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TAKING CHARGE OF BREAST CANCER

JULIA A. ERICKSEN
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University of California Press
Berkeley and Los Angeles, California

University of California Press, Ltd.
London, England

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Library of Congress Cataloging-in-Publication Data

Ericksen, Julia A., 1941--.


p. cm.
Includes bibliographical references and index.
RC280.B8E68 2008
362.196'9449—dc22 2007046303

Manufactured in the United States of America

17 16 15 14 13 12 11 10 09 08 07 06 05 04 03 02 01

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Jo-Ellen’s breast cancer story takes the form of a woman’s worst nightmare. Her adoptive mother was a forty-year survivor, so Jo-Ellen knew the disease was something that women might get but could also recover from. Upon finding a lump at age twenty-eight, Jo-Ellen went to a gynecologist who told her that it was only a cyst, so she did not go for a mammogram and ultrasound until a year later when the lump was still there. After that, things moved pretty quickly through a double mastectomy, breast reconstruction, chemotherapy, and tamoxifen. Jo-Ellen was newly married with her life ahead of her, and, to ensure her future, she chose the most aggressive treatment, including prophylactic removal of her second breast. Tamoxifen put her into menopause by age thirty-three, a serious consequence for a woman who desperately wanted children. Even more serious was the discovery, a year after the original diagnosis, that the cancer had metastasized to her bones.
Jo-Ellen had lots of social support. Her new husband remained devoted through the loss of her breasts, her baldness, her weight gain, her loss of interest in sex, and the realization that she would never give birth. Her mother went with her for appointments, taking long lists of questions to supplement Jo-Ellen’s own. Family and friends encouraged her to talk about her illness openly and to share her fears. She remained optimistic. When I interviewed her two years after the first diagnosis, she still believed she would survive in the face of several new masses, and she was hoping that her situation would not prevent her from gaining approval as an adoptive parent.

In openly facing her illness and talking about it to all who would listen, Jo-Ellen’s response is a modern tale. In the second half of the twentieth century, breast cancer was transformed from an illness mentioned in hushed tones, if at all, to a huge public presence supporting a massive industry. Jo-Ellen’s story is unusual because she was younger than most women at diagnosis and her disease progressed more rapidly. Breast cancer is commonly more virulent among the young. Most breast cancer does not metastasize, and, according to the American Cancer Society, 88 percent of victims live at least five years and 63 percent live at least twenty. Why then is the image of breast cancer so associated with death and so vivid in most women’s minds? In her book *Illness as Metaphor*, Susan Sontag noted that the idea that “cancer = death” has been around for a long time and still continues to exert a strong influence.

The only other illness with an equally visible profile is HIV/AIDS. Like breast cancer, HIV/AIDS has spawned a mass of organizations devoted to its management and cure. However, the two diseases differ greatly. Most people who contract HIV feel the stigma of a disease that is associated with a “wrong” lifestyle. In contrast, few breast cancer sufferers nowadays feel ashamed of having cancer, and most talk openly or even write about their illness. In addition, AIDS severely shortens life expectancies, and, to beat the odds, patients must henceforth, and forever, organize their behavior around complex drug treatments and behavioral restrictions. With breast cancer, although medical treatment is debilitating, doctors rarely make recommendations about lifestyle changes, and most women, once treatment is finished, may return to their former lives.
with impunity. While cancer always brings the threat of a horrible death, the high survival rate for breast cancer means a large group of women have lived to tell their tales. Most American women know others, including family members, in this category. However, those who have survived diagnosis and treatment still live with the threat of a reoccurrence or worse, and they form a potential army of activists to keep the disease in the public eye.

Threats of reoccurrence and of metastasis to other areas of the body remain permanent possibilities for women diagnosed with breast cancer, even if these threats diminish over time. In the 1920s, physicians decided to use five-year survival rates as a benchmark for determining a cure. This benchmark has remained in place, as medical historian Barron Lerner has noted, even though there is no particular significance to the five-year time frame when it comes to breast cancer. However, both the American Cancer Society and the major cancer hospitals have long believed that emphasizing high levels of curability would promote the benefits of early detection.

