

The Personal Is Scientific, the Scientific Is Political: The Public Paradigm of the Environmental Breast Cancer Movement

Sabrina McCormick,^{1,3} Phil Brown,¹ and Stephen Zavestoski²

This paper introduces the concept of “boundary movements” to characterize the distinctive growth and strategies of movements involving citizen/science alliances to contend with environmentally related illnesses. This concept is applied to a case study of the environmental breast cancer movement, which has induced changes in treatment options and public perception of breast cancer. Since the early 1990s, a segment of this movement has consistently criticized the traditional paradigms governing research, the epistemology of breast cancer, and popular understandings. Against the traditional focus on genetics, lifestyles, and personal responsibility, this segment’s broader messages stress environmental causation and women’s participation in science and politics.

KEY WORDS: social movements; environment; health; boundary movement.

Since the early 1990s, the breast cancer movement has advanced a new public paradigm centered on environmental causes of breast cancer. In this paper we describe the framework, history, and strategies of the new national environmental breast cancer movement (henceforth, “the movement”). Our case studies demonstrate the importance of understanding the fluidity of social-movement actors and allow us to demonstrate the new concept of a “boundary movement.” They also provide a narrative of social-movement formation in which a critique of traditional science emerges from embodied perspectives. Therefore, this social-movement case study aims to offer a new conceptual framework to social-movements theory and to illustrate

¹Department of Sociology, Box 1916, Brown University, Providence, Rhode Island 02912.

²Department of Sociology, University of San Francisco; San Francisco, California 94117-1080.

³To whom correspondence should be addressed; e-mail: Sabrina_McCormick@brown.edu.

empirical cases in which social movements have changed scientific processes and agendas, as well as policy outcomes.

Breast cancer surfaced on the public agenda in the 1970s and 1980s on the second wave of feminism, as women began to present their personal stories of the disease to the public. It slowly moved from being conceived of as a private experience that could be overcome with a positive attitude and a supportive family, to being politically relevant, especially in terms of options for treatment. As women gained more control over treatment options, a breast cancer advocacy movement emerged, focused on increasing research funding and finding a cure for the disease. While activists criticized the medical control of their bodies, they did not challenge the biomedical model that focused breast cancer research on methods for treatment, constrained medical strategies to lessen the possibility of getting breast cancer, and promoted individualistic methods for cancer prevention. As the breast cancer movement became more powerful, and the environmental movement put more attention on health effects of toxics, a new breast cancer movement that combined the two emerged to challenge the biomedical model and present what we term a new “public paradigm.”

THE ENVIRONMENTAL BREAST CANCER MOVEMENT AS A BOUNDARY MOVEMENT

The public paradigm promoted by the environmental breast cancer movement (EBCM) focuses on the health effects of environmental toxins. Our notion of a public paradigm builds upon Krinsky's concept (Krinsky, 2000) of a “public hypothesis” that is formed when the public feels it has a stake in scientific study, debates and consequent outcomes, and therefore demands to participate. The public paradigm represents an expanded pattern of public action and attitudes not just for a specific scientific argument, but also for the broad paradigm underlying current scientific and societal processes. In this case, activists base their new 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 (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.⁴ Creating a new public paradigm

⁴By environmental, we mean the effects of toxic substances (primarily chemical) in people's immediate or proximate surroundings.

necessitates participation in science and at least symbolic influence over its formation.

Such influence requires a unique type of social movement—what we term *boundary movements*. Boundary movements are social movements and their constituent organizations that move between social worlds and realms of knowledge. In so doing, they blur traditional distinctions, such as those between movement and nonmovement actors, and between laypeople and professionals. In particular, four characteristics define boundary movements. First, they attempt to reconstruct the lines that demarcate science from non-science. They push science in new directions and participate in scientific processes as a means of bringing previously unaddressed issues and concerns to the attention of the clinical and bench scientists. Second, boundary movements blur the boundary between experts and laypeople. Some activists informally become experts by using the Internet and other resources to arm themselves with medical and scientific knowledge that can be employed in conflicts with their medical care providers. Others gain a more legitimate form of expertise by working with scientists and medical experts to gain a better level of understanding of the science underlying their disease. Boundary organizations gain power and authority by obscuring the boundary between expert and layperson.

Third, boundary movements transcend the traditional conceptions (i.e., boundaries) of what is or is not a social movement. They do this by moving fluidly between lay and expert identities, and across various organizational forms. Their fluidity allows them to move in and out of organizations and institutions in ways that traditional social-movement activists do not. Raising money to fund their own research exemplifies their nature as boundary organizations, since doing so blurs the boundary between previously distinct and autonomous institutions: science and civil society. A fourth characteristic of boundary movements is that they use “boundary objects” (Star and Griesemer, 1989), that is, objects that overlap different social worlds and are malleable enough to be used by different parties.

Boundary movements work in the cultural and analytical spaces between existing social movements in order to negotiate the meaning of science and to challenge the definitions of acceptable scientific practices and products. Many individuals can identify with and participate in such a movement without having to be part of a specific organization. Finally, a boundary movement crosses two or more social movements, while blurring the boundaries of those separate movements.

A central vehicle for blurring these boundaries is the use of what we term the “citizen/science alliance,” a lay–professional collaboration in which citizens and scientists work together on issues identified by laypeople. Such alliances exemplify boundary movement activity. Our conception of boundary

movements is akin to Ray's "fields of movements," in which social action stems from the collective efforts of groups of social movements (Ray, 1999). A field-of-movements approach describes more than just a lineage of social movements. Fields of movement capture lineage, but they also point to the way movements intersect with one another. This unique interaction of social movements is in some ways similar to, but more profound than, "social movement spillover" (Meyer and Whittier, 1994), in which members of a social-movement community transcend their movement boundaries by involving actors, organizations, and tactics that stem directly from another social movement. Similarly, some concepts from "new social movement" (NSM) theory (Laraña *et al.*, 1994) apply to environmental breast cancer activism, but do not sufficiently account for its intricacies. NSM theory argues that modern social movements, including the environmental movement, put forth a postmodern, postmaterialist, nonclass-based politics that differs from traditional redistributionist politics in emphasizing quality of life, self-realization, more humane social relations and communications, and collective participation. The environmental breast cancer movement does not fit solely into this conception since these movement actors also attempt to affect the state. Not only do boundary movements take the best from surrounding movements, they also draw on the crossing over of members from one organization to another and from one movement to another. Because ideas, values, and action strategies move from one movement to another, people find it easier to participate in other groups and movements.

The interaction among boundary movement organizations and groups is made possible by the fluidity with which these groups can move back and forth between organizational cultures and between the roles of activists and experts. This fluidity allows professionals to play varying roles over time, occasionally being part of the movement as either members or "advocacy scientists" (Krimsky, 2000), at other times being somewhat detached scientists, and at other times being uninvolved. Fluidity is similarly represented in Epstein's notion of analytical blurrings (Epstein, 2001). He asserts that we can no longer adhere to binary sets, such as insider/outsider and lay/expert, due to the fluidity of such shifts among both individual participants and organizations.

