate themselves about the research on BRCA1 and BRCA2 before deciding whether or not to receive the

genetic test (Breast Cancer Action 2012b). While the EBCM focuses on restructuring risk assessment away from a focus on biomedical methods like BRCA1 and BRCA2 testing, they also seek to empower women with the science associated with biomedical prevention so they can make their own decisions about prevention options. Rather than contesting the validity of genetic testing, The EBCM is actually contests the mainstream interpretation of the tests and their effect on how women view their own breast cancer risk. The EBCM argues that there is still an unknown factor that causes some women with the mutations to get breast cancer and some to never get the disease. Through the understanding of the complex environmental factors associated with risk, the EBCM claims that the scientific community can better understand how risk factors play out in cancer rates.

In order to understand the complex nature of risk, the EBCM focuses on how multiple risk factors, particularly environmental toxins, interplay to affect risk at a population or community level. The Breast Cancer Fund asserts that looking at “exposures to radiation, carcinogens, and chemicals that act like hormones (known as endocrine disruptors)” illustrate “the complex web of breast cancer causation” (Breast Cancer Fund 2011a). According to the Breast Cancer Fund’s biennial report, “State of the Evidence,” activists not only look at the ways various risk factors interact with each other to increase overall risk but they also assert that women often are not aware of all the toxins they are exposed to (Gray et al 2010:11). For example, the biennial report argues that:

We focus on people's exposures to environmental chemicals, including many of those found in personal care products, household products, plastics, food, air and water, as well as several sources of radiation, including medical radiation and electromagnetic waves. Although we may have control over our personal use of some of these chemicals, exposures to many of these factors are not voluntary. On a daily basis, we are all exposed to many of these agents in the air we breathe, the water we drink, the grounds we walk and play on, the toys and other products we handle, and the substances we put on our bodies. Often we are not even aware of these exposures.

Through scientific research into the role different chemicals play in breast cancer risk, and through making this information accessible to the public, the EBCM asserts that breast cancer risk can be reduced. Understanding the role chemicals play at a population level is also an important part of the NBCC's research and advocacy because population level risk helps to "determine which factors increase breast cancer risk and how much increase in risk is caused by each factor" (National Breast Cancer Coalition 2011a).

The EBCM also explores how the link between social inequalities and breast cancer risk influence community risk. Mainstream organizations focus on risk factors like genetics that not only focus on individual risk but also view risk factors as evenly represented in the data for breast cancer risk. According to Living Beyond Breast Cancer, "what all people with breast cancer have in common are 'bad copies,' or *mutations*, in the DNA of their breast cells" (Living Beyond Breast Cancer 2010). While the mainstream breast cancer movement focuses on the commonality of individual risk factors like genetics, environmental breast cancer activists focus on how social disparities put ethnic minorities and

poor populations at an unequal rate of risk and mortality compared to other populations. Disparities among ethnic minorities, particularly in terms of access to care, illustrate how the social context that minorities live in influences their risk of developing breast cancer. Since white women are more likely to have access to quality health care as opposed to minority populations, it can also be inferred that white women have higher rates of diagnosis (National Cancer Institute at the National Institutes of Health 2008b) because they are more likely to go to get preventative screening and detect breast cancer earlier than minority women. Both the care of higher rates of diagnosis among white women and the high rate of minorities dying from the disease illustrate how access to healthcare is crucial to diagnosis and preventing women from dying of breast cancer. Marisa Walker from the Breast Cancer Fund mentions that “huge disparities in terms of care have complex factors particularly around African American women and breast cancer” (interview, December 10, 2010). Organizations like the Breast Cancer Fund often collaborate with outside research studies, like the University of Pittsburgh (Marisa Walker, interview, December 10, 2010), to understand how access to care affects risk in order to develop advocacy that can help women reduce their risk of breast cancer.

The EBCM also uses migration studies to illustrate how breast cancer risk is related to geography and, more importantly, what kinds and concentrations of chemicals are located in different geographic areas. Individuals from more industrialized countries, such as the United States, have a much higher rate of

breast cancer than individuals from less industrialized countries (Breast Cancer Action 2008a). The EBCM makes the geographic connection even more pronounced by demonstrating that when individuals move from a non-industrialized to a more industrialized country, their breast cancer risk increases. The Breast Cancer Fund's "State of the Evidence" report uses breast cancer rates among Hispanic women to demonstrate that while immigrant Hispanic women have lower rates of breast cancer than "Hispanic women born in the United States,....the longer the period of time these Hispanic women spend in the United States, the greater their risk for breast cancer" (Gray et al 2010:14).

Although there are multiple reasons for the disparity among ethnic minorities and women of lower socioeconomic status in the United States, the Breast Cancer Fund claims, "it is clear that poverty is linked to greater chemical exposure and, thus, greater risk" (Breast Cancer Fund 2011b). While white and more affluent women are more likely to live in areas that have less exposure to chemical toxins and have access to quality healthcare, poor and minority women are less likely to have access to these factors and are therefore more likely to have a greater risk of developing late stage and more aggressive forms of breast cancer. Access to quality housing and healthcare are linked to social inequalities and illustrate how social disparities influence breast cancer risk. Poorer women not only have limited access to health care, which puts them at greater risk for developing late stage breast cancer, but they are also more likely to live near

areas that are polluted and thus increasing their risk of exposure to environmental toxins (Breast Cancer Fund 2011c).

Instead, these communities are situated near factories, waste-disposal sites, agricultural areas or other sources that constantly or regularly spew toxic chemicals or radiation into the environment. Some of these sources are recorded by the Environmental Protection Agency's Toxic Release Inventory (TRI) database. In many cases, sources of pollution are clustered in a small area, meaning that communities near one TRI site are often near several other pollution sources. Research suggests that mixtures of chemicals may multiply risk. In addition, TRI facilities are more likely to be located near communities with higher proportions of people of color and people with lower socioeconomic status.

The potential exposure to multiple types of toxins resonates with environmental advocacy because they argue that exposure to multiple toxins increases breast cancer risk, and that science still does not have adequate ways to test how multiple toxins interplay with each other to increase risk. The Breast Cancer Fund's discussion of communities located near polluted areas also demonstrates how ethnicity and socioeconomic status are interlinked in exposure to environmental toxins. The EBCM uses science and data on social inequalities to contest the mainstream movement's focus on individual risk factors (Spector and Kitsuse 1973: 146). Through understanding how multiple chemicals affect risk on a population level and how social inequalities affect risk, the EBCM seeks to reduce the number of women who get breast cancer.

#### *4.2: Science and Risk Management*

Along with contesting dominant views of breast cancer risk, the EBCM also contests the science related to methods used to manage breast cancer risk. Breast Cancer Action (BCA) calls into question the effectiveness of medical prevention and advocates for prevention that focuses on the environmental causes of breast cancer (Breast Cancer Fund 2007). Breast Cancer Action argues that younger women are getting breast cancer at an increasing rate and prevention strategies supported by the dominant science community are not only failing to prevent overall breast cancer risk but they are also failing to prevent younger women from getting the disease (Breast Cancer Action 2007; Bash 1995:3). The EBCM examines risk in non-traditional at-risk groups like younger women to illustrate that dominant science is not effectively preventing breast cancer. The EBCM focuses on lay involvement in science and legislation in order to change the MBCM's focus on medical prevention to a type of prevention that examines the environmental links to breast cancer. The EBCM also challenges the role of corporate sponsorship in funding and influencing dominant science and lobbying.

In order to challenge dominant prevention and lobbying efforts, the EBCM not only calls for lay involvement in breast cancer research but activists also work for lay involvement in breast cancer legislation as well. According to Karen Miller, "Diseases are politically driven. The things that prevent us from achieving our

successes are political. The things that enable us to achieve our successes are political” (Karen Miller, interview, December 2, 2010). EBCM activists argue that they must also be involved in the legislative process that dictates dominant science and prevention, as well as chemical regulation. The EBCM must also contend with corporate lobbying efforts to further the corporate agenda by focusing on medical prevention while undermining the regulation of chemicals linked to breast cancer risk.