Women have not always been as willing to discuss their experience with breast cancer as they are now. For many years, the stigma of breast cancer usually meant that the disease’s existence was kept in the closet. Ellen Leopold examined the correspondence from 1960 to 1964 between Rachel Carson, the author of the best-selling book *The Silent Spring*, and her surgeon, George Crile. Even Carson, a woman who battled the scientific establishment, was private about her breast cancer. She did not see it as something to share with other women. Rather, she handled it alone with the aid of her surgeon and a close friend. She strove not to be angry but to bear up with courage. Crile, whose own wife had died of breast cancer, was ahead of his time in his willingness to reveal a cancer diagnosis to Carson, something her first surgeon would not do.

In the 1970s, several prominent women broke the silence, including Shirley Temple Black in 1972. The first woman to write about her own breast cancer experience, Rose Kushner, was diagnosed in June 1974. Kushner was a pioneer in insisting that she not be subjected to the then ubiquitous one-step operation. In this procedure, surgeons would perform a surgical biopsy, and, after examining the results, husbands and
surgeons would make the final decision as to what further surgery to perform, while the patient was still under anesthesia. Women would go to sleep not knowing if they would still have a breast when they awoke. In fighting this, Kushner became one of the earliest breast cancer activists. When Betty Rollin was diagnosed in 1976, she was an NBC news correspondent. Rollin’s book about her bout with breast cancer, *First You Cry*, became a best seller. But none of these events produced the publicity occasioned when First Lady Betty Ford announced her breast cancer in 1978 and received an outpouring of public sympathy for her plight plus admiration for her bravery. Nancy Brinker, in her account of the death of her sister, Susan Komen, in whose memory she founded the Komen Foundation, cited Betty Ford as having inspired her sister to finally speak about her own illness. And the Komen Foundation, with its annual Race for the Cure in cities across America, has continually encouraged women to publicly acknowledge their diagnoses.

Increased openness also resulted from the women’s health movement. In the 1970s, feminist health activists began questioning the way American surgeons continued to perform debilitating radical mastectomies when European doctors were switching to less invasive lumpectomies. Faced with growing evidence that the more limited surgery did not lower survival rates, a few American physicians had begun to perform lumpectomies or to modify radical mastectomies. Yet most women, including those—like Betty Ford—with access to the most prominent surgeons, still had the more invasive surgery. This typically occurred because most women consented to a one-step procedure, as did Betty Ford. In their best-selling book *Our Bodies, Ourselves*, members of the Boston Women’s Health Collective made the case that radical mastectomies were abusive, and this idea was picked up by women’s magazines. In 1979, as a result of pressure from both inside and outside the medical profession, the Consensus Development Conference at the National Institutes of Health (NIH) agreed that the radical mastectomy was no longer the accepted procedure, and most surgeons switched to the newer surgery.

The National Breast Cancer Coalition (NBCC), founded in 1991, has taken a more explicitly feminist position than the Komen Foundation. It lobbies Congress to increase funding for breast cancer research and edu-
icates survivors to participate in allocating this funding. By copying the model of AIDS activism, the organization has successfully increased funding for breast cancer research and trained thousands of activists. These two strands of breast cancer activism, represented by the NBCC and the Komen Foundation, continue to exist side by side along with other more militant organizations such as Breast Cancer Action as well as numerous support and educational groups.

The attention and public discussion mobilized by these groups have led to an increase in symbolic representations of the disease, particularly in the media. These images include, among others, the danger to the sexualized breast; death and dying; sacrifice, especially to family; and the miracles of modern scientific medicine. When diagnosed, a woman has to deal with the disparate imagery of her plight as she works her way through the frightening and tedious steps of decision-making and treatment. Of all cancers, that of the breast is currently the best publicized with the greatest resource allocation. In much of the Western world, breasts are the single most important symbol of women’s femininity, and, even though many women feel ambivalent about their actual breasts, surgical removal or partial removal of the breast is traumatic, an attack on womanhood itself. Not only do breasts signify women’s facility for nurturing, they are prime sexual ornaments. In the current era, the ideal female body is seen as a slender figure with large breasts. Since most women cannot expect to achieve this shape without assistance, it is not surprising that liposuction and breast augmentation have become two of the three most common plastic surgeries for women.

