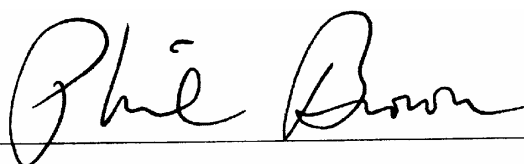


Women of Color, Breast Cancer and the Environment

Brionna Hair
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 Date 5/10/06

Phil Brown, Ph.D.
Professor of Sociology and Environmental Studies
Brown University
Box 1916
Providence RI 02912

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Introduction

There are several factors that may lead to the development of breast cancer in women, including exposure to environmental toxins. Several scientific studies that have examined the link between environmental toxins and breast cancer were the result of the efforts of breast cancer activists. The growing gap in African American mortality rates and the narrowing difference between African American and white breast cancer incidence have stimulated more attention to the possibility of environmental causation, leading environmental justice groups to organize around breast cancer. Considering this and the fact that people of color are disproportionately exposed to environmental toxins, it is beneficial to study the knowledge and attitudes of women involved in women of color breast cancer organizations and women involved in environmental justice organizations regarding the link between breast cancer and the environment in order to discover implications for the future of connecting breast cancer advocacy and environmental justice.

Data for analysis came from a combination of lectures on the subject, grant applications, organizational materials and in-depth interviews. A total of 18 women were interviewed either in-person or by phone after their informed consent was obtained. Twelve of the interviewees were African-American, three were Hispanic, one was Native American, one was African-American and Chinese, and one was African-American and Caucasian. Asian women were not targeted for recruitment because of a lack of breast cancer or environmental justice groups consisting of Asian women.

The participants were recruited by solicitations during breast cancer events, contact with leaders of breast cancer groups and environmental justice groups based on

information provided by websites and referrals from interviewees and other contacts. 12 women were classified as breast cancer activists and 6 women were classified as environmental justice activists, although two of the women were involved in both types of groups. The interview for half of one of the breast cancer interviewees was lost during transcribing. Her responses, based on written notes, were included in the data where appropriate.

The interviews were taped, transcribed and coded. The codes were developed prior to the interviews, and additional ones were developed during the analysis. The questionnaires and code list are provided as appendices.

It was hypothesized that women who were aware of the possible environmental link to breast cancer would be more inclined to have attitudes conducive to the partnering of breast cancer and environmental justice activism. It was also expected that concerns other than ones regarding the environment would be brought up as a reason for the health disparity in breast cancer mortality. The results supported these hypotheses.

This paper first reviews breast cancer epidemiology, details the racial differences in breast cancer incidence and mortality and summarizes the current thinking on the environmental causation of breast cancer. Next, a brief history of the breast cancer activism and the environmental breast cancer movement is provided. The following section gives a brief history of the environmental justice movement and points of comparison between the breast cancer and environmental justice movements. The final section analyzes the transcripts of the women of color who were interviewed for this paper and addresses the possibility of a future linkage between breast cancer activism and environmental justice activism.

Breast Cancer Epidemiology, Racial Differences, and the Environmental Causation of Breast Cancer

This section provides an overview of the epidemiology of breast cancer, the current thinking on racial differences in breast cancer incidence and mortality, and a review of literature researching the environmental causation of breast cancer.

Epidemiology of Breast Cancer and Racial Differences

Breast cancer is the most diagnosed cancer in women and the second leading cause of death from cancer in women. It can be detected from mammograms, clinical breast exams, and self breast exams. Breast cancer develops when a malignant tumor forms from breast cells. There are several types of breast cancer, including ductal carcinoma in situ where the cancerous cells have not spread beyond the ducts; infiltrating ductal carcinoma, the most common form of breast cancer, in which the cancerous cells spread beyond the breast ducts; and infiltrating lobular carcinoma, where the cancerous cells spread beyond the breast milk glands. There are four stages of breast cancer, determined by how far the cancer has spread from its place of origin. The further the cancer has spread from the breast, the more difficult it is to treat. Treatment includes surgery, radiation, chemotherapy and hormone therapy. (1)

Though the cause of breast cancer has not yet been determined, there are many risk factors associated with the disease. Female gender, older age, family and personal history of breast cancer, older age at menopause, and young age at first menstruation are all well-established risk factors for developing breast cancer. Also, being a white woman, never bearing children, use of hormone replacement therapy (which is most often a combination of estrogen and progesterone), and use of birth control pills are associated

with breast cancer. Genetic mutation in the BRCA1, BRCA2 and, to a lesser extent, other genes, can also lead to the disease. Other risk factors that may be associated with breast cancer include obesity, lack of exercise, and alcohol intake. (1)

Women have a one in seven lifetime risk of contracting the disease and a one in thirty-three risk of dying from it. However, the incidence and mortality rates for breast cancer vary widely among different racial and ethnic groups. According to data from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program, the average annual breast cancer incidence rates from 1998 to 2002 were approximately 141 per 100,000 women for white women, 119 for black women, 97 for Asian/Pacific Islanders, 90 for Hispanic women, and 55 for American Indians/Alaska Natives. Although white women have the highest breast cancer incidence overall, it has been shown that black women aged 30 to 39 have a higher incidence than white women of the same age group.(2) The average mortality rates were highest for black women at 35 per 100,000 women. The mortality rate is 26 per 100,000 women for white women, 17 for Hispanic women, 14 for American Indian/Alaska Natives, and 13 for Asian/Pacific Islanders. (3)

There are differences in the type of cancer with which women of different racial groups are diagnosed. Several studies have found that minority groups in general and black women in particular are more likely to have breast cancer diagnosed as advanced-stage. Also, black women are more likely than white women to have larger tumors and to have breast cancer cells that are estrogen receptor-negative (4-6). All of these factors affect breast cancer treatment and lead to poorer outcome.

There have been many studies that have addressed these disparities in breast cancer incidence and mortality. Factors studied to explain the differences in breast cancer range from examining differences in the traditional risk factors(7), to looking at access to healthcare (8,9), to studying the molecular biology of breast cancer (4-6). Although these factors account for some of the disparity in breast cancer mortality between black and white women, they do not explain all of it. For example, when examining breast cancer survival among women treated in U.S. military healthcare facilities, it was found that black women in the study population have a better survival rate than black women in the general population, but a disparity still existed between white and black survival in the study population (8). This suggests that access to healthcare does have an effect on the disparity in mortality rates, but other factors must play a role. Similarly, studies have found that after controlling for factors such as obesity, breast cancer grade, stage at diagnosis, estrogen receptor-status, reproductive status, and menopausal status some, but not all, of the disparity in mortality rates were explained (5,6,7,10)

Only one of the articles reviewed for this paper addressed a possible link between the environmental surroundings of black women and breast cancer disparities(11), reflecting the small but growing attention the topic is receiving. According to the article, studies have found that breast cancer mortality differs by geography among African-American women and that African-American women's different genetic susceptibility to breast cancer, in combination with higher environmental exposure, makes them more sensitive to environmental carcinogens.(11,12) Given the plausibility of an environmental link to breast cancer incidence and mortality and that communities of

color are often more exposed to environmental contaminants, hopefully researchers will gradually increase the study of a link between environmental contaminants and breast cancer incidence and mortality among racial groups, especially in African-American women. The next section reviews current findings on the link between environmental contaminants and breast cancer.