The EBCM contests the mainstream focus on medical prevention through mammograms by arguing that mammograms are not reliable and they do not truly prevent breast cancer. Mainstream breast cancer organizations advocate mammography as an effective way to prevent late stage breast cancer, thereby decreasing the risk that a woman will die from the disease. Komen for the Cure argues for “the life-saving benefits of mammography” and that “mammography is the most effective breast cancer screening tool used” for early detection (Susan G. Komen for the Cure 2012a). Environmental breast cancer activists contest the effectiveness of mammography in their claim that it is not as accurate as mainstream activists claim, and they point out the fact that it only finds breast cancer once it is already formed. According to the NBCC, false positives actually put women in more danger because they “may lead to unnecessary, intrusive surgical interventions, while false negative results will not find cancerous tumors” (National Breast Cancer Coalition 2011c). The NBCC also claims that the more mammograms a woman has, the more likely she is to have a false

positive, which increases her chance of having an unnecessary invasive procedure like a biopsy. Instead of focusing research and public attention on mammography, the EBCM argues that “resources must be devoted to finding effective preventions and treatments for breast cancer and tools that truly detect breast cancer at a time where an intervention will help” (National Breast Cancer Coalition 2011d).

The EBCM also contests mainstream prevention through pharmaceutical drugs like tamoxifen, again arguing that they are not only an inadequate form of prevention, but they also have the potential to harm women and take resources away from finding environmental links to breast cancer. Mainstream breast cancer advocacy argues that prevention drugs like tamoxifen are an effective way to prevent breast cancer in women who are at an increased risk of developing the disease. The National Cancer Institute’s information on tamoxifen demonstrates how it is used prevent breast cancer from forming again or growing (National Cancer Institute at the National Institutes of Health 2008a):

As adjuvant therapy (treatment given after the primary treatment to increase the chances of a cure), tamoxifen helps prevent the original breast cancer from returning and also helps prevent the development of new cancers in the other breast. As treatment for metastatic breast cancer, the drug slows or stops the growth of cancer cells that are present in the body.

In contrast to this position, environmental breast cancer activists argue that drugs like tamoxifen have side effects that put women at risk for other health issues, and their use distracts breast cancer advocacy from focusing on

prevention. EBCM organizations like Breast Cancer Action advocate to inform the public about drugs to prevent breast cancer. In their Policy on Pills for Prevention, the BCA gives information about drugs like tamoxifen and raloxifene, as well as Aromatase Inhibitors (Breast Cancer Action 2011b). In all of the examples of drugs and other medical treatments to prevent breast cancer, BCA argues that there is insufficient high quality research to support the MBCM's claims about effectiveness . BCA uses research from the scientific community (Breast Cancer Action 2011b) to illustrate the numerous risks associated with medical treatments to prevent breast cancer. While EBCM organizations challenge biomedical treatments supported by the MBCM, the EBCM still uses scientific research to back up their claims. Informing the public about the effects of drugs for preventing breast cancer and the effects of drugs on understanding environmental links to breast cancer is at the core of BCA's prevention policy (Breast Cancer Action 2011b):

Women deserve to be fully informed about the benefits and risks of breast cancer "prevention" drugs prior to making a decision about whether or not to take them. At present, individuals are making decisions under conditions of uncertainty. Breast Cancer Action, while clearly understanding the large numbers of women at risk for developing breast cancer, does not advocate using drugs to treat risk. It is difficult to imagine a drug powerful enough to actually reduce the risk of breast cancer that will not have serious side effects. Moreover, the focus on pills for prevention of disease diverts resources from finding and eradicating environmental causes of, as well as effective treatments for, breast cancer.

While environmental breast cancer advocates illustrate the potential harm that biomedical treatments like tamoxifen can have on the body, their argument about

mainstream prevention highlights the unequal attention given to environmental causes of breast cancer. Although there is significant funding for breast cancer, most of these funds go towards research for biomedical prevention and treatment. EBCM activists argue that instead of focusing prevention on pharmaceutical drugs like tamoxifen prevention resources should go to researching environmental factors that are leading to breast cancer and finding ways to reduce those risk factors.

In order to challenge dominant science and the corporate agenda, the EBCM lobbies to remove environmental toxins from environment, particularly in household and personal care items. The Breast Cancer Fund is an example of an EBCM organization that focuses their advocacy on legislation in order to eliminate chemicals linked to breast cancer. A primary way the BCF focuses their legislative efforts is through the Campaign for Safe Cosmetics, which seeks to remove toxic chemicals from personal care products. The Campaign for Safe Cosmetics was created by the BCF in 2004 as “a coalition of environmental health and women’s organizations working in partnership to get toxic chemicals out of personal care products which includes everything from shampoo, lipstick, soap, men’s products, women’s products and baby products” (Marisa Walker, interview, December 10, 2010). The campaign started as a way to hold corporations responsible for the chemicals they put in their products. By 2010, the campaign transitioned into working with federal legislation regarding safe products. Inspired by legislation passed in 2004 by the European Union for safer

cosmetics in Europe, the BCF wanted to bring similar legislation to the United States. In July of 2010, the Safe Cosmetics Act was introduced by Dan Jakowski in the House of Representatives. According to Marisa Walker (interview, December 10, 2010), the goal of the Campaign for Safe Cosmetics is to create a baseline of safety for all consumers:

We don't want to be in a situation where the educated wealthy consumers are the one's who can find the safe products while the person who shops at a dollar store or who doesn't have time to research safe cosmetic ingredients is not getting a safe product. It is really meant to establish a baseline of safety for everyone and to remove the most harmful ingredients that cause cancer and reproductive harm from the products.

The BCF also worked on the Ban Poisonous Additives Act, "which was a ban on BPA in food cans, serving dishes, bottles and packaging" (Marisa Walker, interview, December 10, 2010). The legislation later became an amendment Senator Feinstein offered to the Food Safety and Modernization Act. It was blocked in late 2010 by the American Chemistry Council. The blocking of the Food Safety and Modernization Act by the American Chemistry Council demonstrates how the EBCM must contend with the influence of dominant science in the legislative process. The blocking of this legislation illustrates how lobbying keeps the dominant science agenda on top. This demonstrates that contesting dominant science through the legislative process is a constant battle, despite growing scientific evidence of harmful effects of toxic chemicals like BPA (A3).

The EBCM contests the role of corporate funding in shaping the public perception of risk management, and in shaping agendas for the funding of and legislation related to breast cancer prevention. Corporate sponsorship is often a major source of funding for mainstream breast cancer organizations. The National Breast Cancer Foundation states that “each of our corporate sponsorships is critical in furthering and strengthening our mission to gain the advantage over breast cancer” and that, “the initiatives they have helped us implement have been lifesaving to thousands of women” (National Breast Cancer Foundation, INC. 2012a). Partners for the National Breast Cancer Foundation include MagLite Flashlights, Proctor and Gamble as well as Reynolds (National Breast Cancer Foundation, INC. 2012b). Mainstream organizations like the National Breast Cancer Foundation view corporate funding as a vital opportunity to reach more women with their advocacy.

On the other hand, environmental breast cancer advocates view corporate funding as a way for corporations to manipulate the message of risk and prevention. On the topic of funding, Miram Hidalgo (interview, November 30, 2010) mentioned that Breast Cancer Action does not “receive funding from corporations. That really helps our transparency. It helps us really to be able to give unbiased messages about treatment options and about what’s really going on with the cancer movement.” The EBCM argues that accepting funding from corporations can create biased advocacy because corporations often have stipulations that come with their funds. These stipulations often focus funds on

medical prevention and not on environmental causes of breast cancer. Miriam Hidalgo (interview November 30, 2010) also discussed the connection between corporate pink products and the effects on the consumer and breast cancer funding:

Buying a product makes people feel better momentarily. People don't realize that they need to ask questions about where is the money going, how much of the money is going somewhere. What happens after October? (A4) Does the company still make a profit or do they continue to donate the money?

