

CHAPTER 1

A History of AIDS and Breast Cancer Activism

A synopsis of the history of AIDS and breast cancer activism involves focusing on three different eras. Prior to the 1980s, organizational responses to cancer emerged, many of which are still in existence today. The second era encompasses the 1980s, during which time grassroots organizing occurred in response to the suddenly emerging new disease, AIDS. Finally, the third era begins roughly with the late 1980s and early 1990s. During this time, AIDS organizations became firmly established and grassroots breast cancer activism emerged.

What follows is a brief summary of various events that preceded the cancer and AIDS activism of today. Several comprehensive histories of cancer, AIDS, and the women's health movement have been written by others. I will draw heavily on these works. My selection of historic context attempts to provide the reader with what I consider essential information for a discussion of today's women cancer and AIDS activists who are the focus of this book.

Breast cancer organizing in the pre-AIDS era

Breast cancer has existed as a disease for a long time. During this time, there have been various organizational responses to the disease

that preceded the breast cancer activism of the 1990s. It is beyond the scope of this book to reiterate the various phases of organizational responses to cancer, yet for an understanding of today's organizing around cancer it is essential to know that women have been central in responding to cancer in earlier times.

James Patterson chronicles cancer within American culture. He writes, "Nineteen thirteen marked the completion of the first wave of organization and philanthropy in the field of cancer research."¹ During that year, the American Society for the Control of Cancer was formed. This voluntary health organization did not engage in research directly. Rather, the organization compiled statistics and educated the public about cancer, its early warning signs, and detection. This precursor of the American Cancer Society was founded by a woman, Mrs. Robert G. Mead. Its founding was publicized by the *New York Times* as "Rich Women Begin a War on Cancer."² This voluntary organization, the American Society for the Control of Cancer, continued for many years through ups and downs and experienced a change in its leadership from a medical elite towards more business-minded people, who in 1946 renamed the organization the American Cancer Society.

Patterson mentions Mary Lasker as being a key figure in transforming the more modest American Society for the Control of Cancer into the financial giant, the American Cancer Society (hereafter, ACS). Ironically, "Lasker was the wife of advertising tycoon Albert Lasker, who pioneered a campaign urging women to smoke, using the slogan, 'Reach for a Lucky Instead of a Sweet.'"³ Despite women's influential role in the formation and continuation of the ACS, the organization was criticized, beginning in the 1970s, for its gender politics. The ACS is a male-dominated agency in the sense that men hold the powerful positions, although a majority of women donate their time and volunteer for the organization and its programs, such as "Reach to Recovery." Terese Lasser, a woman who had undergone a mastectomy herself, began the Reach to Recovery program in 1952. This program was later adopted by the American Cancer Society.⁴

Today, the American Cancer Society is considered a prominent part of the "cancer establishment"⁵ and is much criticized by cancer activists. The ACS grew into a multimillion dollar project; it is the largest private charity organization in the United States.⁶ and calls more than 2 million volunteers its real strength.⁷

Criticism of the cancer establishment was voiced in the late 1970s and early 1980s.⁸ Among the criticism was that the cancer establishment is a high-powered, special-interest lobby that held a lot of financial

power and whose members made their living off of cancer.⁹ The ACS was specifically criticized for its constantly cheerful attitude it puts forward, despite a continuous increase in cancer. In addition to knowing about how the best known bureaucratic cancer organization (ACS) came into existence, and how women made an important contribution to cancer organizing, I shift the attention to another early precursor of cancer in the public arena.

