A Historical Perspective on Breast Cancer Activism in the United States: From Education and Support to Partnership in Scientific Research

Janet R. Osuch, M.D., M.S.,¹ Kami Silk, Ph.D.,² Carole Price, A.S.N.,³
Janice Barlow, R.N., B.S.N., C.N.P.,⁴ Karen Miller,⁵ Ann Hernick, B.S.B.A.,⁴ and Ann Fonfa, B.P.S.⁶

Abstract

Breast cancer remained a hidden disease among women in the United States until the 20th century. It was initially brought into the open with public revelations from individual women, which was followed by the development of support groups and ultimately the formation of political activist groups with various priorities. Those concerned with toxic environmental exposures as a potential cause of breast cancer organized, demonstrated, and lobbied for research funding and eventually became partners in the research that arose from their efforts. One representative example was the Breast Cancer and Environment Research Centers (BCERC) Project (2003–2010), supported by the National Institute of Environmental Health Sciences (NIEHS) and the National Cancer Institute (NCI). The BCERC embedded a Community Outreach and Translational Core into its formal organizational infrastructure to ensure advocate involvement in the standing scientific subcommittees of BCERC, the first project funded by NIEHS and NCI to do so. The formal integration of advocates as partners in scientific studies focused on breast cancer is embedded in a rich history of action on the part of many courageous women. This article describes the historical evolution of breast cancer activism in the United States, which provided a critical foundation for the formation of BCERC. This description is followed by a discussion of BCERC as an example of the transdisciplinary research model, a paradigm that strives for inclusion of multiple stakeholders and increased interaction between scientists from a wide spectrum of disciplines, advocates, and lay audiences in order to more effectively conduct critical research and to translate and disseminate its findings.

Introduction

THE HISTORY OF BREAST CANCER ACTIVISM provides a context for understanding the increased awareness, improved detection and treatment programs, proliferation of social support services, and progressive increases in funding for breast cancer research. This article reviews critical steps of individual activists and advocacy groups from the early 20th century until today to illustrate how they contributed to the creation of an alternative model for conducting breast cancer research, one that integrates the public into the process at every critical step.

Cancer in the Early 20th Century—The Unspoken Affliction

Although breast cancer has affected women throughout history,¹ it was considered an unspeakable condition in America² until the 20th century. In general, cancer was seen as an incurable disease.³ The American Society for the Control of Cancer (ASCC), which became the American Cancer Society (ACS) in 1945, was cofounded by physicians and laypeople in 1913 to change this disheartening view. Two influential lay volunteers, Elsie Mead⁴ and Marjorie Illig,⁵ served in leadership roles early in the ASCC's history. Illig helped establish

¹College of Human Medicine, Michigan State University, East Lansing, Michigan.

²College of Communication Arts and Sciences, Michigan State University, East Lansing, Michigan.

³University of Cincinnati Breast Cancer Environmental Research Center, Cincinnati, Ohio.

⁴Zero Breast Cancer, University of California at San Francisco Breast Cancer and Environment Research Centers Community Outreach and Translational Core, San Rafael, California.

⁵Huntington Breast Cancer Action Coalition, Huntington, New York.

⁶The Annie Appleseed Project, Delray Beach, Florida.

the Women's Field Army, a group that recruited hundreds of thousands of women, most from social elite circles, to raise funds to promote cancer detection awareness.²

This singular focus on detection awareness changed when a soon-to-be cancer activist Mary Lasker made a research inquiry to the ASCC in 1943 after her housekeeper was diagnosed with uterine cancer. Describing her reaction to discovering the organization did no research, Lasker said, "I became infuriated when I read that there was no single place which had as much as five hundred thousand dollars for cancer research.... That wouldn't even be a suitable sum for an advertising campaign for a toothpaste."⁶ She began fundraising and eventually attempted to do so on the radio, but was told that the word "cancer" couldn't be mentioned on the air.⁶ She appealed to her influential husband, a successful advertising executive whose brother had died of cancer, and in 1946, he orchestrated radio appeals to fund cancer research, resulting in an avalanche of donations for the newly named ACS. To this day the ACS expends 25% of its budget on cancer research, an agreement that ACS reached with the Laskers.⁶ After her husband died of cancer in 1952, Lasker enlisted the help of influential officials and lobbied tirelessly for governmental funding for the National Cancer Institute (NCI), culminating in Richard Nixon's State of the Union address in 1971 declaring a "war on cancer."⁷ Lasker's relentless drive to invoke change, coupled with her wealth and marriage to a man of influence, resulted in her acceptance as a lobbyist and in accomplishments that began to change how women were perceived in circles of power.