These notions of fluidity and analytical blurrings explain how movement actors in different locations maintain a variety of relationships with the state, other movements, or experts while maintaining a unifying movement philosophy. As we discuss below, a number of Long Island activists found it easy to work with mainstream politicians, while Bay Area activists were more likely to link up with AIDS, women's health, and toxics activists, and Boston area activists found allies among those involved in precautionary principle organizing. Local context shapes the way each area approaches

the problem, even though they are all part of a single social movement. Such localized “cultures of action” (Klawiter, 1999) involve assorted groupings of movement and nonmovement actors in changing alliances.

Boundary movements also lead us to examine the role of “boundary objects” (Star and Griesemer, 1989) that traverse the human/nonhuman boundary. These material and nonmaterial objects transect a variety of contexts, maintaining enough meaning similarity in each to create coherence across circumstances while being used distinctly in each one. Hence we see the importance of “non-human actors” (Clarke *et al.*, 2000). Mammography machines, genetic testing for breast cancer, patents on the BRCA-1 sequence, pharmaceuticals, Breast Cancer Awareness Month, and Avon’s “Breast Cancer Walk” are such boundary objects that play important roles in other social movements and a redefined role in the environmental breast cancer movement. Conceiving of this movement as a boundary movement helps explain its unique features, while also suggesting approaches to analysis of other hybrid social movements. The following section provides the contextual background from which the movement emerges and begins to delineate how it works as a boundary movement. We also outline the social and scientific construction of breast cancer.

SOCIAL AND SCIENTIFIC CONSTRUCTION OF THE BREAST CANCER EPIDEMIC

Breast cancer rates have been increasing steadily for at least 50 years, to the point where in the United States a woman is diagnosed with breast cancer every 3 min, and another woman will die of breast cancer every 12 min. There will be an estimated 203,500 new cases of invasive breast cancer and 54,300 cases of *in situ* breast cancer diagnosed this year alone (American Cancer Society, 2002), and it is the leading cause of death for women under the age of 55. Because of public attention in the past twenty years largely caused by the breast cancer movement, the popular conception of breast cancer has changed radically from a private occurrence to a politicized experience. The breast cancer movement has addressed issues of care for breast cancer patients; knowledge about treatment options, especially in regard to mastectomies, lumpectomies, and radiation; support for those affected by the disease; and increased research funding. Current government action includes the partnership between government and nongovernment sectors in the National Action Plan on Breast Cancer, established by President Clinton in 1994, among other projects. Private sector action includes the first National Breast Cancer Awareness Month, which promotes public awareness of breast cancer and usage of mammography as early detection, first held

in 1985. Today, fund-raising walks and runs during that month involve tens of thousands of people every year. The movement's other successes include the production of a breast cancer stamp, whose additional cost above normal postage is given to governmental research institutions to further breast cancer research, and the Shop for the Cure campaign, whose merchants and credit card companies give a portion of the proceeds to breast cancer foundations. The general breast cancer movement's success can also be seen in the amount of breast cancer research dollars, which have increased from \$90 million in 1990 to \$600 million in 1999 (Reiss and Martin, 2000), and in the ability to win federal legislation, such as the Breast and Cervical Cancer Treatment Act of 2000.

The environmental breast cancer movement has reframed the successes of the broader breast cancer movement in order to focus on potential environmental causes and change how breast cancer is researched and publicly perceived. Some of those general movement successes are criticized by the environmental breast cancer movement, or by what one activist (Brenner, 2000) terms the "political breast cancer movement."⁵ For example, for years people took for granted the position of the American Cancer Society, National Cancer Institute, and other parts of the "cancer establishment" that "mammography is the best form of prevention." Environmental breast cancer activists argue that once a tumor is detected, prevention has failed, since the tumor now exists. This stance is supported by the growing scientific awareness that mammography is not very effective in women under 50 years. Activists also challenge the corporate control of Breast Cancer Awareness Month (discussed later). They have additionally mounted a campaign to have breast cancer stamp revenues shifted to the National Institute of Environmental Health Sciences from the National Cancer Institute, which does not support research on environmental factors.

Concurrent to the change in social perception, there has been scientific debate concerning the causes and treatment of breast cancer. The dominant scientific paradigms used in studying breast cancer have been circumscribed by the biomedical model and have consequently focused on individual-level factors like diet, exercise, age at first birth, and genetic makeup (Kant *et al.*, 2000; Thompson, 1992). However, these studies have also shown that such factors account for a limited number of cases. The discovery of the BRCA-1 gene mutation led to a focus of attention on genetic causes, even though it has since been recognized that genetic causes only account for some 5–10% of all cases (Davis and Bradlow, 1995). Activists also point to the fact the

⁵Our terminology for this movement was discussed with movement actors. They generally agreed that the term "environmental breast cancer movement" is appropriate. However, as evidenced by Brenner's terminology, there is some differentiation in naming the movement.

genome does not change rapidly enough to account for the increase in breast cancer incidence, which, for women who lived to be age 80, was 1 in 20 in 1964 and is now 1 in 8.

A growing body of scientific literature has been exploring environmental causes of breast cancer. Initial studies showed support for environmental causation; for example, Hunter's study (Hunter, 1993) correlated DDE, the chemical breakdown product of DDT, a pesticide commonly used worldwide, with increased risk of breast cancer. Later studies (Hunter *et al.*, 1997, Wolff *et al.*, 1993) showed equivocal results. The most recent research has demonstrated the complexity of studying breast cancer causes by using different types of evidence, such as twin studies (Lichtenstein *et al.*, 2000) and specific groupings or breakdowns of chemicals (Dorgan *et al.*, 1999; Guttes *et al.*, 1998; Hoyer *et al.*, 2000). These studies exemplify the widespread scientific dialogue taking place around the legitimacy of claims pointing to environmental contaminants and increased breast cancer risk.

New breast cancer research employing innovative methods and lay involvement has been promoted by activists dedicated to investigating potential environmental causes. The three areas we are examining—the San Francisco Bay area, the Boston/Cape Cod area in Massachusetts, and Long Island, New York—have higher breast cancer incidence than the rest of the United States, and public attention has led to numerous studies on these areas (Aschengrau *et al.*, 1996; Robbins *et al.*, 1997; West *et al.*, 1998). This activism was initiated in Long Island, developed soon after in Massachusetts, and then spread to the San Francisco Bay Area. A combination of local and national contextual factors influenced the development of the movement, research, and policy in each location. Local factors include media response, the political climate and political connections, preexisting social movements, the response of the local governmental institutions, and potential funding sources. A general movement framework unites the three locales into a national movement. Activism across these locales has primarily emerged from the combination of the same previous movements, the environmental and breast cancer movements.

In exploring the environmental breast cancer movement, we aim to make several contributions to the conceptualization of social movements and to the discipline more broadly. First, examining the characteristics of a specific boundary movement—one that is fairly new and important, yet largely unstudied—allows us to advance social-movement theory through an empirical case. Further, this movement is an interesting case of how multiple social movements (the environmental movement and breast cancer movement) coalesce to form a new movement. Our analysis shows how the perspectives of multiple organizations are combined to create a social movement that is still in its formative stage but has already affected

local and national policy. Finally, we show how the citizen/science alliance, one result of this social movement, has altered scientific processes and legitimacy.