During the early 1970s, despite anti-establishment feelings that had been triggered by the Vietnam War, the confidence and expertise of medical experts was still unchallenged. Even though Patterson acknowledges that many expressed anger or doubts and resentment toward cancer and its cure, he concludes that, "What they shared was a mood, not a passion for organization or coalition. For all these reasons no united movement against the anticancer alliance developed in the 1960s."¹⁰ He points to the late 1960s as a time when there was extraordinary pressure on the federal government to lead a war on cancer. Mary Lasker, who transformed the ACS, was instrumental in leading a campaign that demanded more money for cancer research. One of the arguments was, "The war in Vietnam . . . had killed some 41,000 Americans in four years, whereas cancer had killed 320,000 in one."¹¹ The Lasker alliance, which pushed for more cancer funding, put its confidence into the government, assuming that more spending on research would eventually bring the cancer cure. Further, a redistribution of government spending from defense to cancer was demanded. This is the same argument that cancer activists voiced in the mid-1990s.

The advocates for cancer funding eventually succeeded. One of the reasons for their success is that cancer is an issue that can find a broad base of supporters and unite liberals and conservatives alike. Patterson quotes one contemporary observer, who commented that, "To oppose big spending against cancer was . . . to oppose Mom, apple pie, and the flag."¹² The success of cancer spending advocacy was finalized when President Nixon signed the National Cancer Act in 1971. This bill was seen as the beginning of the "war on cancer." It secured more funding for the National Cancer Institute (NCI) and gave the agency special status among the institutes of the National Institutes of Health (NIH). Further, attached to this legislative bill were expectations that the United States should become the first nation to discover a cancer cure. When the success was elusive and no cure was found, the war on cancer eventually had stalled by the end of the 1970s.

Of further interest for an understanding of cancer activism of the 1990s is the wave of "coming out" or "going public" by well-known women who had been diagnosed with breast cancer in the mid-1970s. The media paid attention to prominent women who underwent breast cancer surgery: "Marvella Bayh, wife of Indiana Senator Birch Bayh, the actress Shirley Temple Black, and [within a month of each other in 1974] Betty Ford and Happy Rockefeller."¹³ One of the immediate results of the well-publicized mastectomies that the president's and the vice president's wives underwent was that the number of diagnosed breast cancers increased, presumably because more women themselves had been screened.¹⁴ Of special interest was the media's framing of the cancer experience of the First and Second Ladies. Newspaper reports were filled with assurances that Betty Ford and Happy Rockefeller were accepting of their surgeries, had their loving husbands at their sides, were in excellent spirits, and had speedy recoveries. Regaining complete mobility after surgery was visually symbolized by a picture of Betty Ford tossing a football a few days after her mastectomy.¹⁵ Betty Ford was also quoted as advising other women, "Once it's done, put it behind you and go on with your life."¹⁶

Rose Kushner¹⁷ is considered one breast cancer activist of the pre-AIDS era, beginning in the late 1970s and lasting until the mid-1980s. Her feminist stand differs gravely from the framing of the First and Second Ladies' surgeries. Ford and Rockefeller underwent Halsted radical mastectomies¹⁸ because this method had been chosen as appropriate by their husbands after consultation with the doctors. Moreover, Rockefeller underwent a second mastectomy a few weeks after her first one because she had been diagnosed with carcinoma in situ¹⁹ in her other breast.

Vice President Rockefeller told the millions in his radio and TV audience that he had withheld this information from his wife after the first operation because of her emotional state. . . . Finally, in the middle of November, Happy Rockefeller was informed of her fate. The second breast was removed as the men around her had decided.²⁰

Contrary to such paternalistic behavior and portrayal of women's breast cancer surgeries, Rose Kushner and other women have taken a feminist position. Their approach to breast cancer had been influenced by the second wave of women's liberation in the late 1960s and early 1970s and by the emergence of the women's health movement. At the

core of the women's health movement was the belief that women must have ultimate control over their bodies. This has been put forward by the Boston Women's Health Book Collective, which, since 1972, has published collaboratively their groundbreaking work *Our Bodies, Ourselves*. Further, other national organizations such as the Women's Health Network emerged, along with many local self-help groups all over the country.