Reach to Recovery

The ACS in the 20th century was dominated by surgeons, mostly from Memorial Sloan-Kettering Cancer Center (MSKCC) in Manhattan, New York,⁸ where the ACS had its headquarters. In 1952, Terese Lasser, the wife of a prominent attorney, went to MSKCC to have a malignant breast lump biopsied. She was treated in the standard way for the time: with a radical mastectomy. Her emotional devastation was deepened by the cavalier attitudes of her surgeon, who paid no attention to her inquiries about resumption of sexual relations, what to tell her children, how to get a prosthesis, and what kind of arm rehabilitation to perform in order to recover as quickly as possible.⁹ Lasser became angry and channeled her anger into action by founding the Reach to Recovery program in 1954 to address the issues her surgeons did not view as important. Despite the open hostility of many surgeons who banned her from their patients, she visited hospitalized women with breast cancer to offer support and reassurance.¹⁰ In 1969, the growth and popularity of the Reach to Recovery program resulted in its incorporation into the ACS. Although criticized by present-day activists for not going far enough,⁷ Reach to Recovery provided social support and encouraged women to participate in their own health care, an important antecedent to the women's health movement.

The Social Backdrop for Cultural Change in the United States

The employment of home front women in the world wars gave women a taste of independence and a new view of their capabilities. For many, returning to traditional household roles after the wars did not offer the same fulfillment as it had

prior to employment, but this dissatisfaction remained largely unspoken for several years.¹¹ The period after World War II resulted in an unprecedented number of births in the United States, a generation termed the "Baby Boomers." The consciousness of the women of this next generation was primed in 1963 by Betty Friedan's book, *The Feminine Mystique*,¹² which spoke to the silent dissatisfaction of millions of women and allowed women to be vocal about events that mattered to them; the book is often cited as the seminal event of the feminist movement in the United States. As the Baby Boomers entered college, the Vietnam war was beginning to escalate as was campus unrest, and for one of the first times, women from a variety of social classes and backgrounds began questioning those in authority, some of whom heard the women and began interacting with them.

Women were further empowered by the 1971 publication of the Boston Women's Health Book Collective health manual exclusively for women entitled *Our Bodies, Ourselves*.¹³ This publication, seen as the beginning of the women's health movement, was revolutionary for the time, encouraging women to understand and own their bodies, rather than succumb to the authoritarian attitudes of their doctors, and empowering them to form disease-specific support groups.^{11,14} Coincident with this was the passage of Title IX of the Educational Amendments of 1972, a law that required educational institutions receiving federal funds to take "specific steps designed to encourage individuals of the previously excluded sex to apply for admission." Although most known for its influence on women's athletics, this law also allowed for the admission of women into professional schools, including those of medicine and law, at a time when those very applicants had been groomed to become activists in college. Because of the length of professional training, their voices would not be heard for some time. However, due to the congruence of these historical events, the complacency with which breast cancer treatment had been accepted by women was forever changed.

Women With Breast Cancer Find a Voice

In 1970, surgeons in the United States routinely biopsied a breast lump and if malignant, performed a radical mastectomy at the same operation, considering it a life-saving procedure. When Babette Rosmond, an editor of *Seventeen* magazine, found a lump in her breast, she became acquainted with and pursued breast preservation as an alternative treatment. This approach was first presented to the public by George Crile, M.D., whose wife had died of breast cancer, in his book *What Women Should Know About the Breast Cancer Controversy*.¹⁵ Under a pseudonym, Rosmond wrote passionately and candidly of her experience with breast cancer in her 1972 book *The Invisible Worm*.¹⁶ She was among the first to publicly challenge, in writing, the assumptions of surgeons treating women with breast cancer.¹⁷ In an often-quoted excerpt, she describes her initial surgeon's reaction when she refused the one-step procedure, terming her "a very silly and stubborn woman," adding "In three weeks, you may be dead."¹⁷ This attitude was pervasive among surgeons and fueled the outrage of an emerging number of outspoken women diagnosed with breast cancer.

One of the most famous was Shirley Temple Black, the childhood movie star, who was diagnosed with breast cancer

in 1972. She was the first public figure to write about her experience in a women's magazine.^{18,19} Like Rosmond, her message emphasized her right to decide what was done to her body and her choice to have a biopsy prior to any needed treatment. Her statement that "The doctor can make the incision; I'll make the decision,"¹⁸ written in the accessible forum of a magazine, empowered innumerable women in mainstream America to question their previously passive role in the patient-physician relationship.

Betty Ford, Happy Rockefeller, and Betty Rollin

The year 1972 ushered in the Breast Cancer Detection and Demonstration Project (BCDDP) of the NCI and the ACS, a program promoting breast cancer screening in asymptomatic women. Two years later, Betty Ford, the First Lady of the country for just 6 weeks, had a routine breast examination and a malignant lump was discovered.²⁰ She was treated with a radical mastectomy, not unusual at that time. What was remarkable was that she shared her diagnosis with the American public through televised press conferences. Three weeks after Betty Ford's disclosure, Happy Rockefeller, the wife of Vice-President Nelson Rockefeller, discovered a malignant lump in her breast and also disclosed her diagnosis to the public. The disclosures of both women, coupled with the influence of television on public views, resulted in large increases in the numbers of women who learned techniques for breast self-examination and participated in the BCDDP.²¹ One year later, Betty Rollin, an NBC news correspondent who had a delayed diagnosis of breast cancer at age 37, wrote a book about her experiences, entitled *First You Cry*,²² which became a bestseller and was subsequently made into a television movie.²³ These private experiences made public by prominent, highly visible women via national television promoted discussion of symptoms and provided encouragement to seek medical treatment early rather than once symptoms were advanced.²⁴ These disclosures coupled with the political climate of the country, increasing use of the media, the coming of age of the Baby Boomers, the women's health movement, and the controversy regarding breast cancer treatment coalesced to initiate a new era of activism for women affected with breast cancer.