DATA AND METHODS

Semistructured interviews ($n = 29$) were conducted with activists and scientists working with movement organizations in the three previously mentioned locations, and with scientists in those locations. Table I describes the breakdown of interviews with movement actors and scientists in each locale. Each interview was based on an interview schedule developed for each group (i.e., researchers and activists). We selected these locations because they are the only sites in which the environmental breast cancer movement has taken place in organized settings. A site was operationalized by the existence of multiple activist organizations promoting increased public and scientific awareness of environmental causes of breast cancer and building citizen/science alliances between these activists and scientists. Such scientists were interviewed in addition to activists. The sample was collected by selecting participants on the basis of their involvement in the movement, and partially through a snowball method. People whose involvement spanned the entire period of time during which the movement had been forming were selected, along with representatives from various organizations involved. This provided a comprehensive picture of the experiences within each location, as well as the national picture. Unreferenced extracts and data come from these interviews and observations.

Ethnographic observations ($n = 11$) were conducted to supplement the interviews, primarily at Silent Spring Institute in Newton, MA, the nation's only center for research into environmental causes of breast cancer. These included public meetings where the researchers presented their work and their larger perspective, scientific review panel meetings, and science/activist conferences. While the interviews were the primary source of analysis, the observations provided a broader contextual picture. For instance, we observed the approaches taken by Silent Spring Institute to bring its scientific

Table I. Sites and Types of Interviews

Locale	Interviewees	
	Scientists	Activists
Massachusetts	7	5
California	3	6
Long Island, New York	4	4
Total	14	15

work to lay activist audiences, and, in another case, we saw how Silent Spring responded to critics at a scientific review panel. Printed materials from each organization were also collected in order to better understand their political stance and public activities.

The data were analyzed using the QSR NVivo program. This software is capable of storing and referencing qualitative data in multiple ways. We first coded the interviews by pinpointing themes that occurred. The quotations used in this paper were representative of the themes that emerged through data analysis.

BACKGROUND OF THE LOCALES

The following section provides the historical background for activism in each locale, the focus of the activism, the relationship of movement activists to other local activism, and the relations each movement locale has developed with government and scientific actors. Details from these sites point to the common themes we take up later in our analytical assessment of this movement. Both state actors and the media have played important roles in influencing the outcomes of activism, and in some ways they can be considered movement actors in their own right. Similarly, alliances between researchers and activists have been central in each location. Through these channels activists, have inserted their perspectives into scientific systems. Therefore this detailed account allows us to see the “fluidity” of these actors in each “site of congruence” (Clarke, 2001).

Possibly most important is the role of science. Activists believe that science has not appropriately served their needs, at least partially because it is a system controlled by people other than disease-sufferers. They seek new approaches to science, particularly the search for possible environmental causation. Activists focus on the importance of the political context, such as the conservative role of the American Cancer Society and the rest of the cancer establishment. They also point to the economic power of the corporations, such as Astra-Zeneca’s control of Breast Cancer Awareness Month. By drawing these connections, activists conceptualize the scientific as political. Consequently they attempt to insert individual-level knowledge into scientific and political processes to affect population-level changes. This valuing of the personal perspective, along with the belief that activism plays a critical role, creates a unified philosophy for all movement actors. Movement actors exemplify boundary movement activity by crossing the often-rigid boundaries of the scientific world as lay actors. They use the personal experience of breast cancer and their individual knowledge of potential environmental exposures to provide themselves with credibility in science.

We begin by providing detailed background information on each locale so that movement formation and development is clear. We then focus on the overarching framework of the movement, which fosters the fluidity of actors and supports the existence of a boundary movement. Following this, we detail the interconnections between preexisting movements that provided the basis for the overarching framework and the political-economic critique of what activists term the “breast cancer industry.” We finally focus more specifically on the role of the citizen/science alliance in this process.

LONG ISLAND, NEW YORK

In the early 1990s, women in western Long Island began noticing that they were surrounded by instances of breast cancer. Women with breast cancer, as well as women who had never had the disease, began to map breast cancer cases in their community. At first, only a few women were involved in what we term “lay mapping,” working with a map onto which they located cases. After an initial group had developed mapping for its area, it assisted similar groups in other areas. Groups interested in environmental causes of breast cancer such as the Huntington, West Islip, and Southampton Breast Cancer Coalitions, among others, were formed around 1992 with the help of preexisting breast cancer support groups sometimes administered through local hospitals. Today Long Island is uniquely characterized by its widely dispersed network of organizations, a configuration of research projects, and multiple, small-scale utilization of geographic information systems (GIS).

This formation process was also facilitated by support from scientists at a local university. Activists sought research from these scientists to support their hypothesis that more women on Long Island were getting breast cancer than in other places. In 1993, they marshaled backing from other well-known scientists and held a conference on the issue at which the Centers for Disease Control, Environmental Protection Agency, and National Cancer Institute were major presences. This alliance enabled the passage of the bill that planned and funded the Long Island Breast Cancer Study Project through the National Cancer Institute. The bill provided \$32 million dollars in federal funding for study of potential environmental causes of breast cancer.

The involved organizations have worked on several fronts. While they each conduct GIS work, they also provide local services to women with breast cancer. They are funded by diverse local sources, and each has its own activist methods. Some personality conflicts between groups have existed alongside a relative level of cooperation. One umbrella organization, the Long Island Breast Cancer Network, serves to unite the diverse set of groups but is not

used as a forum under which to make statements or give opinions. It was only established in order to coordinate efforts. Outside of this forum, projects between organizations only overlap sporadically due to their different areas of coverage and agendas.

Long Island activists were noteworthy in their ability to forge strong connections with Republican politicians, especially Senator D'Amato, on the traditionally Democratic issue of the environment. Preexisting bipartisan support for breast cancer activism probably facilitated this support. These political connections were largely responsible for the government public hearing regarding breast cancer. Involved scientists and activists claim that the attention activists brought to the issue, the political and scientific connections they made, and their individual testimony in the Senate were the causes of the success.

Currently, organizations' relationships with local and state government are much more supportive than in other locales where the movement is active. This may be due to the long duration of the involvement, over which time personal relationships with representatives were nurtured, partly as a result of the acknowledged broader base of voter support. Local awareness of the federal funding supporting the Long Island study also reinforced these relationships. Ultimately, political connections with individually influential representatives have had a strong effect. Another example of the political effectiveness of the organizations on Long Island is that of the Southampton Breast Cancer Coalition. While largely focused on serving local women with breast cancer, these activists keep their voices heard by serving on research advisory boards and the New York State Department of Health's Research Science Advisory Board. This board decides on allocation of funds generated by the breast cancer research check-off box on New York State tax forms. Because of leadership by a local governmental representative, Southampton Breast Cancer Coalition has gained major support from the local government, including a GIS technician to conduct work on environmental hazards and breast cancer and an office in the town hall. Their fund-raising events have become so well known as to attract major governmental officials like the mayor of New York City.

Activists felt that the media has also paid them a good deal of positive attention. Many of them had been on major television news, specials, and talk shows such as "Oprah," "Eye to Eye," and "Primetime Live," and events have been routinely covered in print and broadcast media. This may be due to the large amount of public attention in general that activists generated. Attention by a few papers or stations may have initiated a trend that others followed. The geographical proximity of Long Island to New York City, the media capital of the United States, may have influenced the amount of attention given to concerns there.