Environmental Causation of Breast Cancer

In Cape Cod, Massachusetts, between 1982 and 1994, breast cancer incidence was 20% higher than the disease incidence for the rest of the state. Differences in risk factors between women with breast cancer from the Cape and other women did not completely explain the elevated incidence of disease than other women. Why, then, this increased rate of breast cancer incidence? Some believed the culprit to be environmentally linked. Specifically, it was hypothesized that consumption of contaminated water and the use of pesticides caused the difference. These two factors were the focus of the Cape Cod Breast Cancer and Environment Study (Cape Cod Study). The study found that women who resided longer in Cape Cod than others had a higher breast cancer risk, suggesting that environmental contamination might in fact be a cause for the higher disease incidence. (13,14)

Occurrences such as the elevated breast cancer risk of women in Cape Cod suggest that environmental contamination may be causally linked to breast cancer. Exposure to environmental toxins usually comes from exposure to polluted land, air, or water. The environmental agents targeted for breast cancer research come from these three sources, but exposure to ionizing radiation, which largely comes from x-rays is also

linked to disease incidence. The rest of this section will focus on exposure to chemical contaminants found in the land, air and water.

To assess the validity of study results, it is helpful to understand the scientific foundation for environmental causation hypotheses. It is posited that chemical substances can cause cancer by both genetically altering cells, which affects cell growth and the cell's ability to control tumors, and acting like the hormone estrogen, which, combined with progesterone, is a risk factor for breast cancer (15). It is also believed that environmental contaminants lead to breast cancer by cumulative exposures to different chemicals at different, critical periods of time of a women's life (childhood, adolescence and time to first pregnancy) (15-17). Based on current literature, this discussion will categorize environmental contaminants into ones that act like estrogen and ones that genetically alter cells, although there is overlap between the categories. It has been posited that chemicals that genetically alter cells lead them to be precancerous, while these precancerous cells can be changed into cancerous ones by hormonal metabolites (16).

Estrogen exposure is considered by some to be a risk factor for breast cancer. Extended exposure to estrogen, which can come from beginning menstruation before age 12, reaching menopause after the age 55, late or lack of child-bearing, lack of breast-feeding, and taking hormone replacement therapy, increases the risk of contracting breast cancer (17). There are various estrogen mimicking substances in the environment to which people are exposed. These chemicals are known as endocrine disrupters. Endocrine disrupters include a wide array of chemicals and are found in many different

products. They include pesticides (some of which are made from DDT), PCBs, organic solvents, dioxin, phthalates, and metals.

There have been many studies that have examined a link between breast cancer incidence and the contaminants DDE (a metabolite of DDT) and PCB. These chemicals are the most prevalent of a group of chemicals called organochlorines, and they are used in or are products of pesticides and industrial products. DDE and PCBs are also the most prevalent organochlorine residues found in human tissue. (16) Studies that have examined an association between these chemicals and breast cancer incidence have produced mixed results, many showing no association (16,18,19), a few finding a positive association. It has also been found that African-Americans have higher levels of organochlorines, sometimes as much as twice as high, in their bodies. Further, studies have shown a decline in the amount of these contaminants in white women, but not in African-American women. Two studies that have addressed DDE and PCB levels in African-American women have had mixed results. One found a positive association with exposure to these chemicals, but the findings were not statistically significant; the other found a significant increase in breast cancer risk with higher exposure. (11)

There has been more success in finding a positive association between organic solvents and breast cancer. Occupational exposure from factories that manufacture substances such as glue and paint, dry cleaners, and metal degreasing is the most common route of exposure to organic solvents. Various studies, employing different study designs found a correlation between organic solvents and breast cancer incidence, although confounding factors are also present in these studies. (16) One study found that

in New Jersey, occupational exposure led to increased risk of death in African-American women, but not in white women.(11)

Dioxin, one of the most prevalent chemical toxins, is released when chlorinated compounds are incinerated. Exposure to dioxin comes mostly from consumption of animals that have consumed the chemical from grass contaminated with diesel exhaust or dust from incineration. A couple of studies have found an increased risk of breast cancer from exposure to dioxin. (17)

Other chemicals are believed to cause cancer by genetically altering cells, predisposing them to be cancerous. These chemicals include PAHs, 1-3 butadiene, and aromatic amines. These chemicals are produced by internal combustion of engines, petroleum refineries, tobacco smoke, plastic and chemical industries, and grilled meats. Much evidence for the carcinogenic effect of these substances come from animals. (17)

Given the lack of conclusive evidence, why do breast cancer activists and some researchers continue to pursue the environmental causation of breast cancer? The fact that immigrants from countries with low breast cancer incidence to Western countries soon develop breast cancer at rates similar to citizens of these countries is often cited as evidence for the environmental link to breast cancer (20). Further, the biological plausibility of environmental contaminants being associated to breast cancer incidence remains.

Also, several explanations, focusing on the study design of previous studies, have been posited as reasons for the lack of an association found between organochlorines and breast cancer incidence. One possible explanation is that previous studies focus on current levels of the chemicals found in women's serum instead of past exposure,

meaning that these studies may have misclassified some women as not being exposed when they could have been in the past. Another related explanation is that the effect of organochlorines on breast cancer may occur at certain periods in a women's life that these studies did not focus on, including childhood, adolescence, or time to first pregnancy. (16) The basis for this argument is that at these times, breast cells are rapidly developing, making them vulnerable. Certain risk factors for breast cancer, such as early menstruation, no lactation, and late menopause extend the time of this vulnerability. During these times of vulnerability, breast cells could be exposed to estradiol, which could then lead to breast cancer. (15) Also, some of the studies used women who had benign breast disease, a risk factor for breast cancer, as controls which could have diluted the effect (16).

Considering the complications that arise when attempting to study the effect of an environmental agent on disease, it is reasonable to expect that results of research emanating from study designs with limitations will not be conclusive. Research using study designs that will be able to actually examine the cause-effect relationship of environmental contaminants on breast cancer development will be better able to elucidate an association if there is one. Until there is proof that environmental contaminants do not cause, breast cancer activists will advocate for further research on the issue.

The few studies that have addressed breast cancer risk and the environment in African-American women suggest that there is a possibility that the difference in breast cancer mortality may be due to environmental exposures. Perhaps with increased awareness of this link, women of color breast cancer activists and environmental justice activists will advocate for more resources to be put into researching the topic. The next

section outlines breast cancer activism in the US and describes how a movement addressing the environmental causation of breast cancer began. This movement is used in this paper as the template for a possible similar movement among women of color to address breast cancer as it relates to their concerns.

The Environmental Breast Cancer Movement

The history of the environmental breast cancer movement must be understood in the context of the history of breast cancer activism. This section consists of a brief history of breast cancer activism followed by a section on the environmental breast cancer movement.

Brief History of Breast Cancer Activism

Breast cancer activism is rooted in the personal empowerment of women, which has led them to challenge traditional scientific paradigms that have not produced a satisfactory response to breast cancer. Impassioned by their experience with cancer and taking cues from other movements, breast cancer activism evolved from support groups that provided a space for breast cancer patients to share what they were going through to a sophisticated political movement that managed to turn breast cancer into a widely recognized disease that is on the national radar.

In some respects, the history of breast cancer activism can be traced to local breast cancer groups that were formed by women mostly in the 1970s and 1980s to provide support for women with breast cancer. Until the 1970s, the use of radical mastectomy, a highly disfiguring operation, was common in the US – even after evidence showed that radical mastectomies were not more likely to save a woman from dying of breast cancer than other, less disfiguring, surgeries (21). The earliest of these groups, the Reach to Recovery program was an apolitical group formed to provide support for women who had undergone radical mastectomies. The group was adopted by the American Cancer Society (ACS), which controlled information disseminated by the group and did not want the program to work as a forum for women to share their

experiences with each other, because it did not want women to view mastectomy as a permanent handicap. In the 1970s, the authority of the ACS was challenged by a woman diagnosed with breast cancer, Rose Kushner. She eventually founded the Breast Cancer Advisory Center, an organization that provided people with information about breast cancer. Soon after, many post-mastectomy support groups formed with the purpose of providing a space for women to support each other. (22) These groups functioned primarily to support women through the shared experience of living with breast cancer. Their role in politics was not immediate, but evolved, coinciding with an environment that was increasingly conducive to what was to become breast cancer activism.