From Breast Cancer Awareness to Breast Cancer Activism

Rose Kushner, a medical journalist, discovered a lump in her breast in July of 1974. She wrote several indignant essays advocating that women know as much as possible before deciding on treatment...a concept so out of the ordinary that Leopold wrote that she "...laid the groundwork for what eventually would become the modern culture of breast cancer."²⁵ By the early 1980s, several local breast cancer support groups had been created throughout the country. Kushner recognized the need for an integrated presence and partnership of these groups to enhance their visibility and voice, and thus she partnered with other advocates in 1986 to form the National Alliance of Breast Cancer Organizations. Her prolific writings outlined the treatment alternatives for breast cancer, empowering countless women to make decisions consistent with their own value systems and preferences. Kushner's ability to question those in authority—medical personnel and

researchers alike—and to do so publicly set the stage for the activism that followed her death in the early 1990s.²⁶

Questioning Societal Assumptions

An award-winning poet, lesbian, African-American, and feminist, Andre Lorde was diagnosed with breast cancer in 1980 at age 44. In her personal narrative, *The Cancer Journals*,²⁷ she was one of the first to criticize societal views of breast cancer, which she saw as oppressive. She was particularly critical of the assumption that women with a mastectomy should wear a prosthesis or have breast reconstruction in order to feel whole. Instead, she viewed these approaches as symbolic of disempowerment and alienation of women with breast cancer from one another.²⁸ Lorde died of breast cancer in 1992, a year before she could view the August 15, 1993, cover of *The New York Times Magazine*, which featured the photographer Matuschka modeling her mastectomy-scarred chest with the headline "You Can't Look Away Anymore." Although not the first photograph of a woman after a mastectomy to be published,²⁹ Matuschka's image was the first to be viewed by mainstream America, and many perceived it as shocking; however, women who had been subjected to a mastectomy welcomed it as an acknowledgment of their reality. The stage was set to make the ravages of the disease more visible.³⁰

Focused Philanthropy

In 1981, just prior to her sister Suzy's death from breast cancer at age 36 years, Nancy Brinker promised her she would do whatever she could to "find a cure for breast cancer." With a background in fundraising and the support of her wealthy husband,³¹ Brinker founded the Susan G. Komen Breast Cancer Foundation in 1982, 2 years before her own diagnosis of breast cancer. Thus began the first public effort to raise money specifically for the disease. Renamed Susan G. Komen for the Cure in 2007, the organization has been criticized by advocates for its sometimes conservative approaches and liaisons with the corporate world.³² Nonetheless, the fundraising efforts have raised millions of dollars, partially targeted for research, providing an opportunity for consumers to have a voice in the kind of research that is funded.

Around this same time, women with breast cancer observed from AIDS activists that disease-specific efforts to increase research funding could be successful.³³ More than any other single event, the governmental response to AIDS activists resulted in a new constituency, one that promoted breast cancer advocacy and activism as an effective means to eradicate the disease. Specifically, women began to view themselves concurrently as empowered individuals capable of intelligent interchange with scientists and as activists with the goal of pressuring the government to increase research funding.³³

An Overview of Breast Cancer Policy-Making

Bill Clinton, sympathetic to women's causes, was elected to the White House in 1992, just after the U.S. Supreme Court decision that upheld the restrictive abortion law of Missouri and the televised Supreme Court hearings of Judge Clarence Thomas featuring allegations by Anita Thomas of sexual harassment. That election almost doubled the number of women

in Congress, among them Patricia Schroeder and Olympia Snowe, who focused their efforts in part on breast cancer because it was a less polarizing health issue than others (e.g., abortion). Along with the newly formed breast cancer advocacy groups, the political stage was set for the initiation of legislative action and policy-making in the breast cancer arena.³⁴

Susan Love and the Work of Female Surgeons

Breast cancer has traditionally been a disease treated and controlled by surgeons. As a result of the passage of the aforementioned Title IX, women began entering medical school in record numbers in the mid-1970s. A handful of these women emerged from medical training as board-certified surgeons in the mid-1980s, and some of them specialized in breast surgery. Women with breast cancer now not only had a choice in their surgical treatment, but in some communities, the gender of their surgeon as well.