The EBCM not only argues that money from corporate sponsorship goes to research and advocacy that is in line with mainstream prevention, but also contends that not all of the money goes to actual prevention programs. Only a portion of proceeds go to programs sponsored by corporations, and often corporations profit from any extra money they receive in excess of what they promised to give. The BCA created the Think Before You Pink campaign in 1992 to address the over-saturation of corporate pink products that flood the consumer market, particularly during the month of October. The Think Before You Pink campaign "calls for more transparency and accountability by companies that take part in breast cancer fundraising, and encourages consumers to ask critical questions about pink ribbon promotions" (Think Before You Pink 2011a). According to the BCA, holding corporations accountable in their fundraising practices is a way to reduce corporate profit from fundraising and keep corporations from funding research that only serves their agenda. The BCA uses

the power of consumer choice to demonstrate how the lay community can come together and challenge the role of corporations in perpetuating and shaping mainstream narrative of breast cancer prevention.

#### *4.3: The Precautionary Principle and the Burden of Proof*

One way the EBCM reframes breast cancer risk and prevention is through the precautionary principle. According to Breast Cancer Action, taking a precautionary approach to breast cancer risk is about “shifting the burden of proof so that the companies that make and profit from products and activities must prove that they are safe, rather than the current situation where the public is required to prove that something is harmful before it’s stopped” (Breast Cancer Action 2008a). Instead of waiting until chemicals have already been linked to causing cancer, Breast Cancer Action advocates that producers of chemicals need to prove their safety before using them. If companies cannot prove that chemicals are safe or there is reason to think that certain chemicals are not safe, those chemicals should be regulated. Susan Fenton argues that proving the harm of chemicals should not be the responsibility of individuals but there should be an “increased government regulatory and industry responsibility” in ensuring the safety of chemicals before they are used in consumer products (The Collaborative of Health and the Environment 2011a). The Breast Cancer Fund argues that a more precautionary approach to chemicals is needed because

“more than 90 percent” of chemicals used in the United States “have never been tested for their effects on human health” (Gray et al 2010:14). Since most chemicals that are used by companies have not been proven to be safe, the EBCM argues that they pose a health risk to communities and consumers. The precautionary principle is a tool that environmental breast cancer activists like the Collaborative on Health and the Environment’s (CHE) Breast Cancer Working Group use to make the public and scientific community aware of the potential harm of using certain chemicals. These activists also use the precautionary principle to point out the challenge of scientific uncertainty in linking certain chemicals to breast cancer, and the need to take action towards regulating chemicals despite the uncertainty (The Collaborative for Health and the Environment 2012a).

CHE activists use the precautionary principle not only to challenge conventional science, but also to challenge government legislation to regulate toxic chemicals. The precautionary principle “encourages close scrutiny of all aspects of science, from the research agenda to the funding, design, interpretation, and limits of studies, for potential impacts on the earth and its inhabitants” (The Collaborative for Health and the Environment 2012a). CHE uses the precautionary principle to advocate for equality in breast cancer prevention. EBCM organizations like BCA advocate the precautionary principle as way to eliminate injustice linked to environmental causes of breast cancer. BCA urges that:

With the health and lives of so many at stake, we must adopt a public health approach — a precautionary principle — making policy changes based on the weight of the evidence. Such a principle was used in policy changes regarding the dangers of smoking, even though the precise mechanism of cancer causation has never been scientifically explained.

BCA collaborates with individuals from organizations such as Physicians for Social Responsibility, National Latina Institute for Reproductive Health, and Women’s Cancer Action (Breast Cancer Action 2012) which are committed to similar goals in order to achieve their political and scientific advocacy.

Miriam Hidalgo (interview, November 30, 2010) advocates for “shifting the burden of proof” in terms of their legislative advocacy. An example of the Breast Cancer Fund’s work to incorporate a precautionary approach into legislation can be seen in the 2003 adoption of the precautionary principle by the city of San Francisco Board of Supervisors (Breast Cancer Fund 2011d). The adoption of the legislation demonstrates the role of activists and community leaders in challenging traditional legislation for one in which favors a precautionary approach. Through collaborating with legislative leaders, Breast Cancer Fund activists helped to get precautionary principle legislation passed in San Francisco. Activists view the passing of legislation as a major victory for their precautionary principle efforts, not only because of the overwhelming majority vote in favor of the legislation (A5), but also because the “ordinance reorganized 11 separate pieces of environmental legislation into one environmental code with

a visionary precautionary principle policy statement serving as its first chapter” (Breast Cancer Fund 2011d).

The precautionary principle represents the EBCM’s reframing of risk and risk management from focusing on the individual to focusing on environmental factors that put communities and populations at risk for breast cancer. CHE advocates the precautionary principle as a form of environmental justice that holds producers of chemicals accountable in order to protect communities from exposure to toxic chemicals. According to Richard Clapp, precautionary approaches are a matter of ethics and already exist in fields like public health (The Collaborative for Health and the Environment 2011a):

I just want to emphasize that the public health community...has what they call principles for public health practitioners. One of those principles is essentially a statement that in the absence of complete knowledge of mechanisms and perhaps complete knowledge of all who might be exposed to some agent that might cause disease. We ought to take a precautionary approach and we ought to do it as a matter of principle. It’s an ethical call by the main public health organizations in this country to act when we have reasonable knowledge about the mechanisms of harm aren’t fully known.

The precautionary principle also gives the lay community transparency in science and legislative decisions, and thus shifts power from dominant science and government institutions to the lay community (Gray et al 2010).

#### *4.4: Citizen Science and Scientific Transparency*

Through citizen science, the EBCM seeks to reframe dominant power structure in order to create transparency and democratic decision making in the lay community. The Long Island Breast Cancer Center Project is an example of how citizen science reshapes the power dynamic found in mainstream breast cancer research. The goal of the Long Island Breast Cancer Center Project was to encourage the advocacy and research community to discuss the disparities and limitations in breast cancer research (Karen Miller, interview, December 2, 2010). Through the Long Island Breast Cancer Center project, breast cancer advocates, research scientists, and political leaders realized the redundancies and gaps in breast cancer advocacy. They also realized that more collaboration was needed to fix the gaps and redundancies that existed in breast cancer research and programs. According to Karen Miller “there is still this type of tremendous push to work in a silo...to not trust..to be very competitive” (interview, December 2, 2010). The NBCC uses citizen science to tear down the silos that exist among science, political and advocacy communities through comprehensive collaboration with all three communities, as well as full transparency to the public.

Another example of citizen science can be found in NBCC’s Project LEAD programs. Through Project LEAD, the NBCC offers classes, workshops and seminars “teaching about the science behind breast cancer” (Kathryn Johnson, interview, December 7, 2010). The goal of Project LEAD is to empower the

public by giving them the scientific information to become citizen scientists in their own communities. While the biomedical community as a whole may not be receptive to citizen science, Project LEAD is an example of how critical epidemiologists (Brown 2007:37) support citizen science through educating the lay community about the science involved in breast cancer research. Graduates of Project LEAD can take the scientific information they learn and apply it to their communities to create research and advocacy that reflects the communities' experiences of breast cancer. After completing the program, graduates are not only able to team with scientists and present their findings at scientific conferences, but they are also able to "serve on decision-making boards of local, state and national organizations, committees and Institutional Review Boards" (National Breast Cancer Coalition 2011e). Through programs like Project LEAD, NBCC provides the lay community with the scientific knowledge needed to actively engage with the scientific community and participate in the scientific decision making process. Providing this scientific knowledge allows activists the ability incorporate lay knowledge into scientific decision making process.