The feminist movement of the 1960s helped set the stage for the breast cancer movement by empowering women to challenge traditional authority as evidenced by the Women's Health Movement. This movement consisted of women in politics and the medical field who brought attention to and proposed solutions for remedying injustices experienced by women in biomedical research and medical settings (23). The political arm of this movement, the Congressional Caucus for Women's Issues, formed a women's health agenda, pressured government agencies for policy change, and, very importantly, brought a lot of media attention to women's health issues (23, 24). This movement helped set the stage for breast cancer activism by bringing to the forefront women's health. The potential for activism was also enhanced by the famous women Betty Ford, Happy Rockefeller, and Shirley Temple Black, revealing that they had the disease, the increased awareness of mammography screening for early detection of the disease, and coverage in popular magazines. Breast cancer was beginning to become a women's problem, not just a breast cancer victim problem. (23)

In the 1970s and the 1980s, in the wake of feminist movement, members of early breast cancer support groups became aware that political action was necessary to address issues such as breast cancer research funding and access to care (22). The women involved in these organizations were young baby boomers with experiences and resources that could be honed for political advocacy (24). Examples of early groups include Y-Me, the National Alliance of Breast Cancer Organizations (NABCO), the Susan G. Komen Breast Cancer Foundation, and the Massachusetts-centered Women's Community Cancer Project (WCCP), among others. These groups modeled their own activism after AIDS activism and paved the way for breast cancer activism. They stressed the idea of patient advocacy, which supports the idea that women should be informed about breast cancer and treatment options and be part of the decision-making process (24).

Though these early groups worked to affect change, it was not until the 1990s that breast cancer activism exploded onto the national scene. It was then that breast cancer organizations were successful at increasing research funding, identifying policy changes relevant to breast cancer, and increasing patients' roles in their own healthcare (23). Advocates focused on the need to find ways to prevent and cure breast cancer, setting the stage for the inclusion of breast cancer activists in deciding the research agenda (23).

Breast cancer advocates were successful at both the state and national level of government. Activists pushed for changes in access to screening and information on treatment and made strides in how insurance companies managed breast cancer related healthcare at the state level: by the early 1990s, 42 states and the District of Columbia required insurance coverage of mammograms. Successful campaigns in Vermont and

Massachusetts resulted in those state legislatures giving high importance to the growing incidence of breast cancer and brought about changes in breast cancer screening, provision of information and access to care. In Vermont, breast cancer was declared a national health emergency; in Massachusetts, breast cancer incidence was declared an epidemic and a plan was put in place to address breast cancer education, license mammography facilities, and monitor the disease's incidence in the state. (22)

On the national level, activists targeted federal agencies such as the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the National Cancer Institute (NCI) to change their policies and funding allocation. Their successes include legislation that led to the CDC establishing mammogram screening for low-income women, increased federal funding of breast cancer research for the NIH, NCI and the Department of Defense (DOD), and Medicare coverage of mammography for women over age 39. (22)

An example of a national advocacy group that was very effective beginning in the 1990s is the National Breast Cancer Coalition (NBCC). The coalition, which consisted of groups such as NABCO, Y-ME, and WCCP, was founded in 1991 to promote breast cancer research, improve access to care, and to increase the participation of women with breast cancer in policy and research. By 1994, the coalition had expanded to include member organizations representing every state. NBCC's first political act involved delivering 100,000 letters in support of increased government funds for breast cancer research to the Bush White House. The campaign was successful, generating \$407 million for research from NIH and DOD by 1993, up from less than \$40 million in 1981. (22, 23)

Not only was the NBCC successful in helping to increase funds for breast cancer research, it also brought about the inclusion of breast cancer activist opinions in setting the breast cancer research agenda. At the urging of breast cancer activists, the California Breast Cancer Research Program, which provides grants for breast cancer research, was established. Breast cancer activists are members of peer review panels on equal standing with scientists, and are a part of the grant and funding allocation decision-making process. In 1993, the NBCC urged the then Secretary of Health and Human Services, Donna Shalala, to establish the National Action Plan on Breast Cancer. Both experts from the NIH and breast cancer advocates were included in the planning process (22). This model of participatory research is one of the main goals of the NBCC, ensuring that breast cancer advocates participate in every step on the breast cancer research (22).

Breast cancer activist participation in research is important because it ensures that the concerns they have will be taken into account by the scientific community and that relevant research studies will be designed (25,26). This model of citizen participation involvement is valuable for research in general for these reasons and, as we will see, is a key element in the environmental breast cancer movement.

Breast cancer activism grew out of the shared experiences and concerns of women with breast cancer who met at local support groups. They harnessed their energy and resources to advocate for changes in policy they saw as necessary to find ways to prevent, improve treatment of, and cure breast cancer. Their biggest successes are increased breast cancer awareness, increased funding for research, and the involvement of breast cancer advocates in breast cancer research.

The Environmental Breast Cancer Movement

In the US, the environmental breast cancer movement (EBCM) links breast cancer incidence to environmental factors. It provides an example of how breast cancer activists can shift from focus to achieve the goal of reducing breast cancer incidence. The movement is significant because it consists of lay people and their scientist allies initiating a change in the way breast cancer is researched in their communities. Organizations were established that study the environmental causes of breast cancer and incorporate the opinions of breast cancer advocates into scientific studies. Most research examining the environmental link to breast cancer has been sparked by activists (27). This activist participation challenges the traditional scientific study and treatment of breast cancer by shifting the focus from individual-level prevention and intervention to community-level exposure, and hence community-level prevention. This shift in focus not only challenges scientists to find out more about potential causes of the disease but also attempts to hold accountable corporations whose chemicals are thought be the cause of breast cancer for their actions (26,28).

The EBCM goals are to raise public awareness of environmental causation of breast cancer, to increase research examining the link, to prevent incident cases through policy change, and to increase activist participation in research. The mainstream environmental movement has aided the EBCM by providing a framework that links breast cancer to the environment, especially since the mainstream environmental movement has brought attention to the connection between health and the environment. The EBCM, like the mainstream breast cancer movement, has benefited from both the

feminist movement and its outshoot, the women's health movement. It diverges from the mainstream breast cancer movement, though, not only in its focus on environmental causation, but also in its related criticism of the mainstream movement's emphasis on mammography as prevention (which the EBCM argues is not true prevention) and the heavy corporate involvement in Breast Cancer Awareness Month. It is especially critical of the fact that one corporation, AstraZeneca, which used to produce agro-chemicals, and currently produces Tamoxifen, a leading cancer drug, has control over all materials distributed for the month. Environmental breast cancer activists recognize that the mainstream breast cancer movement is mired in politics and questions what types of research (early detection and treatment versus primary prevention) gets funded. (27-29)

The EBCM also rejects the emphasis the current breast cancer paradigm places on individual responsibility by its promotion of breast self-exams, mammography, and dietary changes. Instead, the movement places responsibility on corporations, the government and the scientific community to prevent the disease from occurring. In an effort to discover the root cause of breast cancer, environmental breast cancer activists have, for the most part, made science central to the movement. They educate themselves, so that they have solid scientific understanding of breast cancer epidemiology and form citizen/science alliances where they collaborate with scientists to research environmental causation. The process of activists arming themselves with scientific knowledge includes scientists teaching lay activists skills that enable them to engage with scientists and serve on review boards. This citizen/science alliance is important, not only because it leads to research that might not otherwise have been conducted, but it also leads to a better understanding of both scientists and activists about each other's roles. (27,28,30)

The characteristics of the EBCM can be seen by examining the efforts of activists in three locales to bring attention to and/or research the environmental causation of breast cancer. The activists in the three locales, Long Island, NY, Massachusetts, and the San Francisco Bay area, have many similarities, but there are also distinctions in how the different groups operate..