By far the most well-known female breast surgeon was Susan Love, M.D., an outspoken, intelligent, articulate, and witty woman, who questioned the assumptions of the medical world about breast cancer and the treatment of women with the disease. She served a key leadership role in working with the public to educate and empower people to advocate for more research funds.³⁵

Community Grassroots Organizations

In the early 1990s, politically active organizations focusing on breast cancer began to emerge, including the Women's Community Cancer Project in Massachusetts, the Women's Cancer Resource Center in California, Breast Cancer Action in the San Francisco Bay area, and the Mary Helen Mautner Project in Washington, DC. Each of these fledgling organizations had a decidedly political agenda aimed at confronting the oppression and silence surrounding the causes and prevention of breast cancer. By definition for these organizations, this meant focusing on toxic environmental issues.

Advocacy and the Long Island Project

Statistics released by the New York State Department of Health in the early 1990s documented that the incidence of breast cancer was higher among women from Nassau (116.1/100,000) and Suffolk (112.5/100,000) counties, located on Long Island, than in other parts of the state (96.3/100,000). A follow-up study released by the Health Department and the Centers for Disease Control and Prevention concluded that these statistics could be explained by population risk factors in the region: Jewish ethnicity, affluence, delayed childbearing, and lack of breastfeeding.³⁶irate that the report did not address environmental influences and concerned about the heavy use of pesticides in the farmlands of the past on Long Island, Karen Miller and others in the region formed One-in-Nine: The Long Island Breast Cancer Coalition. At the same time, Lorraine Pace spearheaded a community-based door-to-door campaign during which women constructed their own maps documenting regional breast cancer clusters. Miller then organized a demonstration at the Nassau County courthouse, which was covered by *Newsday* and *The New York Times Magazine*. The Long Island women subsequently lobbied

Congress at both state and national levels to fund research targeting environmental links to breast cancer.

In 1993, the NCI and the National Institute of Environmental Health Sciences (NIEHS) funded a series of studies, the Long Island Breast Cancer Study Project, that examined environmental factors and breast cancer risk on Long Island and in other parts of the region with an unusually high incidence of breast cancer. To date, most of the results of exposure to environmental toxins have not shown an association with breast cancer risk, perhaps due to the limitations of the study design and techniques for measuring exposure at the time.³⁶ Regardless of the findings, Long Island activists learned crucial lessons that would shape their future. Because they had not had a voice in the factors examined, one of their major concerns—that their drinking water was contaminated—was not addressed in the research. As funding demands continued, advocates insisted they be given a seat at the decision-making table from the project's beginning. This was a foreign concept to most scientists and resulted in a paradigm shift that was to shape the future of funded studies in environmental science.

The National Breast Cancer Coalition

In May of 1991, several different advocacy groups met in Washington, DC, to form the National Breast Cancer Coalition (NBCC). The goals of the NBCC are to increase research funding for breast cancer, access to health care for all women, and the influence of activists in breast cancer decision-making.³⁷ Lessons from AIDS activists ensured that lobbying would serve a critical role in meeting the organization's mission, and the NBCC hired a professional lobbyist to represent it on Capitol Hill. One of their first efforts was aimed at collecting 175,000 signatures to deliver to Congress demanding more money for breast cancer research. The effort was very successful, resulting in 600,000 signatures delivered to Capitol Hill in the fall of 1991.³⁸ In 1992, Fran Visco, an attorney and breast cancer survivor, became the first president of the NBCC. Framing breast cancer not only as a health issue but also as a political issue that can be impacted through public policy and pressure, the NBCC held hearings in 1992 to ask scientists how much money it would take to eradicate the disease. Based on the hearings and other considerations, the coalition determined that the federal government should spend a minimum of \$300 million more than the funds already allocated for breast cancer research, and the organization set out on a multi-pronged strategy to increase breast cancer funding and awareness. In 1993, a second petition to Congress for similar reasons resulted in the delivery of over 2.6 million signatures to then President Clinton, whose mother had been diagnosed with breast cancer.³⁸ The NBCC was successful in having Clinton establish a National Action Plan on Breast Cancer, an effort that involved policymakers, scientists, providers, and consumers sitting at the same table and working together towards the same end. To prepare advocates, the NBCC created Project LEAD (Leadership, Education, and Advocacy Development), an intensive 4-day training program designed to prepare consumers for the important roles they wished to assume in having input into what research projects received funding, how the projects were designed, and how the public was informed of the results.³⁹ The fundraising and advocacy efforts of the NBCC continue

to thrive; the organization has developed into a coalition of hundreds of organizations and tens of thousands of individuals across the United States.

The Department of Defense Breast Cancer Research Program

The Department of Defense (DOD) peer-reviewed Breast Cancer Research Program (BCRP) was created in 1992 as a result of the NBCC's \$300 Million More campaign. Due to NBCC's efforts and the Congressional leadership of senators Tom Harkin (D-IA) and Alfonse D'Amato (R-NY), in fiscal year 1993 Congress appropriated \$210 million from the DOD research and development budget for a breast cancer research program administered by the Department of the Army. Although the appropriation met resistance from some military personnel, it was supported by the Director of Research and Development of the Army, General Richard Travis, who was quoted as saying to representatives of the NBCC, "Ladies, I'm going to lead you into battle and we are going to win this war."¹⁴ Over \$2 billion has been appropriated to the BCRP since its inception. The BCRP brings scientists and consumers together and has changed the way that breast cancer funding is decided. The Institute of Medicine's 1997 review of the program commended the involvement of consumer advocates in all aspects of priority setting and the peer-review process, indicating a new level of support for research and funding models that include a range of stakeholders in the decision-making process. The BCRP reports its progress to scientists, policy-makers, and the public during biennial public meetings called the Era of Hope conferences. The initial meeting in 1997 marked the first time a federally funded program reported back to the public in detail not only about the amount of the funds used, but also about the research undertaken, the knowledge gained from that research, and the future directions to be pursued. The meetings bring investigators from different fields together to share knowledge and ideas that could lead to novel approaches to address difficult research problems.