Long Island groups were not linked to environmental groups for some time, perhaps due to these breast cancer organizations' Republican connections. Now they are also supported by many organizations, including environmental groups. The West Islip group, the first one to form, is now fighting against pesticide use on golf courses. The Huntington Breast Cancer Action Coalition, which initiated one of the largest GIS studies on the Island, is currently focused primarily on environmental causation. They advertise for organic horticulture, and their newsletter promotes displaying pink flags in yards grown without chemicals.

Currently, many research projects are underway or have recently been completed on Long Island. Two of them stand out for their great involvement of and effect on the community at large. The first is the Long Island Breast Cancer Study Project (LIBCSP). Ten subsidiary projects exist under that umbrella, including studies investigating potential impacts of overhead power lines and looking for chemical contaminants in tissue samples. Activists from all over the Island area have sat on advisory boards of many of the studies being conducted. The second project uses GIS to map breast cancer cases and environmental factors in local areas, incorporating new technologies that have elaborated the original lay mapping.

The first results of the LIBCSP were released in the summer of 2002 and garnered wide press coverage. The study found little to no support for a hypothesis that the chemicals scientists had examined correlated with increased breast cancer risk. Although the researchers called for further examination of a link between chemicals and breast cancer and asserted that their results were far from conclusive, the press interpreted the report as proof that collaborations between activists and scientists are detrimental to scientific advancement. Activists and scientists both felt that this presentation was unfair and would potentially discourage funders from pursuing similar projects in the future. The heightened interest and the controversial public interpretation of the LIBCSP results demonstrate three points, among others. First, boundary-crossing activities exemplified by movement are significant for both the public and science. Second, boundary-crossing makes a social movement vulnerable to criticism and defeat in multiple venues. Finally, boundary-crossing in citizen/science alliances threatens the traditional roles of laypeople and scientists and hence has ramifications for power held by these actors.

MASSACHUSETTS

Long Island activists only slightly preceded Massachusetts activists, who gained state recognition in 1994. Like several other areas in the United States,

Cape Cod has an elevated rate of breast cancer: 20% above the state average. After several years of activism based on awareness of this higher incidence, the Massachusetts Breast Cancer Coalition founded Silent Spring Institute in 1994 as a research organization focused on studying environmental causes of breast cancer, using a citizen/science alliance approach. An additional goal was to educate the public about environmental causes of breast cancer. That year they achieved the passage of a bill in the Massachusetts legislature to provide \$3.6 million for a 3-year study to investigate why 9 of 15 towns on Cape Cod had statistically significant elevated levels of breast cancer.

The Silent Spring study is continuing to run in 2002. The first phase, completed in 1997, had three important results: (1) development of the GIS system that enables researchers to map diagnosed women with environmental data; (2) historical study of pesticide use and drinking water quality on the Cape; and (3) establishment of new field methods to study environmental estrogens (Silent Spring Institute, 1998). Phase two, for which data is currently being analyzed, involves interviewing 2500 Cape Cod women to identify individual risk factors (age of first child, physical exercise, exposure to toxic products), testing to determine possible estrogen mimics in households, and estimates of environmental exposure for each interviewee based on GIS mapping.

The Massachusetts Breast Cancer Coalition, a particularly strong affiliate of the National Breast Cancer Coalition, focuses on creating awareness of environmental causes of breast cancer by educating the public and pushing for related research. The national organization, out of which the Massachusetts group emerged, encompasses more than 500 organizations and focuses on three main areas: research on breast cancer, access to medical resources for all women, and enhancing the influence of women with breast cancer on policy decisions that affect them. It has major political influence and exercises it in the legislative arena. The National Breast Cancer Coalition also holds major national conferences in which breast cancer activists of all kinds network with one another.

The Massachusetts group is in many ways distinct from National Breast Cancer Coalition. They are more exclusively focused on environmental causation of breast cancer and the related political-economy critique of industry. Activists have at times mentioned this difference as a point of contention. While the Massachusetts Breast Cancer Coalition wants to push the agenda in a more left direction, the national organization must attend to the interests and needs of a national constituency. The Massachusetts affiliate has urged the national organization to take up environmental causation, and has had some success. Massachusetts Breast Cancer Coalition works primarily through advancing scientific study at Silent Spring and through efforts to educate the public. Its leaders also bring information about environmental

causation to larger breast cancer activist events, such as Race for the Cure in Boston.

The Women's Community Cancer Project is the other main group in Massachusetts. It has focused primarily on a feminist analysis of all cancers. They have engaged in public protest and education, including a large-scale mural in Harvard Square. The more radical nature of this activism includes a critique of the cancer industry, a focus on corporate responsibility, and organizing against direct marketing of cancer drugs.

Because the Massachusetts groups are few and their agendas differ, they can work together in some ways and separately in others. The Massachusetts Breast Cancer Coalition created Silent Spring Institute, and although these organizations are now separate entities, many people are involved in both. The Massachusetts state funding for Silent Spring, the only organization with a research component, provided a focus. Activists felt that the cohesion of groups was the root of their success. The Women's Community Cancer Project is not involved in research, but shares an orientation to the precautionary principle with the Massachusetts Breast Cancer Coalition and Silent Spring. Activists in this area felt that while other factors like the media, which had been fairly supportive, were important, they had not played a major role.

These key groups have been involved in environmental activism collaboratively and on their own. The Massachusetts Breast Cancer Coalition has been and continues to be a key partner in the Precautionary Principle Project, newly renamed the Alliance for a Healthy Tomorrow. This includes forums presented to college, community, environmental, and health groups in order to educate laypeople, government representatives and their staff, and scientists about the precautionary principle, including its relationship to diseases other than breast cancer. In doing this work, they are partnered with Clean Water Action and the Center for Sustainable Production at the University of Massachusetts at Lowell. This is a part of the tactics employed to push the precautionary principle in state and local policy, including a 2001 bill in the state legislature on child health legislation, and local and statewide action to prevent pesticide spraying. The Women's Community Cancer Project also applied the precautionary principle in its educational and organizing activities. One manifestation of the project's environmental focus has been in its active targeting of pharmaceutical companies' direct marketing of cancer drugs. A December, 2000 letter by the project states the organization's dissatisfaction with "the unwillingness of policymakers to place public health ahead of profits . . . the role of pharmaceutical companies in determining the course of cancer research, and . . . the race and gender discrimination found throughout the medical establishment."

Silent Spring Institute broke new ground in acquiring major state government funding to found the institute and fund research, and has been supported by a network of strong activism, but most interviewees attested to the lack of support they felt from state governmental agencies. While legislation established funding, the Department of Public Health controlled that money and has challenged Silent Spring's funding since its inception. Silent Spring has been able to prove the validity of its mission enough to maintain funding, but as a result, it has had limited relations with government. Even this weak level of support was ended by the removal of state funding for Silent Spring in 2002 when the government incurred a massive budget cut.