Case Study 1: Long Island, NY

Environmental breast cancer activism in Long Island consists of a network of various organizations that are involved in research projects and use geographic information system (GIS), as well as provide services to women with breast cancer. The movement began in the early 1990s, when women noticed a high incidence of breast cancer in the area and so set out to map breast cancer cases. They enlisted the help of local researchers to test their hypothesis that Long Island had a higher incidence of the disease relative to other places. The activists enlisted the involvement of the EPA, the CDC, and the NCI and got funding for the Long Island Breast Cancer Study Project, which examined the environmental cause of breast cancer and was developed with input from breast cancer activists. (22,28)

There were some key features of the Long Island environmental breast cancer activism that made them successful in their efforts to bring attention to their cause. They were able to garner and sustain important ties with politicians, leading to a good relationship with the government. The activists were also able to generate media attention. In addition, the activists were able to eventually to gain the support of environmental organizations and some of the groups focus specifically on environmental causation. (28)

The citizen/science alliance the Long Island activists generated is characteristic of actors of the EBCM. Not only did they spark research into environmental causation, they also are involved in the Congressionally Directed Medical Research Program funded by the Department of Defense (DOD), where lay opinions are taken into account (26). Events that occurred in Long Island also highlight some of the risks associated with their brand of activism. The results of the Long Island Breast Cancer Study Project were inconclusive, finding little to no support for an increased risk of breast cancer incidence from the chemicals that were studied, suggesting that further research should be done. (28)

Case Study 2: Massachusetts

Similar to how the Long Island activists got their start, the EBCM in Massachusetts began with the recognition of a higher breast cancer incidence in Cape Cod. This led to the Massachusetts Breast Cancer Coalition (MBCC) founding the Silent Spring Institute (SSI) in 1994. The SSI uses a citizen/science alliance model to research environmental causation of breast cancer (31). They were able to receive funding from the state to examine the higher levels of breast cancer in Cape Cod. Their research has included use of GIS, a study of pesticide use and drinking water, and, recently, a study of exposure to environmental estrogens. SSI incorporates lay opinion into its research via an advisory committee that includes lay women from MBCC (26). The Institute also educates the public about environmental causation. (28, 31)

The other group in Massachusetts that is part of the EBCM is the Women's Community Cancer Project (WCCP). This group examines breast cancer from a feminist perspective and criticizes the corporate influence on breast cancer. Though critical of the lack of research into the role of environmental toxins in breast cancer development (22), the WCCP does not do research, instead focusing its energy on educating about and organizing around the precautionary principle (28), which places responsibility of proof of the safety of chemicals on the companies that produce them. Similarly, the MBCC educates various actors, including politicians and scientists, about the precautionary principle. The MBCC, which is an affiliate of the National Breast Cancer Coalition, demonstrates how organizations that are part of the EBCM deviate from mainstream breast cancer activism. The MBCC focuses more on environmental causation and the politics of breast cancer by pushing science and raising public awareness of the potential link. (28,32)

Case Study 3: San Francisco Bay Area

Like other actors in the EBCM, activists in the Bay Area were moved to action when they learned that the area had the highest rate of breast cancer in the world. Bay Area activists tend to be more radical and focus more on raising public awareness about environmental causation and the precautionary principle than on conducting their own research. The movement can be divided into three geographical areas: San Francisco, Marin County, and East Bay. (28)

Organizations in San Francisco include the nationally oriented Breast Cancer Action (BCA) and Breast Cancer Fund (BCF), and the locally focused Bayview Hunter's Point Community Advocates. BCA primarily educates and demonstrates to raise public

awareness and builds coalitions with other political organizations; BCF works to make environmental causation the focus of breast cancer research and policy. BCA and BCF pushed for lay participation in cancer research and their involvement, along with the National Breast Cancer Coalition (NBCC), in the California Breast Cancer Research Program became the model for the Department of Defense's citizen participation in breast cancer research. Consistent with their support for the precautionary principle, BCF works with NIEHS and the FDA to get stricter standards for regulated chemicals. (28) BCA was a founding member of the Toxics Link Coalition, a collaboration of breast cancer and environmental groups and operates the Cancer Industry Tour which is based on the idea that there is a cancer industry in which corporations produce carcinogens and government agencies do not protect public health (33). In line with their stance against supporting corporations whose chemical products may cause breast cancer, BCA refuses to accept donations from them, unlike many other breast cancer organizations(34).

The Bayview Hunters Point Community Advocates, concerned with high African-American breast cancer rates, involve a minority perspective in their work and criticize research that does not incorporate race. (28) In the area where these advocates work, breast cancer incidence is twice as high as would be expected and there is a disproportionate burden of toxic waste sites (27).

In Marin County, where breast cancer rates for white women aged 45 to 60 increased 60% from 1991 to 1999 and are 72% higher than in any other urban locale in California (27), two local organizations are active in the movement: Marin County Breast Cancer Watch and Marin County Project. The Marin County Breast Cancer Watch has a citizen/science alliance and has received funding to look at environmental causation. In

East Bay, there is the Women's Cancer Resource Center, which also links breast cancer activism to the environment. (28)

The EBCM was sparked in each of the three locales because of an awareness of higher than usual breast cancer incidence. To address this, these activists focused on the possible environmental links to the disease and armed themselves with scientific knowledge to be able to affect change in what research questions were being studied to ensure that their concerns and ideas would be taken into account for future studies. Because of their efforts, research was conducted that might otherwise never have been.

The EBCM can also provide a blueprint for other breast cancer activists and for environmental justice activists who want to address breast cancer from a racialized perspective. The next section outlines the environmental justice movement and address how the breast cancer and environmental justice movements relate to each other.

Intersection between Breast Cancer Activism and Environmental Justice Activism

This section provides a brief overview of the environmental justice movement, then compares and contrasts it to the breast cancer movement to see how the two movements relate to each other.

Brief Overview of Environmental Justice

Environmental justice is a movement that sprung from the recognition that people of color are disproportionately exposed to a variety of environmental exposures, diminishing their quality of life. The movement consists largely of people of color contesting a variety of issues regarding exposure to contaminants in their neighborhoods. Examples of broad concerns that environmental justice activists have taken up include toxic waste siting in African-American communities, exposure of immigrant farm workers to pesticides, and land and water rights of Native Americans. Environmental justice activists aim to eliminate the injustices experienced by people of color using many different tactics, including ones reminiscent of the civil rights movement.

Environmental justice activists contend that racism, either by design or as a result of institutionalized practices, manifest by inadequate responses to environmental infractions by the government and industry, leads to a higher exposure of people of color to environmental contaminants compared to white people. Reasons cited for this disparity include lower income levels, housing segregation, and lack of political power, all of which are tied in with issues of race, and lead to little participation in environmental decision-making (35,36). In response, environmental justice activists have demanded change in the behaviors of polluting industries and government policies.