Breast Cancer and the Environment in the San Francisco Bay Area: A Study in Activism

By the mid-1990s, organizations had been formed in the San Francisco Bay area, an epicenter for political activism, that focused on either preventable causes of breast cancer, including environmental ones (The Breast Cancer Fund), or represented women out of the mainstream, including lesbians of multicultural origin (The Women and Cancer Project) as well as poor and medically marginalized women (The Charlotte Maxwell Complementary Clinic). By the fall of 1994 two main events had increased ties between breast cancer and environmental movements in the San Francisco Bay Area. First, the Toxic Links Coalition formed, representing an alliance of feminist women's health and environmental justice organizations and community groups that focused on the links between environmental toxins and public health. Second, and coincident with the coalition's formation, was the release of a report from the Northern California Cancer Center revealing that the San Francisco Bay Area had the highest incident rates of invasive breast cancer in the world, the highest being in Marin County (127.8/100,000 compared to a state average of 105.5/100,000).⁴⁰ This report was circulated

among attendees at a public hearing in 1995 in San Francisco City Hall,⁴¹ along with a second report that cited breast cancer incident rates for African American women under the age of 50 years in the Bay View Hunters Point area to be 50% higher than expected and the highest in the city. This geographical location, also the site of the origin of the Toxic Links Coalition, intensified the synergy between the breast cancer and environmental movements in the area. In 1995, Zero Breast Cancer (formerly Marin Breast Cancer Watch) was founded to discover and eliminate the reasons for Marin's high breast cancer rates, which were assumed to be environmental in origin.

The California Breast Cancer Research Program (CBCRP) allied itself with the breast cancer advocacy community and provided funding in 1997 for the Adolescent Risk Factors Study, a survey to measure environmental factors, lifestyle habits, and risk factors. As the study's funding agency, CBCRP required researchers to use the Community Based Participatory Research (CBPR) process, which spurred new levels of communication between scientists and activists. In May of 2002, the International Summit on Breast Cancer and the Environment: Research Needs was convened, bringing together experts from a wide array of disciplines and the advocacy community. Advocates at the summit asserted that researchers had an obligation to involve community members in the research process by adopting a CBPR approach because doing so would make results more relevant and understandable for personal and public policy decision-making. This message to researchers echoed the lessons that had been learned during the Long Island Project, and the summit represented one of many public forums that helped set the stage for the Breast Cancer and Environment Research Centers (BCERCs) and the emergence of the transdisciplinary model.

The NIEHS: History of the Funding of BCERC

In 1993, the NBCC began lobbying Congress about breast cancer causation and toxic environmental exposures. Congressional sources, partially because of NBCC lobbying efforts, urged NIEHS to create multidisciplinary research centers to pursue research on mammary gland biology, carcinogenesis, and environmental influences on breast cancer. Dr. Kenneth Olden, the director of the NIEHS at the time, reached out to the NBCC to learn more about their concerns and to involve them in the Institute's priority setting process. He met with the Board of Directors of the NBCC and with its senior leadership on many occasions and spoke at several of their national meetings. These meetings were instrumental in establishing trust between the NIEHS and the activist community. Dr. Olden later explained that "the NIEHS got involved in breast cancer research because of the substantial evidence that implicates the environment" (K. Olden, personal communication to CP). His commitment to listening to the public represented a turning point, given his position at the NIEHS, and advocates responded favorably.

"Dr. Olden provided access to the scientific elite and broke down barriers between researchers and the public...he infused the advocates with hope. The advocates were validated, and subsequently motivated, to continue the work. I trusted him, and therefore I trusted the NIEHS. The NIEHS hears us, and in return we do all that we can to promote the institute. They know that we have more to contribute than blood, urine and tissue samples." (Karen Miller, personal communication to JRO)

In April, 2002, Dr. Olden and Fran Visco co-chaired a "stakeholder" meeting in Charlotte, North Carolina, the purpose of which was to gather input into the creation of a BCERC program. Entitled the NIEHS Brainstorming Session on Breast Cancer and the Environment, the one-day workshop invited scientists, consumers, and public interest groups from around the country, as well as representatives from the NCI. With the passion and support of Dr. Gwen Collman of the NIEHS and Dr. Deborah Winn from the NCI, Request for Applications (RFA) ES-03-001 was released on November 11, 2002. The first sentence of the RFA read as follows:

"The...NIEHS and the...NCI invite applications to create research centers in which multidisciplinary teams of scientists, clinicians, and breast cancer advocates work collaboratively on a unique set of scientific questions that focus on how chemical, physical, biological, and social factors in the environment work together with genetic factors to cause breast cancer."