SAN FRANCISCO BAY AREA

Activism in the Bay Area began in the early 1990s and included the key victory of getting laypeople accepted on state cancer research review committees in 1992. This initial work was significantly enhanced when the Northern California Cancer Center, an independent institution funded by various sources such as the National Cancer Institute, published statistics showing that the Bay Area had the highest rates of breast cancer in the world. Breast cancer groups responded strongly to the publication and dissemination of these data, and the movement flourished. Three distinctive geographic areas are located here: San Francisco, Marin County just north of San Francisco, and East Bay. The major activist groups located in San Francisco, Breast Cancer Action and the Breast Cancer Fund, are primarily nationally focused organizations. Bay View/Hunter's Point Community Advocates is also located in San Francisco, but is focused only on the South San Francisco neighborhoods after which it is named. In Marin there is only Marin County Breast Cancer Watch, and more recently Marin Cancer Project, both focused only on the local area. The Women's Cancer Resource Center is the main organization in the East Bay. The Breast Cancer Fund raises money to support its mission, which is to alter detection, treatment, and prevention policies to recognize and focus on environmental causes. Breast Cancer Action focuses on education, direct action, such as demonstrations, and coalition work with other political organizations. They are active in opposing pharmaceutical companies' direct marketing of cancer drugs.

Bay Area activists have been enriched by the minority perspectives of the Bay View/Hunters Point group, a general environmental justice organization that grew out of the earlier Southeast Alliance for Environmental Justice and has been concerned with abnormally high African American

rates of breast cancer in their area, especially since such women typically have a lower incidence than white women. These activists have loudly criticized the lack of racial identity recognition in epidemiological research and institutional failings of risk assessment (Fishman, 2000). Even though this group is not specifically a breast cancer organization, it has been involved with groups like Breast Cancer Action, thus contributing a more multiracial perspective.

Marin County Breast Cancer Watch was one of the first Bay Area organizations and is the only one that includes a citizen/science component. The organization originally received funding to conduct a study of adolescent risk factors for breast cancer and housed several researchers part time in order to do so. Recently, it has also gained state funding to begin another study more specifically focused on potential environmental causes. Scientists and activists are housed in one office, and additional scientists at nearby universities also work with the group.

These organizations were preceded by other cancer activism groups. Founded in 1986, the Women's Cancer Resource Center was one of the first women's cancer organizations and was a precursor to the movement in the Bay area. Like Bay View/Hunter's Point, it is located in East Bay. It was precedent-setting in providing services to women with cancer and now links its activism with the environmental movement as well. Its mission is to educate the public about cancer and to support women with cancer, as well as to engage in related activism. Their services include educational workshops, a resource library, support groups, and a hotline.

Bay Area groups have different levels of focus. While the movement in San Francisco includes groups with both local and national orientations, Marin activism is only local. The different local and national levels of focus, as well as the slightly differentiated geographic locations of these groups, often keep them from competing for the same resources. These factors and the general lack of large-scale government research funding in most of the Bay Area, excluding Marin, has also reduced competition between groups.

Bay Area activists are less concerned with their comfortably supportive state and political connections than with generating public attention, and so they have used those connections for that purpose. These activists began to push government to apply the precautionary principle as a part of San Francisco's city planning policy in the mid 1990s. In 1992, Breast Cancer Action and the Breast Cancer Fund joined with the National Alliance of Breast Cancer Organizations to push for lay involvement in research proposals funded by the California Breast Cancer Research Program. Their approach became a model for the well-regarded citizen participation in the Department of Defense's breast cancer research program and has included some projects on environmental factors. The Breast Cancer Fund has also

advocated stricter standards for chemicals regulated under the federal Food Quality Protection Act. They work closely with the National Institutes of Environmental Health Sciences and the Food and Drug Administration, with which their work is largely on clinical trial protocols. Breast Cancer Action has collaborated with the San Francisco Department of Public Health Breast and Cervical Cancer Services and various community and health organizations to organize Town Halls on breast cancer in low-income communities of color. Representative Nancy Pelosi (D-CA) has helped these organizations by supporting funding for breast cancer research and recognizing their efforts in public speeches. Other local representatives have offered symbolic support by creating days of recognition for their events. Marin activists have faced more challenges by the local community, such as being prohibited from holding meetings at certain facilities, but have now received a large amount of government funding to research breast cancer incidence there. In 2000 they also received state funds for a new study.

While other locales also focus on issues related to universal access to care, activists in the Bay Area were the only ones who brought it up on a regular basis. A recent change in federal policy attests to their effectiveness. While federal funding supported access to mammography, it gave no aid to women who needed financial assistance for breast cancer treatment. Bay Area activists pushed for new legislation to provide that support.

These activists have been distinct in their focus on public action and awareness, in addition to raising money to fund research. They largely rely on street theater, protests, and graphic displays such as a series of posters and billboards of young women with mastectomies, shown nude from the waist up. Matschuka's self-portrait of her nude torso with a mastectomy, which was shown on the cover of *Time* magazine in the early 1990s, was controversial and drew great attention to breast cancer. These billboards have been similarly received; some activists worry that the billboards may scare women from seeing their doctors and that they portray an unrealistic vision of the disease. Generally, Bay Area tactics have been radical, although a few organizations did coalesce and approach state government agencies to adopt the precautionary principle as state policy. This approach has pushed their agendas more forcefully and is less hindered by the slowness of science. While such radicalism may have caused some difficulty in gaining legitimacy and support, the luxury of engaging in it may be more affordable to California activists because the movement had already gained a sense of legitimacy by the time they initiated a response to the increased local rates of breast cancer. These tactics have been used to focus more intensely on corporate responsibility and to foster a shift in the dominant perception of breast cancer. The movement in California is distinct in its utilization of shock tactics, radical activist attitudes, and a strong focus on access to health care.

Most salient is its radical approach to public awareness. The Marin group's shows its radical nature by hosting speakers and holding events that present controversial ideas. Despite these tactics, Marin Breast Cancer Watch has encountered little resistance within the community, perhaps in part because of the widespread concern over the alarmingly high rates of breast cancer relative to the rest of the Bay Area, much less the rest of the country. The Breast Cancer Fund also plays an important role in raising money to fund breast cancer research that might not be funded by mainstream sources.

Activists in this locale have been intricately connected to environmental activism. In 1995, the Breast Cancer Action became a founding member of the Toxics Link Coalition, and helped organize the first Cancer Industry Tour. One head of a breast cancer group in the Bay Area even described her organization as having a stronger connection with environmental groups than with general breast cancer advocacy. There is even crossover in leadership between breast cancer and environmental organizations. Some Bay Area groups have had a strong environmental component from the beginning. For other groups, a transition occurred as they became more concerned about environmental causation, as noted by an activist in Breast Cancer Action:

We adopted a policy in 1998 about not taking money from known environmental polluters or pharmaceutical companies or anybody profiting on cancer. In the process of doing that, we realized that our alliances were not going to be with breast cancer organizations. . . . [I]n conjunction with that we adopted a policy about when we would join a coalition, and we can't join a coalition which violates that policy. It makes it a little tricky, but not in environmental work. So we began seeing our alliances more in the environmental field and in the broader women's health field.