A third example of citizen science can be seen in NBCC's 2020 campaign. The 2020 campaign is focused on ending "breast cancer by the year 2020 by bringing the best research and public policy minds together to bring as current information as there is about breast cancer" (Kathryn Johnson, interview, December 7, 2010). The NBCC teams activists with scientific and political

leaders to work collaboratively on ending breast cancer by 2020 (National Breast Cancer Coalition 2010). According to the NBCC, “the information and the science and the research and the medical knowledge is out there,” and setting a deadline “presses the issue and focuses the attention” on ending breast cancer (Kathryn Johnson, interview, December 7, 2010).

Like other EBCM organizations, the NBCC contests conventional science and policy’s silo mentality that prevents them from actively collaborating with each other and the lay community. By removing the silo mentality through collaboration with science, policy and lay communities, the 2020 deadline illustrates the EBCM’s reframing of a dominant power structure that keeps knowledge within its respective spheres and does not put value on lay knowledge of breast cancer (Benford and Hunt 2003:161). The 2020 deadline represents citizen involvement in science because it not only focuses on collaborating with science and policy leaders, but it also represents citizen science’s call to focus on ending breast cancer rather than treating the disease.

## CHAPTER 5: DISCUSSION

### *5.1: Contesting Risk*

The EBCM contests the mainstream narrative of risk found in dominant science research and advocacy. The mainstream narrative of risk focus on how individuals are at risk for breast cancer. The National Cancer Institute's information on breast cancer risk factors demonstrates how the mainstream breast cancer movement views risk through individual factors such as genetics and family history (National Cancer Institute at the National Institutes of Health 2010). On the other hand, the EBCM argues that risk occurs on a population level and is more complex than the mainstream narrative suggests because of the interplay between various chemical toxins and social inequalities on communities. The EBCM contests dominant focus on genetic and family risk because the EBCM argues that there is a complex interplay of environmental toxins on communities and populations. Looking at risk on a population level gives a broader and more accurate view of risk. According to the EBCM, risk not only affects communities but social disparities also affect how different communities experience breast cancer risk. Social inequalities influence risk because poor and ethnic communities are exposed to more and more varied chemical toxins, thus increasing their breast cancer risk. Understanding how risk

affects communities and how toxins play into community risk is key to reducing breast cancer.

By contesting individual risk, the EBCM seeks to challenge the way the mainstream causation narrative affects how breast cancer is viewed and treated. Susan G. Komen, a mainstream breast cancer organization, claims that “knowing the basic types of risk can help you understand your chances of getting breast cancer and the steps you can take to lower your risk” (Susan G. Komen for the Cure 2012b). However, the EBCM calls for a different way to examine risk because they claim that the dominant narrative of risk does not adequately address the larger and more complex framework of breast cancer risk.

Environmental breast cancer organizations like CHE look at community risk because they argue that it more adequately addresses the complex nature of chemical exposure and social inequalities that dictate breast cancer risk (The Collaborative of Health and the Environment 2012b). The varied narrative of breast cancer risk by the mainstream and environmental activists represents different “perspectives” and “purposes” in defining breast cancer as a social problem (Bash 1995:27). The purpose in defining risk on a population level verses an individual level illustrates the EBCM’s assertion that social factors influences breast cancer risk. Redefining risk also represents the different perspective of how risk plays into larger the framework of the breast cancer narrative. Focusing on individual risk obscures the larger environmental and social connections that are found when looking at risk at a population level. The

larger framework of risk helps to explain why a larger portion of women get breast cancer and offers a more dynamic solution to the complexity of breast cancer risk.

The assertion of risk at a population level is significant because it illustrates the contested nature of breast cancer and how power dynamics influence risk narrative. Like other contested illnesses, breast cancer has a dominant narrative that influences perceptions of breast cancer risk. Contested illnesses such as asthma (Senier et. al. 2011:171) and learning disabilities (Davis 2007:417) all have a dominant narrative that obscures the environmental narrative from gaining legitimacy in a public arena. With the increase of illnesses like “cancer, asthma, heart disease, birth defects, developmental disabilities, diabetes, endometriosis, infertility, and Parkinson’s disease,” collaborative groups like CHE are using scientific research to show the increasing connection to “chemical contaminants as contributing to the growing toll of human suffering” (The Collaborative of Health and the Environment 2012b).

EBCM activists are part of a larger network of advocates for the recognition of environmental causes of certain illnesses. According to Marisa Walker (interview, December 10, 2010):

It’s not just about breast cancer. Obviously we are breast cancer focused. Many of the chemicals we talk about are linked to other diseases and cancers, Parkinson's, learning disabilities, fertility problems. We work with organizations that represent all of those interests and together it’s very compelling and very powerful.

EBCM movement activists work with other contested illness activists in order to strengthen their argument. By coming together, they are creating a network of contested illnesses and are able to draw on research done about other contested illnesses. Collaborating also allows a stronger argument for environmental connections to illness since more illnesses and activists are involved.

The EBCM seeks a different narrative of breast cancer risk and as a result it challenges the dominant narrative (Blumer 1971:303; Button 2010). By offering an alternative narrative, the EBCM must contend with the credibility that the mainstream has built as the dominant narrative. The “hierarchy of credibility” (Loske 1999:35) exists in the favor of dominant narrative because mainstream science and advocacy favor individual risk. The EBCM must contend with the dominant narrative’s power in mainstream science and advocacy surrounding risk. The dominant narrative represents authoritative knowledge, and as such this “one body of knowledge is privileged over other bodies in that it has greater access to ultimate reality or the ‘truth’” (Malinowski 1922:177). As a result of the dominant narrative’s construction of truth, “rational organizations and human beings are expected to organize their conduct to reflect this truth” (Kroll-Smith and Floyd 2000:85). Rational knowledge “is always a legitimating idea” (Wright 1992:6) on which the reality of an issue like breast cancer is based (Lyotard 1992: 29). The EBCM uses scientific knowledge and

collaborations with scientists that favor critical epidemiology to create a space for lay knowledge within the realm of breast cancer research. Organizations like the National Institutes of Environmental Health Sciences (Brown 2007:36) collaborate with citizen scientists in order to reconstruct conventional biomedical methods.

### *5.2: Contesting Dominant Risk Management*

The EBCM also contests the dominant focus on prevention through technology and pharmaceuticals. The dominant narrative of breast cancer prevention focuses on mammography and pharmaceuticals like tamoxifen to reduce breast cancer risk. Susan G. Komen, a mainstream breast cancer organization, argues that prevention is actually “risk reduction” because they argue that true prevention is not possible (Susan G. Komen for the Cure 2011):

People who brush their teeth can still get cavities. And, people who always wear their seat belts may still get hurt in a car crash. We do what we can to improve the chances of a good outcome, but we don't always have complete control. When talking about cancer and other chronic diseases, the same concept applies. Prevention mainly refers to lowering the risk of getting a disease rather than completely removing the risk.

EBCM activists contest mainstream's assertion that reducing risk is an adequate form of breast cancer prevention. According to the EBCM, mammography and tamoxifen are not true prevention because they are only useful for detecting and treating cancer that already exists or, in the case of tamoxifen, it is also prescribed for women who are at a high risk for developing

breast cancer. The Breast Cancer Fund argues that mainstream prevention methods are not adequate and advocates “moving away from blanket guidelines and toward an investment in safer and more effective alternatives and a better understanding the causes of the disease” (Inside Prevention: Breast Cancer Fund Blog 2009). The EBCM asserts that true prevention must happen before a woman gets breast cancer. According to Karen Miller, President and Founder of Prevention is the Cure, ““There is no cure for disease. There is no immediate magic bullet for disease. Prevention can be the ultimate cure. It takes all of us understanding how we can be apart of this process and really lower the risk for disease” (Blip 2012). Groups like Prevention is the Cure advocate for environmental prevention of toxic chemicals and provide the lay community with the scientific knowledge to empower them to be part of the process of environmental prevention advocacy. The contestation of the mainstream narrative of risk also challenges the role of corporate funding in shaping science and legislation related to risk management because it empowers the lay community to challenge corporate interest when advocating for environmental prevention. Citizen science allows lay experience of breast cancer science and legislation to have an impact on future breast cancer advocacy. Though the public paradigm, lay women are able to bring their experiences with breast cancer into the larger breast cancer narrative and influence science and legislative decisions related to their illness.