The RFA then detailed the requirement that partnerships be established between scientists, breast cancer advocates, and community members. This became the first time in history at the National Institutes of Health (NIH) that such a requirement was overtly articulated for breast cancer research. Breast cancer activists were instrumental in advocating for the funding of BCERC as well as the priorities addressed in the submitted research proposals.

In 2003, four centers were chosen to participate in the 7-year BCERC program, which was jointly funded by NIEHS and the NCI through the U-01 cooperative agreement mechanism. The four centers included The Fox Chase Comprehensive Cancer Center, Michigan State University, the University of California San Francisco Comprehensive Cancer Center, and the University of Cincinnati. Each of these centers included a Community Outreach and Translation Core (COTC) comprised of approximately 10 advocates to serve as partners on the grant. The COTC was charged with the role of participating in work groups, project cores (Biology, Epidemiology, and COTC), subcommittees, and scientific meetings; helping to plan annual conferences and integration meetings; recruitment of participants for human studies; and translation and dissemination of research findings for lay populations. Biologists and epidemiologists were represented within the COTC subcommittee as well. The cross-fertilization between BCERC subcommittees enlarged the vision of both scientists and COTC members as each attempted to widen their lens to include the viewpoints and input from the other as they pioneered a novel model for conducting research.

A New Paradigm for Research

Transdisciplinary research requires researchers and stakeholders (e.g., advocates, funding agencies) to broaden their purview regarding the participatory nature of research,⁴² and adopt a CBPR approach across all levels of a project as advocated by the CBCPR in the late 1990s. Transdisciplinary research is designed to "transcend individual departments or specialized knowledge bases because they are intended to solve...research questions that are, by definition, beyond the purview of the individual disciplines."⁴³ The complexity of breast cancer warrants a comprehensive approach to its eradication, and the transdisciplinary research model provides a higher level of integration among stakeholders in its

efforts to investigate and communicate research findings to the public.

The BCERC approached transdisciplinary research by creating teams of advocates, biologists, epidemiologists, and communication researchers who were organized across the three cores (biology, epidemiology, and COTC) at each of the centers. Collectively, the cores shared a clear research vision to investigate and communicate about the influence of environmental factors on breast cancer. However, in practice, communication within the BCERC revealed conflicting ideas and priorities because reasons for participating in the BCERC varied considerably among advocates and scientists based on their orientations to breast cancer as a personal, women's health, societal, and/or research problem. These differing orientations resulted in conflict, heated discussions, compromises, and sometimes synergistic outcomes for the BCERC. Working collectively in a transdisciplinary model is not a panacea for research; it requires more time to problem solve, more policies and protocols to smooth group processes, more meetings in person and over the phone, and more decision-making and clarity in decision-making processes—and regardless of these efforts, it is unlikely everyone will be satisfied. One fundamental question that remains for the BCERC is when to report research findings to the lay public. Scientists will consistently assert the need for further research before sharing information, particularly when a public health issue is at stake, while advocates support the precautionary principle, which recommends sharing information in a more timely fashion.⁴⁴ Clearly, the transdisciplinary research paradigm deserves reflection and communication, work that has recently begun.⁴⁵

Overall, the historic involvement of the advocate community in the BCERC project served to enhance understanding of the strengths and limitations of research for advocates, while in turn providing synergism and deepened meaning to their work for the scientists. All involved agree that we learned invaluable lessons from the process, including an increased ability to trust one another, and that we became better scientists and better advocates because of it.

Conclusion

Women have had major roles in the evolution of the current culture of breast cancer in the United States, and expectations that doctors present treatment options is mainstream and in some cases legislated because of the women's work. Currently, the insistence that the public has meaningful interaction with environmental research scientists about the causes and prevention of the disease has resulted in a new paradigm in the conduct of scientific research. Neither of these shifts would have occurred without the involvement of outspoken and courageous women who were willing to share their personal stories with the public early in the 20th century. Among other important historical events, the rise of feminism and the women's health movement in the 1960s and 1970s provided a cultural context that empowered women with breast cancer to form support groups, question their doctors, lobby their legislators, and interact with the research enterprise, demanding a seat at the table in research especially focused on toxic exposures in the environment. In return, breast cancer advocates continue to be committed to lobby for the funding of research inquiries on breast cancer and the environment until there are clearly defined causes and ways

to prevent the disease. Future immediate advocacy goals include increasing advocate involvement in the scientific research and increasing the funding allocated to disseminate research findings to the public. The transdisciplinary model exists due to the culmination of efforts by passionate women impacted by breast cancer who were never satisfied with the status quo; they gave voice to a silent disease and continue to have a voice in the ongoing quest to eradicate breast cancer.