Other research on the movement has shown that activists also argue as follows: "The impression today is that breast cancer is a growth industry, with Race for the Cure runs and walks in most major U.S. cities, the constant entry of new drugs and clinical trials to combat the disease, whole bookshelves devoted to the topic at local bookstores, and a cornucopia of tee-shirts, hats, pins, and pink ribbons" (Ferguson and Kasper, 2000). They believe that many corporations are getting good public relations out of donations to breast cancer efforts and have even named breast cancer a "dream cause . . . [because it is] the feminist issue without the politics" (Zones, 2000). This attitude, and related actions, exemplifies the split between the environmental breast cancer movement and the general breast cancer movement in the Bay Area. Environmental breast cancer activists have sometimes stood at the end of the Race for the Cure and handed out their own literature about environmental causation (Klawiter, 1999). Similarly, they were willing to join in a coalition to support the Breast Cancer Summit led by the mayor of San Francisco, yet also to picket outside during the gathering to criticize lack of

attention to environmental causation (Klawiter, 2001). In this process, Myhre (2001) argues, they were acting as “outsiders within.” While the movement has benefited from general breast cancer activism, in some ways there is a tenuous relationship between the two.

Radical activists in the Bay Area point to pharmaceutical companies, medical supply manufacturers, genetic testing firms, and mammography producers that are making lots of money, often by scaring women. These more radical activists point with dismay to methods like those of the gene testing company that put an ad in the *Hartford Jewish Ledger* (since Ashkenazi Jewish women are more likely to have the BRCA-1 mutation) saying, “If you carry damaged breast cancer genes and you live long enough, you are almost guaranteed to develop breast cancer.” They simultaneously claim that pharmaceutical producers and doctors often downplay side effects, including uterine cancer from Tamoxifen. In support of their views, even the National Cancer Institute notes that there are two to three times the number of mammography machines necessary. As a part of their critique of the larger breast cancer movement, these activists point out that imperial Chemical Industries, the parent company of Zeneca (later merged with Astra to become Astra-Zeneca), invented Breast Cancer Awareness Month and retains authority to approve or disapprove of all printed materials used by participating groups. Tying the political economy critique together with their belief in environmental causation, activists point out that Astra-Zeneca at the same time produces pesticides and herbicides that may be causing breast cancer (Zones, 2000).

THE FRAMEWORK FOR ACTIVISM: PERSONAL/SCIENTIFIC/POLITICAL

This overview of movement activism in the three major locales demonstrates the importance of personal experience as a political and scientific tool for the movement as a whole. Activists’ knowledge about self-exposure to environmental toxics led them first to begin a new form of movement activity and second, to challenge scientific perceptions of breast cancer.

THE PERSONAL IS POLITICAL

Environmental breast cancer activists’ work out of a framework centered in the classic feminist stance, “the personal is political.” It is the foundation of activist initiative. The notion of the personal as political underlies the movement in that the politicization of individual women’s experiences

transforms a personal problem into a public agenda. This is seen in one activist's description of the initiation of her organization:

I refused to accept the fact that 1 out of every 11 women will die of breast cancer. I remember reading [that] Gloria Steinem said, "The day the revolution starts is when one person looks back in someone's eyes and says, 'No, I refuse to budge, I refuse to accept that.'"

Our data show that activists believe clinical and support services are crucial, but not enough. For example, the traditional breast cancer movement response is to provide support groups that give emotional sustenance, while the activist movement emphasizes a model of political action that facilitates empowerment in the political realm, replacing the primary focus on individual responsibility with a focus on the responsibility of corporations, government institutions, and science. This individual empowerment was demonstrated by one scientist who had experienced breast cancer:

I was diagnosed with breast cancer and soon after that I went to a rally . . . where they asked women to come down out of the stands and stand in a chalked area that was supposedly to be the shape of Massachusetts and so many people came out of the stands, I couldn't believe it. Young women, old women, black women, white women. And I was flabbergasted, and it was at that point that I said to myself, . . . "When I went to medical school breast cancer was rare, . . . I don't have a family history. I suddenly have breast cancer. I'm looking around at hundreds of women who have breast cancer and this isn't rare."

THE ROLE OF ACTIVISM IN ADVANCING A PUBLIC PARADIGM

All interviewees, both scientists and activists, reported a strong belief that activism and social movements play a critical role in advancing research, educating the public, and changing policy about environmental causes of breast cancer. One scientist said that activists "have been the catalysts. They're the drivers. The environmental movement, the women's movement, specifically the breast cancer activist movement, they're the ones that are driving the establishment of research about environmental factors."

Activists felt that social movements were especially instrumental in the development of research into environmental causation. One long-time activist emphasized the difference between the activist and scientific perspective:

Changes that have to happen around breast cancer and all the things that influence it are going to come from the ground up. They're not going to come from the top down . . . If you think about it, activists were the first to argue for this, and some of the scientific community has been sort of dragged along.

Activists also clearly articulated their wish to advance changes in attitudes and practices outside of breast cancer. This is a demonstration of the new public paradigm they propound:

I think the role of social movements is to push the “establishment,” . . . whether it’s the scientific community, federal government, drug companies, or whoever. . . . We as activists are pushing people to broaden the scope of what they consider to be environmental problems.

Empowerment and politicization for movement activists often involve utilizing knowledge of individual environmental exposures to inform science. In this process, both social-movement actors and scientists are boundary actors crossing into a new world to advance social-movement claims. One example is the citizen/science alliance where scientists collaborate with community groups to search for potential environmental causation of diseases, especially when traditional funding sources and regulatory and public health bodies oppose such connections. Another example is provided by epidemiologists who teach lay activists enough science so that they can engage with scientists and officials, as with the National Breast Cancer Coalition’s Project Lead, where epidemiologists provide breast cancer activists with sufficient scientific capacity to serve on federal review panels (Dickersin *et al.*, 2001). Such a program helps facilitate a process of boundary crossing to advance science and make lay claims related to environmental causation credible in the eyes of science. Additionally, through both the lay challenges and the “critical epidemiology” of sympathetic professionals, we see a thoroughgoing effort to engage in public paradigm development.

SOCIAL MOVEMENT LINKS TO ENVIRONMENTAL BREAST CANCER ACTIVISM

The “personal as political” framework brings together multiple social-movement perspectives in order to highlight the political and economic issues in breast cancer causation, research, and treatment, to challenge traditional epidemiological models, and to draw attention to unrecognized geographic disease patterns. The movement appears to be a merging of actors and agendas from the environmental movement and the breast cancer advocacy movement and is rooted in the larger feminist movement, the women’s health movement, and the AIDS movement. This hybridization of movement activity reflects the boundary crossing that movement actors have accomplished without diminishing the distinct nature of their own agendas.

PRIOR RESEARCH ON THIS MOVEMENT

Previous sociological research on the movement has demonstrated how environmental breast cancer activism in California diverges from other breast cancer activism by focusing on corporate responsibility. Klawiter (1999) looks at three “culture[s] of action” in the breast cancer movement in the San Francisco Bay area. One of them, the Toxic Tour, begun by the Toxics Link Coalition, focuses on environmental causation and corporate responsibility, using feminist and public protest approaches. It confronts the “body-perfect image” presented by National Breast Cancer Awareness Month, and targets that group’s associations with corporations that simultaneously produce putative cancer-causing chemicals and breast cancer treatments. In focusing on one group in Northern California, Anglin (1997) finds that activist success has been limited due to cooptation, marginalization, and lack of access to breast cancer care. She also demonstrates how alternative social movements improve the responsiveness of science to women with breast cancer by engaging patients in disease research and the clinical trial process. Fishman (2000) studied Bay View/Hunters Point activists in San Francisco who are concerned that their community has breast cancer rates twice the average for women under 50. As a predominantly African American community exposed to a disproportionate number of hazardous sites, this group is among the few minority communities that have focused on the link between rising breast cancer rates and environmental racism. Their emphasis on environmental justice adds another dimension to breast cancer activism, even though this group is not specifically a breast cancer group.