In 1981, Byllye Avery founded with others the National Black Women's Health Project, which counts many local self-help groups, plus groups in Kenya, Barbados, and Belize, among its members. This umbrella organization is conceptualized around an understanding of health from the perspective of black women. This perspective either is completely ignored by health and medical literature or neglects to put health into a format that makes sense to black women.²¹ Other health organizations by women of color have emerged as well, for example, the National Latina Health Organization, which was formed to raise Latina consciousness, and the Native Women Reproductive Rights Coalition, which promotes productive rights for Native American women.²²

Media attention to breast cancer diagnoses of prominent women, the emerging women's health movement, and the needs of many women who had undergone breast cancer surgery led to the formation of breast cancer survivor groups in the late 1970s. These groups functioned as important resources and support systems for women who were living with this disease.²³ Such patient-driven self-help and support groups are frequently closely aligned with hospitals and built the dominant breast cancer organizational type of the pre-AIDS era. Many of these support groups were organized under the National Alliance of Breast Cancer Organizations (NABCO), a national umbrella organization founded in 1986 by Kushner and other women. This non-profit organization defines itself as a resource for medical, surgical, psychological, and legal progress regarding breast cancer in the United States.²⁴ NABCO has linked pre-AIDS times with the advocacy-driven post-AIDS²⁵ breast cancer activism of the 1990s, and it is among the primary organizers of the National Breast Cancer Coalition (NBCC), a national advocacy organization founded in 1991.²⁶

A second connection between pre-AIDS times and the 1990s has occurred with regard to patient-driven self-help groups. These groups, closely aligned with hospitals, still exist today. They continue to give valuable support and information to women who share in the experience of a cancer diagnosis. However, several of the grassroots breast

cancer activism groups of the 1990s, on whose members this book focuses, expanded on the former self-help groups by offering support within the context of political advocacy.

Third, an early pioneer who carried breast cancer organizing into the 1990s was Audre Lorde. She published *The Cancer Journals* in 1980, and her writings continued to raise awareness about cancer until she died of breast cancer in 1992. Lorde outlined a political response to breast cancer and demanded political action on breast cancer long before grassroots cancer groups organized to do so in the late 1980s and 1990s. Moreover, *The Cancer Journals* contained Lorde's speech on "The Transformation of Silence into Language and Action," which she had delivered in 1977.²⁷ In it she was voicing statements about silence and cancer, years before the famous "Silence = Death" slogan of the AIDS movement appeared in 1986.²⁸

AIDS organizing

This brief history of organizational responses to the AIDS crisis gives the reader some background facts that are helpful in understanding women's AIDS activism of today. My focus on women's activism may differ from readers' preexisting knowledge about the AIDS epidemic and AIDS activism, which is most likely generated by the highly publicized AIDS history that commonly stems from a male perspective. Even though the majority of AIDS organizations of both the beginning years and today are gender-mixed ones, I do not present women's activism as a comparison to men's activism.²⁹

The World Health Organization (WHO) has divided the AIDS epidemic's history into three periods: "the silent period (ca. 1970–1981), the initial discovery (1981–1985), and worldwide mobilization (1985–1988)."³⁰ This division of the epidemic's history supports an important argument that a number of authors have made. It is the argument that an adequate organizational response by the public health officials to the AIDS crisis in the United States was delayed because of society's and the health organizations' homophobia.³¹

Overall, the public health officials' response was one of neglect. Their lack of action lasted until the mid-1980s, when the perception of AIDS shifted from being a "gay disease" to being a threat for the "general population" or "heterosexual community."³² Early on, this caused the gay and lesbian community to respond to the epidemic by pulling together their own resources. Gay and lesbian community-based AIDS organizations were in place by 1985 and had achieved

hegemony when public health officials finally responded.³³ AIDS service organizations emerged first in the three epicenters of the HIV epidemic (New York, Los Angeles, and San Francisco). They shaped organizational styles that were picked up by second-tier cities such as Boston, Chicago, Washington, Atlanta, and Houston.³⁴

Further, early AIDS organizers oriented themselves toward other health-related organizations, the foremost being cancer organizations, such as the ACS.³⁵ That early AIDS organizers envisioned an AIDS organization similar to the ACS is one of many examples that shows how organizational responses to these two diseases are interrelated.