Acknowledgment

This manuscript was written within the Breast Cancer and the Environment Research Centers, a network of centers led by the Fox Chase Cancer Center, Michigan State University, the University of Cincinnati, and the University of California San Francisco Comprehensive Cancer Center and supported by grant numbers UO1 ES/CA12770, 012771, 012800, and 012801 from the NIEHS and NCI, NIH, Department of Health and Human Services. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIEHS or NCI, NIH.

Author Disclosure

No competing financial interests exist.

References

1. Wagner FB. History of breast disease and its treatment. In: Bland KI, Copeland EM (eds) *The Breast—Comprehensive Management of Benign and Malignant Diseases*. Philadelphia: WB Saunders, 1998, pp 1–16.
2. Lerner B. Inventing a curable disease: breast cancer control after World War II. In: Lerner B (ed) *The Breast Cancer Wars: Fear, Hope, and the Pursuit of a Cure in Twentieth-Century America*. Oxford: Oxford University Press, Inc., 2001, pp 41–68.
3. Ross W. Halfway to victory. In: Ross W (ed) *Crusade: The Official History of the American Cancer Society*. New York: Arbor House, 1987, p 3.
4. Batt S. “Perfect People”: cancer charities. In: *Patient No More: The Politics of Breast Cancer*. Chartottetown, PEI, Canada: Gynergy Books, 1994, 215–216.
5. Ross W. Transformation. In: Ross W (ed) *Crusade: The Official History of the American Cancer Society*. New York: Arbor House, 1987, pp 34–35.
6. Ross W. Transformation. In: Ross W (ed) *Crusade: The Official History of the American Cancer Society*. New York: Arbor House, 1987, p 33.
7. Boehmer U. A History of AIDS and breast cancer activism. In: Boehmer U (ed) *The Personal and the Political: Women’s Activism in Response to the Breast Cancer and AIDS Epidemics*. Albany: State University of New York Press, 2000, pp 8–9.
8. Lerner B. Inventing a curable disease: breast cancer control after World War II. In: Lerner B (ed) *The Breast Cancer Wars: Fear, Hope, and the Pursuit of a Cure in Twentieth-Century America*. Oxford: Oxford University Press, Inc., 2001, p 50.
9. Lerner B. “I alone am in charge of my body”: breast cancer patients in revolt. In: Lerner B (ed) *The Breast Cancer Wars: Fear, Hope, and the Pursuit of a Cure in Twentieth-Century America*. Oxford: Oxford University Press, Inc., 2001, pp 143–144.
10. Ross W. Reach to recovery. In: Ross W (ed) *Crusade: The Official History of the American Cancer Society*. New York: Arbor House, 1987, pp 161–71.
11. Leopold E. Breast cancer within the history of the women’s health movement. In: Leopold E (ed) *A Darker Ribbon: Breast Cancer, Women, and Their Doctors in the Twentieth Century*. Boston: Beacon Press, 1999, pp 188–214.
12. Friedan B. *The Feminine Mystique*. New York: W. W. Norton & Company, 1963.
13. Boston Women’s Health Book Collective. *Our Bodies, Ourselves*. New York: Simon & Schuster, 1971.
14. Gillon S, Olaquera N. The “second stage” and other struggles for women. In: Gillon S, Olaquera N (eds) *Boomer Nation: The Largest and Richest Generation Ever, and How It Changed America*. New York: Free Press, 2004, pp 191–211.
15. Crile G. *What Women Should Know about the Breast Cancer Controversy*. New York: Macmillan, 1973.
16. Campion R. *The Invisible Worm*. New York: Macmillan, 1972.
17. Lerner B. “I alone am in charge of my body”: breast cancer patients in revolt. In: Lerner B, ed. *The Breast Cancer Wars: Fear, Hope, and the Pursuit of a Cure in Twentieth-Century America*. Oxford: Oxford Press, Inc., 2001, pp 151–158.
18. Black S. Don’t sit home and be afraid. *McCall’s Magazine* 1973;82:114–116.
19. Lerner B. No shrinking violet: Rose Kushner and the maturation of breast cancer activism. In: Lerner B (ed) *The Breast Cancer Wars: Fear, Hope, and the Pursuit of a Cure in Twentieth-Century America*. Oxford: Oxford Press, Inc., 2001, pp 170–171.
20. Olson J. Out of the closet: breast cancer in the 1970s. In: Olson J (ed) *Bathsheba’s Breast: Women, Cancer and History*. Baltimore: Johns Hopkins University Press, 2002, pp 132–134.
21. Lerner B. No shrinking violet: Rose Kushner and the maturation of breast cancer activism. In: Lerner B (ed) *The Breast Cancer Wars: Fear, Hope, and the Pursuit of a Cure in Twentieth-Century America*. Oxford: Oxford University Press, 2001, p 173.
22. Rollin B. *First You Cry*. Philadelphia: Lippincott, 1976.
23. Olson J. Out of the closet: breast cancer in the 1970s. In: Olson J (ed) *Bathsheba’s Breast: Women, Cancer and History*. Baltimore: The Johns Hopkins University Press, 2002, pp 138–139.
24. Lerner B. No shrinking violet: Rose Kushner and the maturation of breast cancer activism. In: Lerner B (ed) *The Breast Cancer Wars: Fear, Hope, and the Pursuit of a Cure in Twentieth-Century America*. Oxford: Oxford Press, Inc., 2001, 174–175.
25. Leopold E. From the closet to the commonplace, 1945–1975. In: Leopold E (ed) *A Darker Ribbon: Breast Cancer, Women, and their Doctors in the Twentieth Century*. Boston: Beacon Press, 1999, pp 232–238.
26. Lerner B. No shrinking violet: Rose Kushner and the maturation of breast cancer activism. In: Lerner B (ed) *The Breast Cancer Wars: Fear, Hope, and the Pursuit of a Cure in Twentieth-Century America*. Oxford: Oxford University Press, Inc., 2001, pp 175–181.
27. Lorde A. *The Cancer Journals*. London: Sheba Feminist Publishers, 1980.
28. Rosenbaum M, Roos G. Women, their bodies, and the illness experience: women’s experiences of breast cancer. In: Kasper A, Ferguson S (eds) *Breast Cancer: Society Shapes an Epidemic*. New York: Palgrave, 2000, p 157.