The widely accepted beginning of the movement was in Warren County in 1982 where a group of mostly African-American women and children physically blocked trucks from dumping dirt contaminated with PCB into a landfill in the community. This protest was key in bringing race into the thinking about of exposure to environmental contaminants (37,38). Later, in 1987 the United Church of Christ Commission for Racial Justice published a report finding that race was the major predictor of hazardous waste placement, with more than half of African-American and Latino communities living near toxic waste sites (37). In that same year, the term environmental racism was used to define these incidences. By 1990, many environmental justice organizations had formed and in October of 1991, the first National People of Color Environmental Leadership Summit was held in Washington, DC. At the summit, delegates from the US and other countries met to share their experiences and exchange information. Out of this summit came a document, the Principles of Environmental Justice, consisting of 17 principles adopted by environmental justice activists. These principles call for protection from various types of environmental contaminants, the elimination of discrimination in public policy, accountability of the producers of toxins, and community participation at all steps of the decision-making process (39).

There are some defining characteristics of the environmental justice movement, separating them from mainstream environmental activism. These characteristics are based on how the environment is defined, how the inequities fought against are characterized, and the techniques used to affect change. Environmental justice activists define the environment as where people live, work, and pray whereas mainstream environmentalists, who are largely middle-class whites, tend to separate what they

consider the environment from where people have settled. Resulting from this clash in perspectives, environmental justice activists view mainstream environmentalists as not being concerned with the causes of people living in urban areas. This was a source of tension between the two groups, but as the environmental justice movement gained attention, some mainstream environmental groups have become more involved in environmental justice issues (36,37).

Many environmental justice activists characterize their concerns as issues of social justice as opposed to a primarily environmental issue. This reflects the race and class components that are complicit in causing the inequality. In the early stages to the movement, environmental justice activists often appealed to social justice groups for aid (35). Accordingly, many of the techniques used by environmental justice activists are reminiscent of those used by civil rights activists. They include direct confrontation, public protest, petitions, lobbying, and community education (35).

There have been many environmental justice related activities since the Warren County incident. The movement has been successful in garnering attention to its cause and political influence, despite a lack of conclusive evidence about the effects of disproportionate environmental exposure on health due to the difficulty of ascertaining the health consequences of environmental injustice (36). In 1992, the Environmental Protection Agency created an Office of Environmental Justice and in 1994 President Clinton signed an Executive Order directing all federal agencies to ensure their programs concerning health and/or the environment did not disproportionately harm minorities or the poor (40).

One of the challenges of the environmental justice movement is to push for change without solid evidence outlining the health impact of exposure to environmental contaminants. Breast cancer incidence and mortality as a result of environmental exposure provide an example of an issue that could be taken up by environmental justice groups without certainty of a causal relationship. Although breast cancer has not been a high priority of many environmental justice groups, its possible link to environmental contaminants make it a potential target for environmental justice activism.

*Intersections between Environmental Justice Activism and Breast Cancer
Activism*

We have already seen some overlap in breast cancer activism and environmental justice activism through the Bayview Hunters Point Community Advocates group. Another example is a conference put on by the New York-based environmental justice group, West Harlem Environmental Action, titled “Breast Cancer, the Environment and Communities of Color”. The conference gave participants information on the link between environmental toxins and breast cancer and suggestions for how to reduce exposure to these toxins (41). The conference was co-sponsored by another environmental justice organization, For a Better Bronx , and the Silent Spring Institute assisted in its organization(42).

In another important development, there is a study currently underway that links environmental justice to breast cancer advocacy by researching indoor contaminants that may have implications for knowledge of the environmental causation of breast cancer. The study, which employs community-based participatory research, will test for the household exposure of endocrine-disrupting compounds and other indoor pollutants in

Cape Cod, Massachusetts and Richmond, California, a predominately minority area. The study is a collaboration between an environmental justice group, Communities for a Better Environment and researchers from the Silent Spring Institute and Brown University (43).

Collaboration between environmental breast cancer activists and environmental justice activists is not surprising. Not only do the same environmental contaminants that concern environmental justice organizations concern the environmental segment of the breast cancer movement, but the two movements also have similar principles and overlapping tactics. Both groups shift responsibility for disease incidence from the individual to bigger institutional forces and work to eliminate disparities from within this framework. They both aim to rectify social inequalities. Both groups seek changes in the way research is conducted and in what political decisions are made (44). Therefore, to link the environmental breast cancer movement to the goals of achieving environmental justice is a natural connection.

But does the potential for future collaboration hold for activists who are part of the bigger breast cancer movement? The broader breast cancer movement and environmental justice activism also have similar goals and tactics. Activists in the two groups are proponents of community-based participatory research, ensuring activist input in all stages of research and/or policy implementation. Further, both groups have taken to issues of social inequality, pressing for better access to care and targeting outreach to communities of color. Also, both groups work to influence legislation at different levels of government.

These commonalities suggest circumstances suitable for partnership. However, there are some obstacles that would have to be overcome in order to facilitate a linkage between these two movements. One is that mainstream breast cancer activists have tended to focus on improving detection and treatment for the disease and finding a cure. The prevention of breast cancer has not been a major target of their organizing activities. An environmental justice framework would address the root cause of the disease. A collaboration between the two groups would have to find a way to reconcile these different goals.

Also, organizations within the broader breast cancer movement frequently accept donations from corporations members of the environmental breast cancer movement feel are part of the cancer industry that profits from breast cancer and may make products whose manufacture may be causal in the disease. Environmental justice activists would demand that these corporations discontinue their potentially harmful operations and compensate those affected.

Another consideration to take into account is do members of both groups feel that an environmental link to breast cancer is a valid social justice issue that can be eliminated with activism. In order for a collaboration to take place, the two movements must feel that there is a concern that is of interest to both of their causes to work on.

The next section explores these issues by analyzing interviews with women of color who are active in either breast cancer organizations, environmental justice organizations, or both.

Results: Implications for Linking Breast Cancer and Environmental Justice Activism: The Knowledge and Attitudes of Women of Color

This section will report the findings from interviews with 18 women of color who are involved in either breast cancer activism or environmental justice activism and will discuss what the results mean for the future of linking these two movements. To determine whether a joint movement is feasible, the interviewees' responses were assessed using four categories: belief in environmental causation of breast cancer, approach to activism, view of environmental justice and/or breast cancer activism, and belief about the environmental causation of the difference in mortality from breast cancer of women of color.

Belief in Environmental Causation of Breast Cancer

One component necessary to link breast cancer activism and environmental justice activism is the belief by actors in both movements that environmental contaminants are causal in breast cancer. The majority of the breast cancer activists and all of the environmental justice activists believed that there were environmental agents that could be linked to breast cancer incidence. Interviewees mentioned agents linked to disease incidence, including air pollutants, consumer products such as deodorants, make-up, and cleaning products, environmental estrogen mimickers, radiation, and pesticides.

Corresponding with their beliefs about environmental contaminants leading to breast cancer, seven of the twelve breast cancer activists and four of the six environmental justice activists had made changes in their personal lives to avoid unnecessary exposure. The most common behavior was the consumption of organic

foods to avoid pesticides. Other changes included not using certain deodorants or cosmetic products and only using environmentally safe household products.

Another marker of the activists' belief in the possible environmental causation of breast cancer was their thoughts on the appropriate focus for future research. Most of the women thought that there should be an increased focus on studying the link between the environment and breast cancer. Some conveyed disappointment with the way current breast cancer research is going, especially with the concentration on genetic research. One young activist expressed her concern:

I think that increasingly, they put a lot of attention on the genetic basis for breast cancer and that really scares me because it really sort of deflects people's attention from a lot of the bigger environmental issues...

Many of the environmental justice activists believed that more research should focus on the prevention of breast cancer, a key goal of the environmental breast cancer movement. It was also important to concentrate on the cumulative effect of the variety of exposures people experience, instead of looking at chemicals in isolation. According to a woman who was both an environmental justice and breast cancer activist:

[We] don't think all the right questions are always being asked, because we've spent billions of dollars on research up to this point and we have slightly better treatments, but we don't have a cure, and we're also not dealing with true prevention, which is getting rid of things that cause breast cancer in the first place.