The media, particularly women’s magazines, frequently run stories about breasts. Most of these stories are about breast cancer. A search of top-selling women’s magazines published during a five-year period produced an average of almost one article per issue on some aspect of the disease. In studying the representation of breast cancer in the media, Cherise Saywell and colleagues described it as having the most visible press coverage of all cancers. When Jennifer Fosket and colleagues examined breast cancer stories in popular women’s magazines, they found that the overriding message was women’s personal responsibility for detection, prevention, and survival. Describing the various faces of
breast cancer portrayed in the media and elsewhere, and the fears created in women, helps us understand how women respond to a diagnosis and how they cope during their months of treatment.

For the media, breast cancer is a sexy subject. Although the majority of sufferers are over fifty years old, magazines frequently portray it as a young woman’s illness. And even where writers note the actual age distribution, they emphasize youth indirectly. Self magazine’s annual section on breast cancer for 1999 noted that this “has never been primarily a young women’s disease” but undermined this point by illustrating the section with portraits of young survivors. The magazine’s selection of photographs, which emphasized youth and ongoing reproductive lives, showed a woman diagnosed at age twenty-eight who gave birth four years later, a thirty-three-year-old writer who “wants young women to pay attention to their bodies because their symptoms can be easily overlooked,” a “fitness enthusiast” diagnosed at thirty-one, and a woman diagnosed at twenty-nine who subsequently married and gave birth. The visual message, that breast cancer is a disease of young women, was underscored by the inclusion in the issue of an advertisement for Ford Motor Company, which showed a little girl being hugged by her mother; the caption read:

My breast cancer hero is my mommy. In April 1993, at the age of 27 and six weeks before her wedding day, she discovered a lump in her right breast. She survived lumpectomy and lymph node dissection. In June of that year, she married my daddy. . . . [When] I was conceived . . . she decided she had to live. She would not allow me to grow up without her. . . . She promised me that she would make it to my fourth birthday so that I would remember her if nothing else. I turned five this year. . . . Through her love for me and my Daddy, she survived.

Such images have great emotional appeal and stress the idea that surviving breast cancer is a matter of courage and perseverance. By implication, therefore, women who do not survive lack these attributes.

A titillating image of breast cancer appeared in the annual fall fashion promotion, “Fashion Targets Breast Cancer.” For the four days of this event, 2 percent of Saks Fifth Avenue’s sales went to breast cancer chari-
ties. An eight-page spread in the *New York Times* told the story. On the first page, three very young fashion models wore their tresses long and full, much of their skin bare, tight jeans, and the campaign T-shirt, the logo of which is a bright blue and navy bull’s eye surrounded by “Fashion Targets Breast Cancer” and “Council of Fashion Designers of America.” This T-shirt was designed by Ralph Lauren, one of many prominent supporters of breast cancer research. Other similarly dressed young women adorned subsequent pages, in every case wearing full sets of perfect breasts, not breasts already altered by disease. These were threatened breasts, threatened because even beautiful, vibrant young women might succumb. The use of the bull’s eye positioned on their chests and the word “Targets” underscored the danger.

These newer images of breast cancer, portrayed in the media and by cancer organizations, compete with older ones of death and disability. There remains an overwhelming fear of dying. Many women grew up in families where breast cancer was rarely mentioned. Memories of older relatives with the disease frequently involve debilitating surgery or painful death. This image of silence and death still appears in the media. Indeed, Brinker’s account of Komen’s death is in this tradition. Brinker described her sister as a hometown girl who trusted her family doctor and questioned neither his advice nor that of the surgeon to whom the doctor sent her. It was too late by the time Komen switched to competent treatment.