The contestation of mainstream views of prevention by the EBCM connects with a broader theme of contesting science as expert knowledge. Since mainstream prevention narrative favors medical technology and pharmaceuticals, science is placed in a higher authority when it comes to methods of prevention. According to BCA Resource Liaison Zoe Christopher, “there are no effective means for truly early detection of breast cancer” and “even if you get a positive result, there currently isn’t anything you can do to be more vigilant about breast cancer than what you are already doing” (Breast Cancer Action 2011c). Despite the EBCM assertion that medical breast cancer prevention is not true prevention, the dominant narrative looks to science for prevention because it has an authoritative voice in society and it is linked in the public consciousness with life saving treatments for women who have been diagnosed with breast cancer. Scientific knowledge is placed at a higher authority because society values “the language of biomedicine” in understanding disease cause and prevention (Kroll-Smith and Floyd 2000:85). Since biomedical models of prevention are favored by the dominant narrative, any other view of prevention is viewed as challenging the dominant narrative and is kept out of the dominant breast cancer narrative. Nancy Evans describes the importance of understanding and utilizing biomedical knowledge in advocacy (The Collaborative of Health and the Environment 2006) :

Those of us in the advocacy community realize that understanding the science of breast cancer including the statistics is what gives us credibility, not only with scientists but with the public. Getting the numbers right

when we are talking about the rising incidence of breast cancer over time is particularly important in establishing environmental links to breast cancer in a changing world.

Not only does The Collaborative of Health and the Environment use biomedical knowledge to understand breast cancer risk, but they also advocate the methods of analyzing breast cancer data should be reassessed. Making sure that the data is understood correctly is an important element in understanding breast cancer risk and prevention.

The EBCM's contestation of dominant prevention narrative acts as a "practical epistemology" (Geertz 1983:151) in that it "joins the world of personal and biographical experience to forms of instrumental rationality" (Kroll-Smith and Floyd 2000:85). Because the EBCM includes the personal narratives of the lay community in its argument for prevention, the dominant narrative does not view the EBCM's narrative on prevention as valid. Although the mainstream narrative provides methods to help women understand risk and treatment methods, both the lay and certain individuals within the scientific expert community realize that more needs to be done in order to stop women from getting the disease.

Environmental activists see the degradation of their environment and how it impacts their health and the health of their communities. These experiences and observations serve as a basis for their activism in the EBCM. Although the public did not know about her breast cancer diagnosis at the time of the publication of her book *Silent Spring* (Silent Spring Institute 2012), her activism inspired the lay

community to educate themselves about the science related to environmental links to breast cancer. In Sabrina McCormick's (2007) book *No Family History: The Environmental Links to Breast Cancer*, she mentions women's experiences with breast cancer and how these experiences lead them to environmental activism. One example McCormick mentions how Barbara Balaban (McCormick 2007:91), who herself did not have breast cancer, realized that women in her Long Island community were getting breast cancer and worked with the scientific community to understand the cancer clusters in her community. The experience of Rachel Carson as well as women like Barbara Balaban illustrate how personal narratives reflect a desire to understand the environmental links to breast cancer. Despite this personal narrative found in the EBCM, the mainstream tries to "exclude public knowledge" in order to maintain what the dominant narrative views as a "pure" knowledge found in traditional scientific knowledge (Tsing 2005 also cited in Button 2009:167). Breast Cancer Action's webpage on Pills for Prevention articulates the differing views of prevention and how prescriptions fit into the dominant narrative of prevention (Breast Cancer Action 2008b):

The prevention of breast cancer is the ultimate goal of most people involved in breast cancer work: from activists, to doctors, to research scientists. There is far less agreement, however, about how to achieve that goal. For many people in the medical and scientific community, the answer lies in finding pills that will protect people against the disease. For Breast Cancer Action and many women's health activists, the acceptable approach to breast cancer prevention lies in putting the public's health before private profit, which involves finding and eradicating the causes of breast cancer instead of medicating healthy women.

Breast Cancer Action not only argues that pharmaceuticals are not an adequate form of breast cancer prevention, but that pharmaceutical companies are profiting from medical prevention. EBCM organizations like Breast Cancer Action argue against pharmaceutical companies profiting from prevention because it gives these companies an incentive to perpetuate medical prevention as well as a way to distract public attention from their role in producing chemicals linked to illnesses. Similarly to contested illnesses like endometriosis (Capek 2000:356), environmental breast cancer activists also contest pharmaceutical funding because some of the same pharmaceutical companies that want to provide funding are producing chemicals that are linked to that same illness. Environmental breast cancer activists cite Astra-Zeneca is an example of a pharmaceutical company that funds breast cancer research while producing chemicals linked to the disease. Because pharmaceutical companies are tied in with major scientific research, they are in a position to shape breast cancer research and to undermine other research that contests medical prevention methods.

Since pharmaceutical companies are tied in to dominant science, they are part of the hegemony which “asserts the economic and political interests of some while simultaneously ‘mystifying’ this essential inequality in power-relations for others” (Malinowski 1922:179). Pharmaceutical companies are hegemonic because they uphold the interest of medical prevention while keeping knowledge contesting medical prevention out of the mainstream breast cancer narrative.

Organizations like Breast Cancer Action realize that since pharmaceutical companies are tied in with dominant science, accepting funding from pharmaceutical companies would bias Breast Cancer Action's advocacy. Since BCA focuses on "providing unbiased information," it does not take money from corporations that manufacture harmful chemicals, or from pharmaceutical companies or health insurance organizations (Breast Cancer Action 2011d).

Karen Miller (interview, December 2, 2010) from the National Breast Cancer Coalition describes the concern of becoming biased through pharmaceutical funding:

Certainly if I am to talk about Gentech or AstraZeneca, ... each one of those pharma industries contacts our organization, as well as other organizations, and they say we have funding for you. We don't want to be associated or when we look at the fine print they have some control over what you can and cannot say.

Organizations like the National Breast Cancer Coalition do not accept money from pharmaceutical companies like Gentech or AstraZeneca because they have funding stipulations would give them the power to shape the organization's breast cancer narrative, as well as methods for cure and prevention (Hyatt 1997:234). Pharmaceutical companies control "the production of truth" (Foucault 1980:133) in terms of the breast cancer prevention narrative through their funding of science and organizations that are in line with their breast cancer narrative. Organizations like Breast Cancer Action and National Breast Cancer Coalition realize that if they accept money from pharmaceutical companies, their organizations would end up becoming tools to continue a pharmaceutical-

friendly narrative and would compromise their environmental prevention advocacy.

### *5.3: Reframing Risk Through the Precautionary Principle*

The precautionary principle is a method that the EBCM uses to contest dominant paradigm's focus on personal risk. The EBCM uses the precautionary principle to deal with the complexity and uncertainty of environmental risk that is the source of its contestation in the larger breast cancer narrative. CHE argues that contested illnesses like "breast cancer and other cancers result from a complex web of causation" that not only includes environmental toxins but the effect of social inequalities as well (The Collaborative of Health and the Environment 2012b). The EBCM uses the precautionary principle to illustrate that looking at the source of risk is important to ending breast cancer. Looking upstream not only shows the cause, but it also illustrates how communities are impacted by chemical exposure. The precautionary principle is used to "shift the burden of proof to the chemical manufacturers" (Colborn et. al. 1996:219). The precautionary principle makes producers of chemicals accountable for safety instead of waiting until toxins effect communities. Since the precautionary principle advocates for regulating chemicals despite the inability to definitely prove their harm, uncertainty becomes a benchmark for further analysis of the potential harm of chemicals.