Although the majority of the interviewees believed that there could be a link between the environment and breast cancer, there were a few breast cancer activists who were skeptical. One breast cancer activist emphasized that there was no solid evidence linking environmental contaminants to breast cancer. Another concern of both groups of

activists was frustration with the findings of research regarding environmental agents and breast cancer that later studies failed to confirm, as noted by a health activist from NY:

I did look at certain deodorants that had aluminum. I would ... try to avoid them, but then I know there were other studies that said that hasn't been really proven, like they'll disprove that... [The] weird thing about it, is that you know, you may have evidence, okay this works, and people have used this product for a while and then something comes out and says that it doesn't work and then ... people stop using it and you know years down the line, it comes back again.

Other breast cancer activists also expressed irritation with information they considered to be untrue, that foods, such as broccoli and caffeine, and consumer products, such as lipsticks, were linked with breast cancer. Accordingly, one breast cancer activist thought that public awareness of a link should only be raised with strong scientific certainty.

Another breast cancer activist was unconvinced that anything could be done to avoid environmental contaminants in order to reduce breast cancer incidence:

I don't really believe that there is a cure, and if there is a cure, it's not going to do any darn good if we gotta keep, like I said, breathing the same air, and drinking the same water, and keep reinfecting ourselves with the same thing.

Some breast cancer and environmental justice activists were not proactive in making changes in their personal lives to avoid exposure to environmental contaminants, even though they believed the products could be linked to breast cancer. In particular, many still used cosmetic products, despite concern that they could cause breast cancer.

Overall, the activists believe that there could be a link between the environment and breast cancer. This is auspicious for a potential collaboration between breast cancer activism and environmental justice activism. However, some issues did come up that could impede a partnership. The lack of strong, solid evidence demonstrating a link between breast cancer and the environment makes some of the breast cancer activists

skeptical, probably rendering them cautious in joining a movement focused on environmental causation. Also, that all of the activists who believed there was a link between the environment and breast cancer did not change their behavior to avoid exposure demonstrates that accepting an idea as true does not necessarily lead to action. Further, some of the interviewees thought that breast cancer research was on the right track, but there should be more emphasis on genetics and on better methods of detection and/or screening. These foci are oriented more to treatment and cure than to prevention.

Approach to Activism

In order for two movements to converge, there must be some compatibility in their approach to affecting change. As addressed in the previous chapters, some important traits and goals of breast cancer activism are activist participation in research, influencing legislation, and social equality. Some important elements of the environmental justice movement are adherence to the precautionary principle, emphasis on eliminating disparities, and influencing legislation. The environmental breast cancer movement also presses for use of the precautionary principle and influence of legislation. All of the interviewees' approaches to activism were assessed using these elements as guidelines as well as evaluating their various organizations' priorities.

With regard to approach to activism, the transcripts were analyzed for interviewees' perceptions of their organizations' activism and for the interviewees' individual perspectives on the matter. Markers of approach to activism from individual perspectives include views on activist involvement in research, the precautionary principle, and outreach to women and communities of color.

The majority of the organizations of the breast cancer interviewees' priorities lay in early detection and access to care for underserved communities. These organizations stress the importance of education about breast self-examinations and mammography. The organization of one of the activists was focused on identifying and addressing health disparities in general. Only one of the breast cancer activists was involved in a group whose main goal was to "eliminate the environmental causes of breast cancer". Two activists mentioned they worked on influencing legislation: one focused on environmental issues, while the other worked to pass legislation to increase access to mammography and to keep breast cancer funding separate from other cancer funding.

The priorities of the organizations of the environmental justice activists included creating sustainable development projects for the surrounding community, serving as environmental watchdogs, being advocates for the community, community organizing, influencing public policy, and dealing with issues of social justice. Most of the organizations focused largely on asthma. Two of the organizations of the activists interviewed had previously worked on a conference discussing the link between breast cancer, the environment, and women of color. However, only one of the three interviewees who worked with these organizations knew about the conference. One activist said their organization would respond to community concerns about breast cancer and the environment, but the interest would have to come from the community. Taking up issues of community concern is a common characteristic of environmental justice activism.

The breast cancer activists' organizations were largely concerned with access to healthcare issues without much focus on environmental concerns. The priorities of the

environmental justice groups were also centered on increasing quality of life issues in their communities. The issue of breast cancer was not high on most of the environmental justice organizations' priorities. Although both groups are concerned with social justice issues, their activities had a different focuses. However, there is overlap in their approach to activism in general.

Both groups of activists held activist involvement in research in high regard. The majority of the breast cancer activists interviewed believed that activist opinion should be taken into account when it comes to breast cancer research. They cited reasons such as experience with the disease made them both knowledgeable and important stakeholders. The opinion of this breast cancer activist was representative of most of the interviewees:

I think a lot of times the grassroots individuals are usually individuals who are survivors ... they've been on the frontline. I think always listen[ing] to someone who's been on the frontline makes sense. They put up the fight, they've seen the struggle, they're in the struggle.

One breast cancer interviewee, went further, saying:

[Several] years ago I testified for the state legislature here along with other activists about environmental issues, so I think it's up to us because nobody else is doing it. And nobody else is going to take it, so it's up to us to make sure it stays in the public arena and that political arena.

Another activist, who is involved in both breast cancer and environmental justice activism and sits on boards with scientists to review research proposals, expressed disapproval with how activists' opinions are received: "Breast cancer activists are at the table with scientists today. However, I don't know that they're taking us as seriously as they should be." This opinion was also voiced by other interviewees who felt that many researchers might not take activists seriously because of the scientists' perceptions of activism or that researcher conflict of interest could be a problem. Only one breast

cancer interviewee expressed concern with activists guiding research because of a lack of scientific knowledge.

The environmental justice activists also thought that activists and the community should be involved in guiding breast cancer research. This is the opinion of an activist who has worked in both environmental justice and breast cancer activism:

I think that [activists] definitely have to be the main voice around how research is being done. I think that researchers often work in a vacuum. I don't think they're bad people but I was in academia. There's a lot of great people who are well-intentioned there, but I really think that the people living with breast cancer has to have a voice at that table through looking at grants and peer-reviewing some of the things that are being funded by being at cancer meetings and kind of talking to researchers about what, about what questions they really want answered. And I really do think in order for that money to be spent well, that we have to have advocates kind of voicing their opinions about what's important in the research arena.

Another approach to activism on which the two groups overlapped were views on the role of the government in chemical regulation and how these relate to the precautionary principle. With regards to the role of the government in regulating chemicals, seven of the breast cancer activists thought that better regulation was essential, while four of the interviewees felt that better communication was necessary, either in the form of providing more information about what it is that the government does or the use of a labeling system on consumer products. Two breast cancer interviewees expressed that the precautionary principle should be used when regulating chemicals. According to a fundraiser for a healthcare center: "I think unfortunately for our government, they are reactive as opposed to proactive." Some of the breast cancer interviewees thought that stricter penalties should be in place. A few of them brought up the idea that politics

regarding regulation was affected by the monetary power of drug companies. According to a young activist:

[Money] basically controls politics in this country. If you're a big business and, you know, you have enough money to lobby and do this and do that, you're always going to get your way, that's the way it is, that's how the system is designed.

Similarly, none of the environmental justice activists were happy with how the government dealt with environmental toxins. Most of them mentioned that the precautionary principle should be used and that better regulation was needed. One activist was very distrustful of the government, believing them to be guided by money. Another activist thought that a labeling system was needed. Many of the environmental justice activists believed that a general social movement among the people is what is needed to affect change in the government.