At first, gay community-based AIDS service organizations started with an uncritical view of modern medicine, one that expected to find a cure for AIDS. Such an approach to modern medicine was soon replaced, however, by a critical political analysis of medicine and health care. Dennis Altman credits the lesbians who were active in AIDS organizations with having caused this shift in thinking:

The growth of AIDS organizations has not meant a corresponding growth in analysis of medicine and health as a social and political issue. Where such analysis has occurred, it was often due to the work of lesbians, many of whom had already been active in feminist health groups.³⁶

Altman characterizes the organizational response of the gay and lesbian community as having a historical parallel to the women's movement of the 1970s. AIDS organizing of the 1980s became the most visible effort of the gay and lesbian community, similar to women's health concerns (such as reproductive rights), which had often been the most visible feminist activities of the women's movement in the 1970s. Nevertheless, Altman concludes that while AIDS had brought gay men and lesbians closer together, it also clearly highlighted the differences between the two. Gay male issues took center stage, but lesbians' health concerns remained unacknowledged.

The history of organizational responses to AIDS is narrated differently with regard to women's contribution depending on the author covering the period. The best-known chronicle of the AIDS epidemic—*And the Band Played On*—has been criticized for its many shortcomings.³⁷ I like to emphasize that Shilts' lack of acknowledgment of women's activism is among his serious shortcomings. Concerning the omission of women from the history of AIDS organizing, Judy Macks and Caitlin Ryan write the following:

The pioneering contributions of lesbians have been lost or obscured as the written and oral history of AIDS has been reported in both the general and gay press. The involvement of lesbians in the formation of community-based AIDS organizations as direct service providers, fundraisers, community organizers, educators and activists has rarely been acknowledged. Yet that does not make our varied contributions any less real, historic or vital.³⁸

The motivations for lesbians and straight women to be part of the AIDS movement are discussed in chapter 4. Cindy Patton's assessment of women's activism is that by the mid-1980s, white middle-class straight women had joined the AIDS service organizations as volunteers.³⁹

Around that time, other changes occurred within AIDS organizations. Following the gay and lesbian community that had responded to AIDS first, other communities acted according to their cultural framework. Within communities of color, AIDS was first added as yet one more issue for already existing multiservice organizations that had always been catering to the Haitian, African-American, or Latino communities. Only later did single-issue AIDS organizations emerge in communities of color as well as AIDS organizations that targeted women specifically. The gay community-based AIDS service organizations adjusted to the changing face of the epidemic by expanding their services and catering to women and communities of color.⁴⁰ Beth Schneider discusses the mobilization of affected peoples and communities:

Shaw (1988) documents in her analysis of community organizing efforts, the course of mobilization for women and ethnic minority communities necessarily differs from that of the gay community given aggregate differences in wealth and political power and, hence, in the ability to marshal resources. . . . In most large cities, there has been a proliferation of AIDS organizations as the lack of governmental funds and municipal services placed responsibility for the crisis squarely on the shoulders of the communities most affected. The emergence of a private sector of nonprofit organizations devoted to AIDS, reliant on volunteers from the lesbian/gay community, partially masked the failure of, or virtual lack of, health care delivery.⁴¹

One seldom acknowledged arena is the responses by prostitutes who were active in self-empowerment and prostitute rights organizations. These women acted as AIDS peer educators for other prostitutes. Similarly, a less publicized response was AIDS education projects that emerged in prisons.⁴² AIDS also formed many new communities such as the People Living with AIDS movement (PLWA), which was launched in 1983.⁴³

The founding of ACT UP (AIDS Coalition to Unleash Power) in New York in March 1987 marked a revolutionary shift in AIDS organizing and activism. ACT UP chapters were soon mushrooming all over the country and spread as far as the major cities of Western Europe, South America, Australia, and South Africa. This "diverse, nonpartisan group of individuals united in anger and committed to direct action to end the AIDS crisis"⁴⁴ consisted predominantly of white gay men and lesbians. ACT UP effectively used the media and engaged in many actions of civil disobedience that targeted institutions such as government agencies, pharmaceutical industries, and anyone who was perceived as harmful to their declared goal—ending the AIDS crisis. ACT UP's actions became widely known through their presence in the media. The organization came to symbolize AIDS activism of the late 1980s and early 1990s. ACT UP shifted the strategy from the political activism of the early years and organizing around AIDS to a direct and visible approach. ACT UP was not, however, the beginning of AIDS activism.