The precautionary principle serves as a public paradigm (Brown 2007) that offers contested illnesses like breast cancer a way to reframe science and advocacy to serve the public interest rather than the traditional paradigm that serves private or corporate interest. As a public paradigm, the precautionary principle “seeks to transform large and multifaceted aspects of social belief” and “synthesizes the concerns of diverse social sectors: environmental policy, health policy, economic planning and development, transportation, community planning and development, international treaties, protocols, cooperation, and the general democratization of society” (Mayer et. al 2002:576). The precautionary principle reframes power relations among the lay community, the science community, and the legislative community to provide the lay community with more equal voice in the research and regulation of toxic chemicals. The Breast Cancer Fund’s “prevention is power” slogan resonates the message of empowerment through prevention when it calls for the lay community to “take action to demand safer products from companies and smarter laws from elected officials” (Breast Cancer Fund 2011e). This message of empowerment is particularly important in contested illness narratives like breast cancer because non dominant groups must reframe the expert power dynamic of the dominant paradigm in order to change the way science and legislation deals with toxic chemicals and chemical regulation.

In terms of contested narratives, the precautionary principle serves as a way for communities to contest the unequal power dynamic in society that allows

manufactures of toxic chemicals to not only use chemicals with little regulation (Ley 2009), but also lobby against regulation. Contested illnesses use the public paradigm to claim that there is a social problem (Benford and Hunt 2003:160) in terms of the power dynamic in chemical regulation. The precautionary principle is used in contested illnesses as a way to assert a public paradigm that holds chemical producers responsible for safety, and allows communities to actively engage science and government to hold chemical manufacturers responsible for the safety of their products. Contested illness narratives reframe the way society looks at an issue and defines it as a social problem (Troyer and Markle 1984). In the case of breast cancer, the precautionary principle reframes the way the dominant narrative rests the burden of proof on communities and populations rather than on the manufacturers of toxic chemicals.

For example, illnesses like asthma (Brown 2007:100) are often contested by the dominant narrative of the illness as unable to definitively prove environmental causation. The use of scientific uncertainty by the dominant narrative provides scientists, policymakers, and others working within this narrative with a way to “cast doubt on their critics and seek to undermine challenges to the *official* narrative” (Button 2010:13) in order to maintain power over the illness narrative. On the other hand, “advocates for the precautionary principle counter that science is always a continuum: one answer leads to another question, which leads to another answer, and so on” (Shapiro 2007:12), and therefore scientific uncertainty should not hinder research and regulation of

chemicals that may be responsible for illnesses. Groups like CHE argue that scientific uncertainty should encourage further scientific research rather than be a reason to cast doubt on the validity of environmental connections to contested illnesses. CHE claims that “research on environmental contributors to breast cancer and other diseases should be aggressively expanded” because “breast cancer is a symptom of a larger public health crisis that demands action by society as a whole” (The Collaborative of Health and the Environment 2012b). The precautionary principle offers a way for the lay community to contest the need for certainty. The lay community is then able to use scientific uncertainty to demand government regulation and scientific research of chemicals. The precautionary principle allows the lay community to reframe scientific uncertainty to contest the dominant paradigms control over the official illness narrative (Button 2009:167).

#### *5.4 Reframing Risk Management Through Citizen Science*

Citizen science reframes the power dynamic in science through inclusion of lay knowledge. The lay community works with critical epidemiologists in the scientific community on science research and science decisions through scientific collaborations and serving on advisory boards. Lay activists use citizen science as a method to insert their experiences with breast cancer into the breast cancer narrative. Citizen science challenges expert knowledge as the only valid

form through incorporating lay knowledge along with scientific knowledge. Karen Miller describes the importance of incorporating lay and scientific knowledge (Blip 2012):

One of the most important things I think is as science is providing us with continuous information about the connections between environmental triggers and disease, we need to have that translated and disseminated so it has a positive health impact. There is a tremendous gap between science and political and public health impact. I think the activist community is trying to fill in those gaps.

Despite the exclusion of lay knowledge in conventional science, biomedical models of knowledge are important to understanding the role of environmental toxins in breast cancer risk. Instead of creating an entirely new model to include lay narratives, the public paradigm uses citizen science as a way to restructure the conventional science model to include lay knowledge. The lay community becomes involved in science and science decisions by doing research and analyzing how to use research findings. Citizen science is part of a larger public paradigm (Brown 2007) in that it seeks greater transparency and democracy in the scientific research process.

Part of the public paradigm in EBCM activism involves citizens actively collaborating with the scientific community. The National Breast Cancer Coalition's Breast Cancer Deadline 2020 campaign is an example of how activists use "strategic summits, catalytic workshops and collaborative efforts with a multi-disciplinary and diverse group of stakeholders" to redefine breast cancer science through citizen science: (National Breast Cancer Coalition 2011f)

That's why the National Breast Cancer Coalition's (NBCC) advocates...are calling for an end to breast cancer by January 1, 2020—Breast Cancer Deadline 2020®. This serious and strategic plan of action is creating a paradigm shift in the breast cancer community to refocus resources and efforts on the goal of ending breast cancer.

Citizen scientists use biomedical knowledge in scientific collaborations. Like other contested illnesses, environmental breast cancer activists are using biomedicine to challenge traditional power structures in science. By using biomedical knowledge, environmental breast cancer activists are “challenging the received wisdom about the body by linking their somatic disorders to rational explanations borrowed from the professions of medicine” (Kroll-Smith and Floyd 2000:83). Biomedical knowledge gives legitimacy to citizen scientists since biomedical knowledge is valued in the science community. Like other embodied health movements (Morello-Frosch 2006), EBCM activists must collaborate with the scientific community using biomedical knowledge in order to reshape the power dynamic found in traditional science. Rather than refusing scientific knowledge (Sagan 1996), activists are using “language of biomedicine” to redefine research methods and discourses of power in the scientific community (Kroll-Smith and Floyd 2000:83).

According to social problems literature, these activities articulate the claims of a group, and therefore lay participation in citizen science illustrates the EBCM's contestation of dominant science knowledge in undermining lay knowledge (Spector and Kitsuse 1977). Collaborating with the scientific community and acting on the results of collaborations are an important part of

citizen science. Marisa Walker articulates how citizen science uses scientific knowledge in their advocacy: “We then go and put it [scientific research] into action. We put it into a solution to reduce exposure or to explore the chemical further. So now [that] we have all the science, what are we going to do with it [is] to turn it into solutions” (interview, December 10, 2010). According to the National Breast Cancer Coalition’s State of the Evidence report, citizen science offers “opportunities for citizen involvement in raising scientific questions and for personal and civic responses to the resulting exposure data” (Gray et al 2010:31).

Julia Brody cites the lack of success in certain prevention programs in minority communities as an example of the importance of including communities in scientific advocacy (The Collaborative of Health and the Environment 2011b):

When you talk to the general public, particularly communities of color, they do not want to talk about it, they don’t know about it. Even the targeted programs, whether it be for screening, many of these programs are put out there but are not being used. So the excuse is we built it but they did not come. I think what we need to start looking at is research that is more community based so that communities can become involved in what the problem is and once they buy the problem they will buy the solution.

This illustrates not only the potential of citizen science to enrich breast cancer science, as a whole but it also shows how citizen science can empower communities to seek environmental solutions that they view as important. Citizen science not only allows for a more democratic process in research design, but it also allows the lay community more control over how the research is translated into further research and legislative decisions as well.