ROOTS IN OTHER SOCIAL MOVEMENTS

The EBCM draws primarily from the environmental and breast cancer movements, as well as the AIDS, women’s health, and feminist movements in subsidiary ways. By the time the movement had begun in the early 1990s, the national breast cancer movement had already achieved major successes in several different venues. The first breast cancer movement activity took place in 1952 in the form of Reach for Recovery, a self-help organization (Weisman, 1998). Breast cancer activism took further shape in the 1970s and 1980s as a part of the general women’s health movement. In each one of the locales that we analyze, general breast cancer organizations preceded the development of the movement, whose activists often emerged from the general breast cancer movement. Their organizational strength also came partly from connections to the National Breast Cancer Coalition and other previously established organizations. The origination of the movement in

the breast cancer movement has simultaneously provided a strong basis of activism from which to organize and some tension between movement actors as the philosophy of the movement diverged from that of general breast cancer activism. Interviews with activists showed that despite these differences, there was a clear linkage between the former and latter movements.

The environmental movement provided legitimacy for environmental causation theories and offered an environmental activist network that could provide support. As environmental activists became more sophisticated in focusing on health effects, they developed a logical basis for connecting to breast cancer activism. The awareness created by a national grassroots environmental movement provided a basis of information that helped the public to understand potential environmental causation and allowed the government to recognize a constituency of voters. There is also some overlap in leadership and agendas among local environmental organizations and movement actors. The movement also had roots in the previously established women's health movement, which has worked to increase funding for research on women's illnesses, to educate women about their bodies, to include women in clinical trials, to criticize the medicalization of women's experiences, and to fight for self-determination of health care options (Ruzek *et al.*, 1997). While the movement is primarily concerned with a single disease, it broadens the implications of a health movement to address environmental issues, lay involvement in science, and corporate responsibility.

The EBCM benefited from the feminist movement in terms of increased public attention to women's issues, existing mobilized women's groups, tactics for activism, and ideological foundations. Feminism has been instrumental in developing a critique of the lack of women's involvement in science and the construction of knowledge that fails to take account of women's experiences. While most movement activists do not articulate a direct link between this movement and the broader women's movement, an implicit connection is often very clear from their philosophical stance and mission statements. For instance, one founder of a movement group, also involved in a network of environmental organizations, called breast cancer a "wedge issue" for larger gender equality and environmental issues:

We want to share leadership, and bringing ourselves [women] into balance in this issue will help to bring the whole planet into balance. I do think that environmental health, using breast cancer as a wedge issue toward that larger issue, is the issue of the millennium.

An activist in another locale extended this as follows: "We're just a breast cancer organization; you'd think we could stay focused. But breast cancer touches on every aspect of health, the economy, politics, so we get

to do it all.” These quotations, coming from different sides of the country, exemplify the overarching approach that unites these “cultures of action” into one movement. That approach specifies breast cancer as an issue with broad ramifications for gender equality and larger sociopolitical issues.

While they generally did not connect their activities to feminism, some activists did note how the AIDS movement influenced their methods. For instance, one activist articulated two specific tactics derived from it:

Originally, the founders of the organization were following the lead . . . of the NBCC [National Breast Cancer Coalition] and the AIDS activists in drawing attention to the [breast cancer] issue. Such methods included public protest, as well as promoting the inclusion of women with breast cancer in advising research.

The AIDS movement has been an exemplary model for activists in the movement in terms of citizen/science alliances, as well as public education and social protest. The methods utilized by AIDS activists, such as working with researchers to change scientific study, provided an example for future breast cancer activism. Additionally, as the movement has done, AIDS activists have utilized public protest tactics to subvert the social perception of AIDS victims, as well as to generate more funds for research and activist involvement in research (Epstein, 1998). There were some cross-memberships between ACT-UP and Breast Cancer Action, and several wealthy AIDS activists were key donors to Bay Area breast cancer groups. In the movement, involvement in public education and social protest varies across locales, while popular epidemiology and activist involvement in research permeates the entire movement.

This hybridization of movements exemplifies the activities and methods of actors in a boundary movement. For example, some activists are mainly based in the breast cancer or environmental movement but join in movement activities. Similarly, methods and their related objects are brought from the world of AIDS activism to that of the movement in order to demonstrate an entirely different point.

CITIZEN/SCIENCE ALLIANCES

The citizen/science alliance specifically exemplifies the “analytical blurrings” that take place through boundary movements. Expert and lay roles are altered, and typically rigid scientific practices take new forms as a result of these blurrings. For example, one woman spoke about the attempts of breast cancer activists to find “a place at the decision-making table” that would bring out “not just our intuition, and our native intelligence, and our common sense, and our perspectives as the patient [and] the affected community, but also [help us to really learn] the science and the medicine of breast

cancer.” Through such analytical blurring takes place in the citizen/science alliance, the role and the knowledge base of activists change.

The citizen/science alliance plays a key role, especially in New York and Massachusetts, by (1) supporting activism; (2) changing the attitudes and practices of scientists and activists; and (3) providing a new value structure to some research. While such alliances are less widely utilized in the Bay Area, activists there support the idea. Being asked to work with scientists on boards advising such research not only provided the opportunity to influence research construction and potentially improve the knowledge base for environmental causation, but also helped initiate independent research projects directed by activist involvement.

Activist involvement in science was implemented in different ways in each area largely depending on the structure mandated by the funding source. On Long Island, activist involvement was implemented through the Congressionally Directed Medical Research Program funded by the Department of Defense. Defense’s involvement stemmed from concern that the Republican capture of Congress in 1994 would result in massive cut-backs in National Cancer Institute funding. Senator Tom Harkin (D-IA) led a successful effort to place considerable funding in the Defense Department, where cuts seemed less likely; this is primarily nonmilitary research. However, activist involvement there has been less feasible than in Massachusetts because Long Island research is supported by federal agencies that have greater reticence concerning lay involvement. This is different than the experience of Silent Spring Institute where the mission statement explicitly seeks citizen/science collaboration. Silent Spring’s research has always operated on that basis. The nationally focused San Francisco organizations are not involved in research projects, though Marin activists are. However, a few individual activists in San Francisco organizations have been involved in research in a variety of ways. Overall, the Bay Area groups can be more radical in their approach since their freedom from state or federal research funding gives them more leeway. In all locales, activism connects science to public concerns to promote public awareness. For example, on Long Island, activists motivated the government to hold public hearings to inform research studies they were funding. The Massachusetts Breast Cancer Coalition’s participation in the Precautionary Principle Project is another way in which Massachusetts activists join science and the public in pursuing research and policy.