ACT UP has been sometimes perceived as an organization of angry gay white men who came together motivated by self-interest. That perception is erroneous. Perceiving ACT UP in such a way denies the importance and participation of women. Moreover, ACT UP's actions were instrumental in publicizing the discrimination that women and people of color with AIDS endured. Therefore, the organization has to be credited with being at least partially successful in eliminating the discrimination that these groups suffered. As a matter of fact, the women's caucus of ACT UP brought a feminist analysis to the AIDS crisis; that is, the women in ACT UP publicized the ways in which women with AIDS have been scapegoated and framed as carriers of the disease. Women were often blamed for giving AIDS to their children. Prior to ACT UP's highly publicized actions, women and people of color had frequently been excluded from experimental drug trials. Finally, ACT UP's women fought the CDC (Centers for Disease Control) to change its AIDS definition to include the women-specific HIV/AIDS-related symptoms.⁴⁵

The women AIDS activists interviewed for this book come from any of these organizational responses to AIDS that reach from gay community-based to community of color-based, women-only AIDS organizations, or to advocacy-only AIDS organizations.

Breast cancer activism in the post-AIDS era

The zeitgeist in the post-AIDS era has both enabled and constrained grassroots organizational responses to breast cancer. AIDS has been an enabler for the grassroots breast cancer movement in the 1990s, because AIDS activism has served as a model for organizing around a disease.⁴⁶ On the other hand, there is also ample evidence that these two diseases have been pitted against each other by politicians who were deciding about the distribution of resources.

The general perception that AIDS organizing had been tremendously successful in changing AIDS policies set off a spark in women and triggered organizing and activism around breast cancer. While AIDS organizing has been widely acknowledged as the model for breast cancer activism, there exists a second legacy upon which the breast cancer movement draws—the women's health movement. Organizational responses around women's health are one organizational background for many women who have entered AIDS activism. Hence, AIDS and breast cancer organizing weaves together different organizational resources. Women within AIDS were able to draw on their experiences in the women's movement and the women's health movement in particular, while women in the breast cancer movement were able to draw on AIDS organizing as a model. Since the breast cancer movement of today draws on both AIDS and the women's health movement, it has created a new organizational hybrid.⁴⁷

Activist grassroots breast cancer organizations expanded in the late 1980s in various parts of the country. Some examples of early cancer activist organizations follow: In Berkeley, California, Jackie Winnow, a lesbian and an AIDS activist who had been diagnosed with breast cancer in 1985 and metastatic disease in 1988, founded the Women's Cancer Resource Center. In 1989, the Boston-based feminist Susan Shapiro, who had breast cancer, published an article in the feminist newspaper *Sojourner* entitled "Cancer As a Feminist Issue," in which she called on women to attend a meeting. Women followed her call, and from this meeting emerged the Women's Community Cancer Project of Cambridge, Massachusetts. A different organizational type, the Mary-Helen Mautner Project for Lesbians with Cancer, opened its

doors in Washington, D.C., in January 1990. This project was founded by Susan Hester, after Mautner, her partner, died of breast cancer in her early forties. The Mautner project is modeled after the AIDS buddy system,⁴⁸ and its main focus is on providing services to lesbians with cancer. Advocacy for lesbians is an additional part to the main mission of caring for lesbians with cancer. In July 1990, Eleanor Pred, a veteran of the civil rights and antiwar movement of the 1960s, founded Breast Cancer Action in San Francisco, consciously modeling the organization after AIDS activist organizations.⁴⁹

These organizations largely exemplify the differences among the existing grassroots activist cancer organizations of today. While all of these organizations are political organizations based on the understanding that cancer is a political issue that has to be tackled through advocacy, some women's organizations focus on all cancers, others on just breast cancer, and some exclusively on lesbians and cancer. Further, these different advocacy organizations provide varying degrees of direct services for women and lesbians with cancer. Some of today's organizations are only dedicated to advocacy, some combine advocacy with a support group, and some function as a direct service agency combined with activism.