An arenas approach illustrates that contested illnesses like breast cancer exist as “a putative condition or situation that is labeled a problem in the arenas of public discourse and action” through citizen science (Hilgartner and Bosk 1988: 55). According to the arenas approach, competition exists among groups trying to define a particular social issue in different ways. Different or nuanced definitions of a social problem are challenged in the public arena as the different groups engage in a power struggle for the dominant social narrative of the particular social problem (Hilgartner and Bosk 1988: 55). Power comes from a groups definition of the social issue taken as the mainstream definition in the public arena. By using biomedical models in scientific collaboration, EBCM activists are able to gain validity in the public arena in order to get more research and legislation for the environmental links to breast cancer. Much like other contested illnesses, the MBCM’s power comes from the adoption of the mainstream narrative as the main narrative in breast cancer advocacy (Hilgartner and Bosk 1988:55). Reframing science and the science decision process allows the EBCM to gain legitimacy in the public arena and therefore diminish the power of the dominant narrative in breast cancer discourse.

## CHAPTER 6: CONCLUSION

Like other contested illnesses, the EBCM activists challenge the dominant breast cancer narrative through contesting and reframing (Benford and Hunt 2003:154) dominant narratives of risk and risk assessment. Dominant illness narratives focus on individual risk and medical prevention methods. However, EBCM organizations like the BCA realize that social and environmental factors influence risk in their assertion that “creating awareness that not just genes, but social injustices--political, economic, and racial inequalities--lead to disparities in breast cancer outcomes” (Breast Cancer Action 2011e). Dominant illness narratives also place legitimacy on expert knowledge in order to silence alternative narratives (Button 2010:179). Through the implementation of a public paradigm (Brown 2007:181), which promotes a precautionary approach and lay involvement in the scientific process, EBCM activists contest the dominant breast cancer narrative. The precautionary principle provides a way for activists to demand research and regulation for chemicals linked to breast cancer despite mainstream science’s argument of uncertainty linked to proving. Citizen science provides activists a way to reconstruct the power dynamic found in mainstream biomedicine to include lay knowledge.

This chapter will address recommendations for future research and final conclusions. In the first section, recommendations for future research will use information and limitations discovered during the research process to bring up areas for further investigation. The role of funding in mainstream breast cancer

contestation, collaboration between environmental and mainstream groups and the impact of geographic clustering on EBCM advocacy all offer potential for future understandings of breast cancer as a contested illness. Lastly, this chapter will conclude with final thoughts on the research and analysis.

### *6.1: Recommendations for Future Research*

After analyzing the research conducted during the study, several recommendations for future research became apparent. One area that warrants future research is the EBCM's standpoint on the corporate funding of breast cancer research and advocacy. Corporate funding represents the dominant trend found in the mainstream breast cancer movement because it funds science and advocacy programs that focus on individual risk in advocacy campaigns. Corporate funding also supports medical prevention and research that focuses on finding a medical cure for breast cancer. Medical prevention and cure research is contested by EBCM activists, and therefore receiving corporate funding contradicts the advocacy of the EBCM. Although some literature already addresses the role of funding in breast cancer advocacy, more research and literature is needed (King 2006:xxii), particularly to address the environmental contestation of mainstream advocacy. Many of the people interviewed echoed the concern that "accepting corporate funding can create a real or perceived conflict of interest and undermine the credibility of an organization to reliability

analyze and disseminate scientific information, especially data regarding clinical trials for new drug protocols” (Frickel and Moore 2006:267). Marisa Walker (interview, December 10, 2010) mentions that the Breast Cancer Fund does not “take money from companies who make or sell toxic products” because that would violate their environmental breast cancer advocacy and credibility in advocating against toxic products in order to reduce the environmental risks associated with breast cancer. Similarly, Karen Miller (interview, December 2, 2010) claims that National Breast Cancer Coalition would not take money from pharmaceutical companies because it might undermine the organization’s ability to run programs like their Crush and Flush Campaign. Funding represents an important element in the contestation of the mainstream and warrants further research.

Collaboration between environmental and mainstream breast cancer organizations also requires further research. There is a varied level of collaboration with the MBCM within the EBCM. Some organizations are opposed to collaborating with mainstream breast cancer organizations because they do not agree with mainstream involvement with corporate sponsors or the general focus of their advocacy. Breast Cancer Action’s Think Before You Pink calls out organizations like Susan G. Komen for the Cure and their collaboration with sponsors on pink (Think Before You Pink 2011b). Also, Karen Miller (interview, December 2, 2010) of National Breast Cancer Coalition argues that “most of the large organizations are looking heavily...the majority of their money and their

interest...is on treatment and screening” and this direction is not in line with National Breast Cancer Coalition’s advocacy on prevention through elimination of environmental toxins. Other environmental organizations like Silent Spring Institute (2007) are more willing to partner with mainstream groups in their advocacy programs. Research on the dynamic within EBCM towards collaboration with MBCM would lend to the understanding of the variation of the EBCM narrative and how that influences their advocacy.

The geographic clustering of EBCM organizations also requires future research. Most EBCM organizations are located in the Northeast and California. While some research facilities that the EBCM collaborates with were located in areas other than those specified above, the location of the actual organizations are found in the Northeast and California. Part of the reason for the geographic clustering stems from higher rates of breast cancer found in New England and California. Organizations like National Breast Cancer Coalition and Silent Spring Institute started when women realized that there was a high percentage of women getting breast cancer. Although these particular geographic areas have seen significant effects of toxic chemicals in local communities, environmental advocacy has implications for chemicals used nationwide. Future research needs to examine the social and political reasons for the geographic clustering and how it affects the EBCM’s national advocacy. Research should also include an analysis of environmental breast cancer advocacy in areas with no such breast cancer organizations, like the Midwest and the South. There are also

nuances in the narratives in Eastern verses Western organizations.

Organizations located in California, like the Breast Cancer Fund focus more on ethnic and socioeconomic factors linked to breast cancer risk than organizations located in New England, like National Breast Cancer Coalition. Understanding the nuances in the regional narratives found within the EBCM is an important area for future research. Analyzing the nuances in regional narratives will illustrate how regional politics and social understandings breast cancer influence the larger environmental breast cancer movement. The geographic nuances in the environmental breast cancer illness narrative provide a dynamic look at how local social networks influence illness narratives on a national scale.

### *6.2: Final Conclusions*

After collecting and analyzing the research used in the study, three main conclusions have been formed. The first conclusion is that the EBCM's contestation of the dominant breast cancer narrative represents a wider pattern of the use of alternative narratives use to contest dominant illness narratives. In terms of contested illness, the EBCM represents the way alternative narratives can challenge dominant illness narratives through the public paradigm (Brown 2007:181). The precautionary principle and citizen science provide advocates for alternative narratives with methods to reconstruct forms of legitimacy used by dominant narratives to assert their dominance over illness narratives. Michael

Foucault “argued that expert knowledge about human ‘normality’ and ‘abnormality,’ which is not objective or naturally given, is the principal form of power in modern societies” (Conrad and Barker 2010:S69). Dominant narratives assert their dominance in society by undermining the legitimacy of other narratives. The public paradigm offers a way for alternate narratives to assert their legitimacy in order to contest the dominant narrative and the power it has over the illness narrative. Despite the contestation of social knowledge by mainstream narratives, science operates on “strong objectivity” (Harding 1991:142) which means understanding that the fact that “all knowledge, including scientific knowledge, is rooted in social constructs does not negate the idea of objectivity in the sense of fairness, justice, and intellectual honesty” (Wing 2000:40). The public paradigm not only represents a way for alternate illness narratives to gain legitimacy, but it also enables the inclusion of social transparency and equality in scientific research.

Drawing from and collaborating with advocacy groups focused on other contested illnesses (Karen Miller, interview, December 2, 2010; Brown 2007:278) offers another way for EBCM activists to contest dominant narratives and build a network of scientific credibility to establish the environmental links to illnesses. Advocates for contested illnesses argue that causation is a part of a wider framework of social and environmental factors. Different contested illnesses find common ground in the complex framework of causation. This illustrates how social and environmental factors contribute to the causation of multiple illnesses.