29. Lerner B. The past as prologue: what can the history of breast cancer teach us? In: Lerner B (ed) *The Breast Cancer Wars: Fear, Hope, and the Pursuit of a Cure in Twentieth-Century America*. Oxford: Oxford University Press, Inc., 2001, p 270.
30. Ferguson S, Kasper AS. Introduction—living with breast cancer. In: Ferguson S, Kasper AS, eds. *Breast Cancer: Society Shapes an Epidemic*. New York: Palgrave, 2000, p 6.
31. Brinker N. *My Story. The Race is Won One Step at a Time*. New York: Simon and Schuster, 1990.
32. Brenner B. Sister support: women create a breast cancer movement. In: Kasper AS, Ferguson S (eds) *Breast Cancer: Society Shapes an Epidemic*. New York: Palgrave, 2000, pp 335–336, 343, 345, 347.
33. King S. The culture of survivorship and the tyranny of cheerfulness. In: King S (ed) *Pink Ribbons, Inc: Breast Cancer and the Politics of Philanthropy*. Minneapolis: University of Minnesota Press, 2006, pp 105–108.
34. Weisman C. The politics of breast cancer: breast cancer policymaking. In: Kasper AS, Ferguson S, eds. *Breast Cancer: Society Shapes an Epidemic*. New York: Palgrave, 2000, 214–219.
35. Stabiner K. *To Dance with the Devil: The New War on Breast Cancer*. New York: Delta, 1997.
36. Winn DM. Science and society: the Long Island Breast Cancer Study Project. *Nat Rev Cancer* 2005;5:986–994.
37. Lerner B. The past as prologue: what can the history of breast cancer teach us? In: Lerner B (ed) *The Breast Cancer Wars: Fear, Hope, and the Pursuit of a Cure in Twentieth-Century America*. Oxford: Oxford University Press, Inc., 2001, p 159.
38. Altman R. *Waking Up, Fighting Back: The Politics of Breast Cancer*. New York: Little, Brown, 1996.
39. Weisman C. The politics of breast cancer: breast cancer policymaking. In: Kasper AS, Ferguson S, eds. *Breast Cancer: Society Shapes an Epidemic*. New York: Palgrave, 2000, pp 224–226.
40. Perkins C, Morris C, Wright W. *Cancer Incidence And Mortality in California by Race/Ethnicity, 1988–1993*. Sacramento, CA: California Department of Health Services, Cancer Surveillance Section, 1996.
41. Ley B. From touring the streets to taking on science. In: *From Pink to Green: Disease Prevention and the Environmental Breast Cancer Movement*. Piscataway, NJ: Rutgers University Press, 2009.
42. Hall KL, Feng AX, Moser RP, Stokols D, Taylor BK. Moving the science of team science forward: collaboration and creativity. *Am J Prev Med* 2008;35:S243–249.
43. Gebbie K, Rosenstock L, Hernandez LM (eds). *Who will keep the public healthy? Educating health professionals for the 21st century*. Washington, DC: The National Academies Press, 2003.
44. Raffenberger C, Tickner JE. *Protecting Public Health and the Environment: Implementing the Precautionary Principle*. Washington DC: Island Press, 1999.
45. Silk KJ, Neuberger LB, Nazione SA, Osuch J. The Breast Cancer and the Environment Research Centers: a transdisciplinary model. In: Query J, Brann M (eds) *Contemporary Issues in Health Communication: Theoretical and Practical Case Studies*. New York: Springer Publishing, 2010.

Address correspondence to:

Janet R Osuch, M.D., M.S.
 Professor of Surgery and Epidemiology
 A253 Life Sciences
 College of Human Medicine
 Michigan State University
 East Lansing, MI 48824

E-mail: janet.osuch@hc.msu.edu