These collaborations between citizens and scientists have influenced research as well as the perceptions of scientists and activists. Activists described drastic changes in their expectations about what science could prove in terms of environmental causation, their perception of the length of time necessary to conduct research, and the processes involved. They often

became so educated about the methodology involved that they had specific recommendations for ways science could be improved in the future. Such education includes the National Breast Cancer Coalition's Project Lead, which offers intensive orientation programs to prepare advocates to serve on grant review panels and scientific advisory boards for major studies. Activists without prior experience with researchers found their feelings toward scientists had changed from fear and anxiety to mutual respect and comfort. One woman who had worked on high-level government advisory panels said, "The thing that I came away with that was most surprising was how much the scientists and the MDs have come to value the activist perspective on these panels . . . [they are] not only just putting a face on the statistics . . . they appreciate that . . . you ask the questions 'Why is this relevant? Who cares?'" Her statement exemplifies a theme that ran throughout interviews regarding the alliances: It was a transformative experience for both parties that taught them to appreciate the very different perspective of the other group. This occurred despite initial reservations.

As this process changed perspectives about science and researchers, activists raised concerns about becoming accustomed to the process of research and potentially losing their activist perspective. However, such co-optation was not common. One older activist who had played a critical role in gaining access to the research table and who was one of the first to be involved expressed this as follows:

I remember sitting at an NBCC [National Breast Cancer Coalition] board meeting years ago, and we were talking about, I don't remember the issue, and we were voting against it. It sounded like individuals really wanted it, but we decided it wasn't a good idea, and I said, "Go back to our beginnings even a couple of years ago." I said that had this question been raised then, we would have been amongst the loudest voices saying we want this and now we know it's not a good idea. [I] said, "Oh, we've become educated. But we never want to lose our fire."

We might expect scientists to worry that their legitimacy would be threatened if they worked with laypeople. Scientists involved in alliances in this movement described some initial fear, but generally felt mutual respect between themselves and activists. They often greatly appreciated the input activists supplied, in addition to their efforts in bringing research projects into existence. Of course, this may be a biased sample of scientists who were previously open to activist involvement in research, even though they came from a wide diversity of backgrounds and experience.

Apprehension and prejudice on the part of both activists and scientists against the other group were the most serious obstacles to alliances. Still, most laywomen came to feel that they were respected and that their work was worthwhile and transformative. These initial fears and prejudices

were verbalized by one activist whose experience demonstrated how this transformation took place:

I think there is a respect for bright people, and I think the assumption often is that activists are going to be hysterical women. And I think once most scientists realize that we're not hysterical women, they find themselves, you know, intrigued. And they might come to the table with a lot of prejudices and worries but I have rarely seen it continue to be a problem.

Part of the learning process for activists was gaining more knowledge about science and learning how their own knowledge was valuable to science. The activist quoted below shows the knowledge about science that laypeople acquired, as well as understanding of how alliances would work best:

I know that professionals like to build up their own vocabulary and their own aura and arena so that it can't be pierced by anyone because, after all, they paid their dues. But it's nothing more than communication and relationships. Everything is understandable and pierceable. The more people are willing to share their expertise, realizing that the others are not trying to replace their expertise or their judgment, I think the more effective we can be.

Another activist expressed the same sentiment of collaboration while still emphasizing the distinct roles of each group: "I just think that it's important that we all work together. Activists have a seat at the table, not because we want to be scientists, but because we need to push along some of the work that should have been done long ago." In the words of one scientist involved in the Long Island Breast Cancer Study Project, "And so there get to be fads in research . . . dogmas . . . of what an acceptable area of research is, and so one thing I find very helpful about having a diverse group of advocates is that it can sometimes help to . . . loosen up whatever the current dogma is and get people . . . out of whatever dogma trench they're in."

These quotations also show how activist involvement in science provides a new value structure for science. In the case of breast cancer research, the value system of science has traditionally not questioned the biomedical model. Consequently, research has typically been focused on individual factors and responsibility in treatment and prevention. This movement subverts that status quo by taking a broader view of responsibility. In doing so, the movement is able to create a new value system for science. They do this by pushing scientists to examine why they ask certain questions and not others, why they use certain methodologies, and, more important, by pushing them to examine how their research affects women with breast cancer. An activist provided an emblematic example of such questioning: a lay member of a review panel listened to a scientist give an extremely high score to a proposal simply on the basis of excellent methodology. When the laywoman pressed the scientist on the actual relevance of the project, the scientist realized the error and revised the score downward. Alliances between scientists and

laypeople are valuable not only for environmental breast cancer activists, but also for many other arenas of environmental health. Citizen/science alliances represent one of the most significant legacies of this movement.

CONCLUSIONS

Our case study of the environmental breast cancer movement aims to contribute to the social-movement literature by presenting the notion of a public paradigm that guides movement activity, by theorizing boundary movements, and by suggesting that the components addressed within social movements must be more broadly conceptualized. This movement has influenced the production of science and policy by beginning to produce a new public paradigm that informs the scientific study of women's health issues and the creation of environmental policy. This introduction of values into a supposedly value-neutral world has the potential to overcome the disconnection between environment and health, and influence the methods through which health is generally researched. The potential shift in focus from individual to corporate and government responsibility faces much resistance, but has the potential to create a more broad-based political shift in accountability. Despite existing challenges to the perspectives of this movement, it has become a unique example of a successful movement that combines health, environment, and women's movement ideologies. The movement's multilevel successes include the significant amount of public awareness it has generated, the amount of research that has been performed, the dialogue created with the scientific community, and the development of citizen/science alliances.

Our examination of the movement provides important lessons about the *character* of social movements, that focus on health and, we expect, other social movements as well. As we have shown, this social movement developed as a boundary movement that crossed the lines of several other social movements. Cultural variations make each locale of the movement somewhat different, but we believe that sufficient similarities exist to justify viewing this as a coherent national movement. It exemplifies social-movement activity at the intersection of health and the environment, which may be the largest new arena of social movements, encompassing activism concerned with lead poisoning, asthma, toxic wastes, nuclear power, food additives, biotechnology/genetically modified organisms, toxics reduction, and the precautionary principle (Brown *et al.*, 2002). This case study leads us to predict that future social movements, especially those involving health and environment issues, will arise in similar boundary-crossing fashion. We must therefore be more flexible in defining social movements and their

development. Social movements have an enormous range of facets: political challenges to governmental authority, scientific challenges to medicine and science, organizational challenges to health charities and related organizations, contention for power and authority among various organizations within a movement, cultural manifestations, and activities to increase public awareness. The movement exemplifies these multiple facets and shows how they are interlinked. Most prior social-movement theory does not provide for such a perspective, so we view this as a new way to examine social movements.

Our case study also includes important lessons about the *components* of social movements. The various issues of “fluidity” that we have addressed force us to see the flexible nature of the actors within social movements, which are not discrete objects, but changeable social phenomena. By understanding these, we discover more complex approaches to discussing not just social movements, but social change more broadly. A better understanding of boundary movements such as the environmental breast cancer movement has the potential to reshape the priorities of science and medicine, while altering the delivery of medical care.

Boundary movements such as the environmental breast cancer movement are centrally concerned with democratic participation in science and in social policy involving that science. Ordinary citizens in this movement have had the strength and ability to learn science, to demand a seat at the table for reviewing research proposals, to collaborate in research enterprises, and to press for broad extensions of citizens’ right to participate in all aspects of society. Thus, the environmental breast cancer movement continues in a long line of social movements that seek to expand democracy, doing so in a qualitatively new fashion that holds great promise for empowering citizens, while at the same time helping to improve scientific practice, improve the health of the public, and reshape the priorities of science and medicine.

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