Advocates for contested illnesses like cancer and asthma (Lockwood et al 2009:3) argue that illness fits into a larger framework of environmental causation. In terms of how breast cancer risk fits in to general cancer risk, Nancy Evans argues that “It may be time to stop staying it’s 1 in 8 or 1 in 9 and talk about breast cancer in the larger context of cancer. The risk of which is now 1 in 3 for women and 1 in 2 for men.” (The Collaborative of Health and the Environment 2006).

Alternate illness narratives argue that contested illnesses not only fit into a larger environmental context, but they also fit into a social context in which dominant illness narratives vie for control of illness narratives. The dominant illness narrative’s “legitimization and reproduction of power” (Button 2006:432) within the dominant hegemony creates a struggle for alternate narratives to have their knowledge of illness causation viewed as valid by scientific and legislative communities. While the “underlying cultural logic of mainstream narratives tends to reinforce the hegemonic forces of our society,” (Button 2006:438) alternative narratives collaborate through the public paradigm to not only challenge mainstream narratives, but also the hegemony that contributes to the social and power inequalities that keep communities at risk for illness.

The EBCM’s adoption of the public paradigm also represents how the challenge to dominant science by alternative narratives, through community knowledge, can reconstruct credibility traditionally placed on expert knowledge (Button 2010:13). The public paradigm represents a way for lay activists to

challenge the authority of expert knowledge in defining social problems.

Embodied health movements like the EBCM are an important example of lay contestation of the importance placed on expert knowledge. The contestations of expert knowledge in embodied health movements “serve as a critical counter-authority aimed at democratizing and reshaping social policy and regulation in a way that transforms the socioeconomic and political conditions that underline unequal distributions of health and disease in the United States” (Morello-Frosch et al 2006:267). Embodied health movements demonstrate how lay knowledge can be legitimized through lay collaboration with the scientific and legislative communities. Equality in research and decisions offers the lay community a way to add to scientific knowledge and how it is used. Since expert knowledge focuses on the technical aspects of a social problem, lay knowledge brings a community perspective into the research and decision making process because lay knowledge represents how communities view a problem and possible solutions.

Connected with the public paradigm, community-based participatory research (CBPR) offers the lay community a way to reconstruct the power placed on expert knowledge by putting lay knowledge into science and legislation. The National Breast Cancer Coalition’s Project LEAD (National Breast Cancer Coalition 2011g) and The Long Island Breast Cancer Study Project are both examples of how CBPR’s reframe expert knowledge to include lay knowledge. Although value is placed on expert knowledge, lay communities do not always

think expert knowledge is adequately addressing their problem. CBPR offers a way for communities to reshape scientific knowledge to incorporate lay perspectives (Baralt and McCormick 2010:1669). Lay perspectives reflect community knowledge and experience. Through CBPR, lay activists are able to have a say in research design and their involvement in the research process. The collaboration in research decisions and the goal of the research process aids in “establishing mutual trust and cooperation between advocates and scientists” (Baralt and McCormick 2010:1669-1770; Baker et al. 1999).

Educating the community about the science related to the health issue they seek to address is another way CBPR contests expert knowledge (Baralt and McCormick 2010:1770). By educating the community, CBPR aids in the equality of power between lay and expert because the lay community is armed with the biomedical knowledge to include lay knowledge in the research process. Lay “experiences” and “perspectives” on the issue are incorporated into a biomedical framework that aids in their collaboration with the science community (Becker 1997). Once situated in a biomedical framework, lay narratives are “empowering” because they “represent power and agency” that lay activists have within the scientific process (Button 2006:432). Marisa Walker states that “We try to propose solutions for people before they go to that place of being very fearful which is a totally natural response to it. In that sense empowerment is very important. We are trying to grow the understanding...” of biomedical knowledge linked to breast cancer. CBPR exists within the larger context of the public

paradigm in that it shifts power from expert communities to the general public. CBPR offers lay activists a way to reconstruct (Bash 1995:11; Benford and Hunt 2003:161) traditional forms of knowledge within the larger public paradigm by including lay knowledge alongside traditional forms of knowledge. Lay activists can incorporate their knowledge to inform legislation and science to create solutions that meet their needs rather than the interest of the dominant narrative.

Lastly, the public paradigm found in contested illness narratives, like breast cancer, illustrates how paradigm shifts represent a pendulum of social change. Due to environmental breast cancer advocacy, the scientific and legislative community is increasingly incorporating the public paradigm into their respective fields. As a part of the public paradigm, environmental justice advocates to empower lay communities with knowledge and decision making power related to environmental issues and as a part of the public paradigm it “faces efforts to delegitimize it” (Capek 2000:357). Environmental justice, including the EBCM, has helped to build the credibility of the public paradigm among scientific and legislative communities. Environmental justice has helped to gain this credibility through successful measures to “redirect federal research dollars to support new scientific avenues of research that more purposefully address how social context and economic inequalities impact public health” (Morello-Frosch et al 2006:266; Morello-Frosch et al. 2002). The role of environmental justice as a part of the public paradigm represents “institutional shifts in medical science and public health [that] have helped nurture a new

cadre of scientists who support activist efforts to democratize knowledge production through their roles as program officers in federal funding agencies and as researchers working collaboratively with EHM organizations to address persistent challenges in disease treatment and prevention” (Morello-Frosch 2006:266). While the public paradigm is gaining momentum in scientific and political spheres, it is still vulnerable to delegitimization by mainstream illness narratives (Capek 2000:357).

Through continued advocacy, social movements like the EBCM are able to tip the scales of social change towards their view of a solution to a social problem. However, activists must realize that the pendulum of social change depends on persistent advocacy. Karen Miller’s (interview, December 2, 2010) warning represents the understanding of the pendulum of social change by social activists:

My caution too is that at any moment for any reason when our heads our turned on something else everything can go back. The pendulum can swing and take us back ten years. That’s what drives the activists and the advocate community. You are going to find that everybody you are going to talk to is going to be unbelievably articulate, passionate and totally committed. This is definitely something that is driven by your heart and not your head. If you were doing it from your head, you would not be doing it.

The combination of desire and an immense knowledge of the social problem drives the advocacy community to create and maintain social change. The inclusion of both emotion and logic contests expert knowledge that emphasizes

the lens of logic. However, the combination of passion and knowledge are essential in maintaining the balance of the pendulum of social change.

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## APPENDIX

A1: Tamoxifen is used as a treatment for early and late stage breast cancer (National Cancer Institute at the National Institutes of Health 2008).

A2: Phone interviews were scheduled via e-mail and phone with individuals from Breast Cancer Action ([www.bcaction.org](http://www.bcaction.org)), National Breast Cancer Coalition ([www.breastcancerdeadline2020.org](http://www.breastcancerdeadline2020.org)) and Breast Cancer Fund ([www.breastcancerfund.org](http://www.breastcancerfund.org)). Zero Breast Cancer ([www.zerobreastcancer.org](http://www.zerobreastcancer.org)) and Silent Spring Institute ([www.silentspring.org](http://www.silentspring.org)) were also contacted for interviews via phone but did not contribute to the research.

A3: Exposure to bisphenol A (BPA) has been linked to “breast and prostate cancer, and infertility (Environmental Working Group 2012).

A4: October was designated by Zenica (now AstraZeneca) to promote awareness of breast cancer and prevention methods like mammography (National Breast Cancer Awareness Month 2012). Organizations like Komen for the Cure spend the month of October generating awareness and fundraising efforts for breast cancer research.

A5: The first chapter of the San Francisco Precautionary Principle Resolution mandates the use of the precautionary principle in San Francisco and requires safer alternatives for products purchased for San Francisco city and county (Taking Precaution.org 2004).

## VITA

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