Another important factor to consider when comparing approaches to activism is how people view outreach to women and communities of color. Not surprisingly, both groups thought that this type of outreach was important. The breast cancer interviewees believed that specific outreach to women of color and communities of color should involve raising awareness of general healthy living, which would be inclusive of educating about the environmental link to breast cancer. One interviewee emphasized the need for organizations who wanted to be responsive to the concerns of women of color to ask community members what they were, instead of coming in and dictating them. Three breast cancer activists emphasized the need for outreach to involve people of color in leadership roles. According to a fundraiser for a healthcare center:

I think certain organizations need to set up shop and be a part of the community because I think communities of color are so used to people coming and "reaching out to us" to help us, and we're kind of tired of the

missionaries coming in to save us, and I think that's that attitude a lot of individuals have.

Some of the activists expressed the view that some mainstream breast cancer organizations were not diverse enough. According to a long-term breast cancer survivor:

I remember our former mayor had a breast cancer summit here in '96, and I was asked to sit on the steering committee and I was just one of probably 3 women of color on this committee and the rest were white women, and of course they wanted to focus on incident rates, and I asked, are we going to be left out again...

And in the opinion of a long-term breast cancer survivor:

[Up] until about 5 years ago, maybe 6 years ago, ...anytime I would see something about breast cancer, Susan Banks, she was a news commentator, you would see her, she's a white woman, and then you see white women, you see something with Susan G. Komen race, it was always the white women on the posters. The posters were always put up in the hospitals, but they were usually where mostly black people didn't really go in and out, you know, they would look at the posters, say, 'Hey that didn't really concern them,' cause they didn't see any black faces there.

All of the environmental justice interviewees felt that outreach to communities of color was necessary. Most of them emphasized that other people of color from the community would have to be involved to make the outreach successful, similar to what the breast cancer activists said.

There is a lot of overlap in the approaches to activism in these two groups. They are both concerned with quality of life issues of people of color and underserved people. They believe the government should do more to protect public health, and they are willing to lobby and hold demonstrations in support of this, though the environmental justice activists are more explicitly in favor of the precautionary principle. They both are advocates of community-based participatory research. All of these similarities make a future collaboration plausible.

Views on Environmental Justice and Breast Cancer Activism

An integral component of determining the future convergence of two movements is understanding how the groups regard the other's cause. Both the breast cancer activists and the environmental justice activists respected the validity of the other's cause.

All of the breast cancer interviewees acknowledged that communities of color are more likely to be exposed to environmental toxins, though most did not know the term environmental justice. Many gave examples of environmental justice issues, such as bus depots and power lines concentrated in communities of color. According to a long term breast cancer survivor:

That's why a lot of the white people live out in the suburbs. There's ... cleaner air, you know, grass is cleaner ... here in the city, you have pollutants coming from the, just exhaust pipes, you know, lead in the window sills and stuff... We got a lot of stuff, a lot of stuff.

Highlighting the knowledge of people of color of environmental justice issues without knowing the terminology, a fundraiser for a healthcare center says: "Anyone saying NIMBY, you know, most people of color don't even know what that means. If you say, not in my backyard, then they know, oh it's going to be in our neighborhood."

In response to why this injustice existed, one young activist said:

...it has a lot, well everything to do with the race, class difference, you know, that's still very much alive in the United States... [It's] so easy to concentrate toxins, it's so easy to concentrate things like cell phone towers in you know poor communities, that, that also happen to consist of people of color.

Three of the breast cancer interviewees thought the issue was one of economics more than racism. According to the 10-year breast cancer survivor:

Well I don't know if it's injustice, or it's just basically where we have to live. You know, maybe it's a matter of, of where we can afford to live. And sometimes those houses are in those areas. But, you know certainly I

think the localities can do more to eliminate some of the hazards for those people. But again you have to put the power line somewhere, you have to live somewhere. So, you know, it's kind of like a catch-22 situation.

Compared to the breast cancer activists, the environmental justice activists more explicitly mentioned communities of color being targeted by polluting companies.

Reasons cited for this include racism and a lack of political power of these communities.

According to an activist that has worked for both breast cancer and environmental justice organizations:

I think it's ... just a lot of racism involved in how a lot of decisions are made. And the fact that's it's low income communities of color have, tend to have less political voice, and so if you're a company looking to site a polluting facility somewhere, it's easier to do it there. The land is cheaper, it's usually easier to get pass the legislators. You might not have people organizing before you go to that community.

Despite the environmental justice activists appearing to have stronger convictions about issues of environmental justice, the breast cancer activists overwhelmingly believe that environmental injustice exists in communities of color.

The environmental justice activists were generally positive about breast cancer organizing in the US. They expressed the importance of these organizations in supporting their members and appreciated their efforts. One recurring theme was there was not enough presence in communities of color. An environmental justice activist working in Harlem summarized a major issue facing both groups in communities of color and an impediment to a future linkage between the two groups:

I mean, if I don't know about them, you know, that's probably part of the problem. I don't know really of any breast cancer organizations that are organizations dedicated solely to breast cancer ... in communities of color. I'm sure that's just perhaps my own ignorance. If I research, I'm sure I'll find a bunch of them, but ... I don't know of any. But, you could say the same thing about our organization... [We] go out and people are like, I didn't know you guys exist.

There is mutual respect for the causes of both types of activism, but visibility is a problem for both groups. In order for these movements to be linked, it is important that they are aware of each other.

Beliefs on the links between women of color, breast cancer mortality, and the environment

How women in both breast cancer groups and environmental justice groups view the link between women of color, breast cancer, and the environment is the most important element in deciding the future of a union between the groups.

The breast cancer activists believed that one of the reasons for the difference in mortality between African-American and white women could be tied to environmental contaminants, but most of them also stressed that issues of access to care was a significant reason for the disparity.

Eight of the breast cancer interviewees believed that there could be a link between the disproportionate exposure of people of color to environmental contaminants and the difference in breast cancer mortality between African-American women and white women. Two interviewees were not sure if the two were related, citing economic issues and questioning if women of color were exposed to the environmental agents that were causal in breast cancer. One interviewee did not believe there was a link.

When talking about this disparity, seven of the breast cancer activists brought up access to care as one of the biggest causal issues. Other issues brought up were people being in denial or being afraid of the disease which would affect their seeking medical

treatment. Distrust of the medical field was also mentioned. According to the president of a chapter of a national African-American survivor organization:

We have tried to find, or figure out [why African-American women die more from breast cancer], but there are several reasons that we have come up, or several hypotheses that we say that when we target the underserved areas, we say maybe is it insurance, are you just afraid, you know, people are just afraid.

Another opinion given by a long-term breast cancer survivor, was representative of many of the other women's opinion:

I think environment plays a big part, but I also think that if you had a white woman and a black woman living in the same area ... just maybe the white woman, if she discovered something, she'd be more apt to go to a clinic, whereas the ... black woman would kind of push it aside.

The interviews with the environmental justice activists suggest that many of them believed that the disproportionate exposure of people of color to environmental toxins could be linked to the difference in mortality rates. Only one said she did not believe it was the environment that caused the difference, but rather difference in access to health care:

I think what's hurting people of color is sort of having access to health care vs. the clusters, the big hot-spots for breast cancer, it's not a large minority community, so, from an environmental standpoint, that is not what is hurting women of color. What's hurting them is that they don't have access to early detection, and they don't have access to mammograms, and regular medical check-ups. So, I don't know how you want to answer that, but that's the disconnect for me. Figuring out how the movement could bring equity in access to healthcare.

Other environmental justice activists thought both issues were important.

The data shows that both breast cancer activists and environmental justice activists believe that when looking at breast cancer incidence in women of color, it is important to look at both access to care and environmental issues.