These activist organizations began to merge into national organizations in the early 1990s. In April 1991, the National Coalition of Feminist and Lesbian Cancer Projects was formed after a panel discussion at the National Lesbian Conference in Atlanta.⁵⁰ In May 1991, the National Breast Cancer Coalition was formed in Washington, D.C.⁵¹ The political goals of these activist organizations and their national umbrella organizations as well as the goals of AIDS activism are discussed next.

Political goals of the movements

There are certain differences and similarities in terms of the political goals of the two movements. At the beginning, emerging AIDS organizations provided services for people with AIDS and pressed for research dollars both to find a cure and through education to prevent the further spread of the disease. Overall, these broad goals were not unlike those of the cancer movement. With cancer, similar goals were put forward: prevention of cancer by finding its causes and, sometimes, access for women with cancer. Organizations that emphasized direct services are replicating what the AIDS movement had put forth as a model. Predominantly service-oriented organizations are lesbian

organizations such as the Mautner Project in Washington, D.C., and the Lesbian Community Project in Chicago. But the biggest effort of the breast cancer movement has been to raise dollars for research on the causes of breast cancer—research that investigates the link between cancer and the environment.

The issue of prevention marks a difference between the two movements. After all, AIDS is a preventable disease, whereas cancer is not, since its causes are still unknown. While the AIDS movement puts most of its pressure on finding a vaccine, or at least on developing drugs that prolong life for people with HIV/AIDS, the cancer movement relies primarily on basic scientific research to find the causes of cancer. While one of the biggest accomplishments of the AIDS movement has been to revolutionize how drug trials are administered and how new drugs are approved by the FDA, the cancer movement's revolutionary aspect has been to bring attention to the disease and the toll it takes on women's lives. Contrary to the AIDS movement, the cancer movement seeks to decrease research that focuses on drug-related issues, such as specifying amounts of chemotherapy and the length of time a woman undergoes chemotherapy, and instead to shift the research focus to the environmental causes of cancer. With cancer, drug-focused research has for many years been dominant and has traditionally been done by and in cooperation with pharmaceutical industries. The cancer activists of today demand instead that research ought to focus foremost on prevention—especially as cancer activists point out, since the treatments for cancer have not changed in the last fifty years. They have included surgery, radiation, and chemotherapy, or, as many refer to them, "slash, burn, and poison."

From this focus, a certain direction and political strategy emerge concerning the implementation of goals. There is no single strategy that summarizes the politics of all grassroots cancer organizations. The decision of which goal to implement (i.e., access, direct service, education, advocacy, cure, or prevention) differs from one organization to the next. While the strategy of the National Breast Cancer Coalition is heavily influenced by an understanding that breast cancer is a bipartisan issue, other local grassroots cancer organizations take a more radical stand.

Some of these more radical cancer organizations push most heavily for prevention by focusing on the environmental causes of breast cancer. They thereby draw a line between grassroots cancer organizations, on the one side, and the cancer establishment (e.g., the ACS), pharmaceutical industries, and large corporations that manufacture cancer-

causing products or pollute the environment, on the other side.⁵² By dividing the arena in this way, these environmentally concerned and motivated cancer organizations seek to build an anti-cancer lobby and turn to various environmental organizations such as Greenpeace for coalition building around the environment.⁵³

The broad goals of AIDS organizations and the AIDS movement are similar to the goals of cancer organizations and the cancer movement. For instance, the Women and AIDS Coalition in Washington, D.C., states its mission as follows:

The Women and AIDS Coalition takes its direction from the women on the front-lines; we are working to open doors so that more women will feel for the first time as though they have access to and representation in processes which will profoundly affect their lives. The participants work together to bring women's perspectives to the AIDS policy arena and to ensure that women's concerns are not neglected in federal legislative and executive branch HIV/AIDS policy. . . . We work with other NORA [National Organizations Responding to AIDS] Task Forces to incorporate women's needs in prevention, care and treatment, and research priorities for federal funding.⁵⁴

However, coalition building and working relationships within the AIDS arena are distinctly different from coalition building and working relationships within cancer.

Whereas more radical cancer activists argue against a unity with the cancer establishment and have chosen to build coalitions outside of the establishment, coalitions and relationships in the AIDS arena started from an opposite vantage point. Since its emergence, AIDS had been strongly linked to homophobia, and because of this connection, gays and lesbians were confronted with homophobic government officials and civic powers. Therefore, early AIDS activists who were gays and lesbians started as outsiders and sought to influence public policies around HIV/AIDS and to exert pressure for anti-discrimination ordinances for people with HIV/AIDS. Further, one of the greatest successes of the AIDS movement has been that AIDS activists have built working relationships with large pharmaceutical companies and have obtained standing as consumer advocates who are included at the table when new drug applications are investigated.

Cindy Patton argues that a shift from initial grassroots responses by the gay and lesbian community to a more assimilated AIDS service

organization structure occurred in the mid-1980s.⁵⁵ However, Patton points out that, prior to 1986, the gay and lesbian response to AIDS was framed by empowerment through community self-determination. The search for AIDS services was internal to the gay and lesbian community and independent, because government had historically shown antagonism toward gay men—including personal surveillance. Patton distinguishes this analysis within the gay and lesbian community from an analysis within the African-American community. African Americans were much more inclined to view social problems within their community as an outcome of government discrimination. An empowerment strategy for the African American community is to demand governmental services and access in payment for years of discrimination.

The shift by gay community-based AIDS service organizations to work more closely with the government beginning in the mid-1980s intensified even further toward assimilation through an influential decision that gay AIDS activists made in the mid to late 1980s. To gain more access to resources and to attract more attention to the disease, gay AIDS leaders made a conscious political choice to “de-gay” AIDS.⁵⁶ These leaders’ rationale for a de-gaying of AIDS was that society’s deep-seated homophobia required such a step to remove the stigma of homosexuality from AIDS. The strategy of de-gaying AIDS meant, among others, to build single-issue AIDS organizations, to use non-gays as spokespeople, to focus narrowly on AIDS instead of on the underlying themes of racism and homophobia, and to emphasize that AIDS is not a gay disease. In hindsight, this decision of de-gaying AIDS has been acknowledged as being highly problematic, because it realized its short-term gains but in the long term depoliticized AIDS by separating it from its gay and lesbian liberationist roots.⁵⁷ Along with the decision to de-gay AIDS, AIDS became de-sexualized when attention shifted from gay male sex to committed gay male relationships. This decision is under revision today by some of the same gay men who were initially influential in the de-gaying of AIDS.⁵⁸

In summary

Within this section, the two health-related movements have been located within their historical political context. The differences and similarities have been discussed and highlighted that have both set the two movements apart from each other and provided similar struggles for each. Further, it is noteworthy how intertwined the two movements are. The AIDS movement benefited from the experiences

of feminist and women's health movement activists, while the breast cancer movement of the 1990s used the experiences of AIDS activism and feminist strategies as its roots. With regard to politics, the two movements have started from opposite vantage points. AIDS had been linked to male homosexuality; consequently, AIDS activists began outside of the political arena struggling for influence through a strategy of assimilation and coalition building with straight health officials, government officials, and drug industries. In contrast, breast cancer started as a mainstream issue; therefore, the progressives among cancer activists have pushed against coalition building with a cancer establishment that has neither served them nor represented their interests in the many years of their existence.