Conclusion

Many elements make the linkage of breast cancer activism to environmental justice activism possible and probable. Many women of color breast cancer activists believe in the environmental causation of breast cancer and think that environmental causation could be linked to the difference in mortality between African-American women and white women. Environmental justice activists share these beliefs. Also, there are many similar approaches to activism, a key consideration when thinking about future collaboration. Further, both groups see the importance of the other's cause. These results matched the expectation that women of color involved in breast cancer or environmental justice activism would have attitudes conducive to a movement that would address the environmental causation of breast cancer as it relates to women of color.

In addition to the findings of the analysis, the fact that activists in the environmental justice movement and the environmental breast cancer movement are interested in the same environmental contaminants, endocrine disrupting compounds, albeit for different health effects, further lends credence to a potential link between environmental justice and breast cancer activism.

However, there are some hindrances to a combined movement. There is some skepticism surrounding the environmental link to breast cancer on the part of some breast cancer activists, especially given the lack of strong evidence. Also, the priorities of many breast cancer groups is on access to care, which is different from the prevention angle of many environmental justice groups. Additionally, breast cancer activists are less apt to believe that racism is to blame for issues of environmental justice. Importantly, some

activists believe that the issue of the difference in mortality is due to economic issues more than to environmental exposure. Another concern is a lack of visibility of each other. Many of the breast cancer activists did not know the term environmental justice, even though they recognized that it is an issue. Most of the environmental justice activists thought that breast cancer organizations could reach out more to communities of color.

When taking all of this into consideration, it appears that a future movement combining breast cancer and environmental justice activism has potential. It will require one or both groups reaching out to the other, greater publicity on the part of both groups, and more solid evidence tying breast cancer incidence and mortality in women of color to environmental exposure. We have seen that breast cancer and environmental justice activism come together in Bayview Hunters Point and we have seen the two groups reach out to each other to raise public awareness with WEACTION in Harlem. Further, the study of household exposure to environmental contaminants by the environmental research organization, the Silent Spring Institute that will involve the environmental justice group Communities for a Better Environment is more proof that links between breast cancer advocacy and environmental justice activism are gaining momentum. As breast cancer incidence continues to rise, the disparity in mortality continues to exist, and the environmental justice and breast cancer movements continue to advocate for change, future collaborations between the groups are on the horizon.

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Appendix A: Sample Questionnaire

Involvement in Breast Cancer Activism

1. Tell me how you got involved in breast cancer activism.
2. Tell me about the organization or organizations you are involved with. We're interested in both breast cancer groups and other kinds of groups.
3. What are the main goals and priorities of the groups you're involved with?
4. Where do environmental factors fit in the order of priorities of your organization(s)?
5. If your organization deals with environmental factors, how did they decide to make this issue a priority? What kinds of discussions were held on this? Did this involve organizational members, staff, and/or board members?
6. If your organization does not deal with environmental factors, why do you think this is so?
7. Are you or other people in your organization(s) thinking about working on environmental issues, even if your organization is not?

Knowledge of environmental causation

8. Thinking back to your organization(s)' mission and priorities, how does that affect your individual understanding of causes of breast cancer?
9. What is your understanding of potential environmental links to breast cancer?
[probe: manufacturing, combustion, household products, personal care products]

Effect on individual behavior

10. If you have concerns about environmental links to breast cancer, have you considered making any changes in the kinds of personal care and consumer products you purchase and use in your home?
If yes, probe:
 - a. Can you tell me about any changes you have made, or are planning to make?If no, prompt:
 - b. Are there changes that you would like to make, but aren't sure what alternatives there are?
11. Have you considered making any changes to the kinds of foods you buy?
If yes, probe:
 - a. Can you tell me about any changes you have made, or are planning to make?If no, prompt:
 - b. Are there any changes that you would like to make, but aren't sure what alternatives there are?

- c. Have you considered buying organic food, to reduce your exposure to pesticide residues in food?
12. Tell me about any other changes you've made in your life.

Effect on breast cancer activism

13. Are you familiar with the Safe Cosmetics campaign? If so, prompt:
a. How do you think it has impacted breast cancer activism?
14. Are you familiar with the Think Before You Pink Campaign? If so, prompt:
a. How do you think it has impacted breast cancer activism?
15. In your opinion, what should scientists conducting breast cancer research focus on over the next 5-10 years?
16. To what extent should breast cancer research focus on environmental pollutants?
17. How should the opinions of breast cancer activists and the public be used in guiding the priorities set for breast cancer research?
18. Do you believe that more should be done to raise public awareness of the possible link between breast cancer and environmental pollutants?
a. If yes, what should public outreach campaigns focus on?
b. If no, why not?
19. What about specific outreach to women of color? What should outreach to this diverse constituency focus on? What are their main concerns?

Effect on environmental justice advocacy

20. What should be the most important priorities of breast cancer organizations that want to be responsive to the needs and concerns of women of color?
21. Have you heard of the concept and/or practice of environmental justice? If so, prompt
a. What does this term mean to you?
22. Are you connected with any environmental justice organizations or networks? If so, which ones?
23. Are there any changes that you would like to see in how the government regulates chemicals, especially if it does not have complete knowledge of their effects? If so, probe:
a. What changes do you think are necessary?
b. How do you think those changes can be made?
24. Do you think that people of color are disproportionately exposed to environmental toxins?
25. If so, do you think that environmental exposure plays a role in the different incidence and mortality rates of breast cancer between women of color and white women?
26. Do you think that breast cancer activism should focus on the disproportionate exposure of people of color to environmental pollutants?
a. If so, what should breast cancer activists be doing to address this issue?
b. If not, why not?
- Is there anything else you would like to add?

Appendix B: List of Codes

AAA

- absence of women of color in breast cancer movement
- access to care
- access to health care (women of color)
- activist agenda
- activist experience/knowledge
- activism, breast cancer
- activist involvement (other)
- air pollution
- anger (environmental justice)
- anger regarding environmental causation

BBB

- beauty products (women of color)
- belief in environmental causation
- better treatment/cure
- breast cancer disparities/stigma
- breast cancer research
- breast cancer survivor and involvement
- breast cancer movement

CCC

- certainty regarding environmental causation
- coalitions and breast cancer
- coalitions and environmental justice
- community (people of color)
- Community involvement (breast cancer research)
- consumer products and individual behavior
- corporations' behavior
- corporations' priorities
- corruption and corporations

DDD

- disbelief regarding environmental justice
- distrust of medical field
- distrust of corporations

EEE

- economic issues and health
- economic issues and environmental justice
- education (women of color)
- environment (breast cancer research)
- environmental activism
- environmental causation
- environmental causation and skepticism

environmental justice
environment and breast cancer activism
environmental justice and breast cancer incidence in women of color
estrogen/hormones

FFF

food intake
frustration with research
funding (foundations)
funding (government)

GGG

genetics (breast cancer research)
government and activism
government and communication
government and communities of color
government and restructuring

HHH

health activism
hopelessness (environmental justice)
hopelessness regarding environmental causation

III

inequities and environmental justice activism involvement
interest in health inequities
involvement in social movement

LLL

lack of action (women of color)
lack of knowledge (women of color)

OOO

optimism (environmental justice)
organization priorities
organizations outreach to women of color
other effect on individual behavior
other environmental justice involvement
other knowledge of environmental causation
other social movements and environmental justice involvement
outreach to women/communities of color

PPP

pesticides
precautionary principle
prevention regarding breast cancer activism

public awareness of breast cancer and environment

RRR

race-related activism

racism and environmental justice

radiation

research regarding environmental causation

researcher conflict of interest

SSS

staff

WWW

women's issue activism