Other accounts make a different point. A number of descriptions of courageous and independent women who still died have appeared, among them Sandra Butler and Barbara Rosenblum’s account of their shared experience of Rosenblum’s diagnosis and eventual death from breast cancer. Sometimes stories of death in top-selling women’s magazines describe courage in death’s face. For example, a woman with metastatic breast cancer told how she taught her daughter important lessons about life and death. More frequently, articles with titles such as “Will I Inherit My Mother’s Disease?” contain frightening implications of dying too young. In one account, a woman’s mother, grandmother, and great-grandmother had all died of breast cancer; after much hesitation about undergoing genetic testing, the story’s subject tested positive for one of
the known breast cancer genes and chose prophylactic breast removal to increase her chances of beating the survival odds.\textsuperscript{38}

Another immediate concern for many women upon receiving a diagnosis of breast cancer is how family members will cope with their diagnosis. Here, too, images of death and disfigurement abound. Many women are the main caregivers in their families, the person around whom family life revolves. Family members do not always know how to respond when this caregiver becomes seriously ill, and their fears for her survival mix with concerns about their own potential loss of support. Women often anticipate such problems, both because of previous personal experiences and because of the cultural expectations about wives, mothers, and daughters. Newly diagnosed women may find themselves having to provide emotional support to family members, rather than focusing on their own treatment.

Women’s magazines present stories lauding the choices women make. In these tales, motherhood is woman’s central imperative, and accounts abound of survivors who risked their lives for their families. The most common story, in this genre, has been of the woman diagnosed with breast cancer either while pregnant or even before she had a chance to become pregnant. Chemotherapy’s danger to fetuses may postpone urgently needed treatment, and pregnancy can cause estrogen-receptor positive tumors—the great majority of tumors—to grow more rapidly. In these accounts, doctors often advised pregnant women to have abortions and childless young women to avoid pregnancy. But, in most of the stories, the natural desire to be a mother overcomes the fear. Most such stories ended with a beautiful baby and a triumphant mother. Only one account described a woman choosing to have an abortion rather than risk worsening her cancer. This woman lost a badly wanted baby and was angry with doctors who missed her early symptoms. Furthermore, her abortion was not to protect herself but to ensure that her existing child would not grow up motherless. Many stories make the point that “A pregnant woman with breast cancer confronts agonizing choices.”\textsuperscript{39} The message here tells women that self-sacrifice is their role even when their lives are at stake.

Once women enter the formal medical system, scientific images of
breast cancer overshadow private ones. Arthur Frank has described the modern experience of illness as beginning when “popular experience” is “overtaken by technical expertise.” Where sick people used to go to bed at home to be cared for by family, they now go to paid professionals who “reinterpret their pain as symptoms, using a specialized language that is unfamiliar and overwhelming.” Both science and medicine are accorded high status in our culture. Women with breast cancer quickly learn that theirs is a complex disease with each treatment phase bringing its own specialist. Bruno Latour has argued that scientific truth is established when scientific “facts” become accepted. When this happens, further developments in a field of discovery are constrained. So knowledge production involves more than a disinterested accumulation of evidence. Instead, some knowledge is reified, while some falls by the wayside. Furthermore, science becomes the place where the truth is determined. The presentation of scientific truth and the circulation of these truths become important in framing breast cancer and its treatment, even if, as Charles Bosk has stated, illness definitions depend more on everyday values than on scientific expertise.

Continued prospects of medical miracles in cancer treatment receive widespread media attention. Such stories are told in technical language, which may serve to mystify science and medicine. These stories are not about death but about cures and the lifesaving benefits of early detection. Newspapers, women’s magazines, television, and the Web sites of organizations like the American Cancer Society all report on treatment options, especially new potential breakthroughs. They portray the quest for a breast cancer cure as involving courageous, humanitarian genius searching for truths that will inevitably be revealed with time. Well-publicized mass events such as the Race for the Cure position breast cancer as a deadly plague whose spread will only be arrested by increasing the pace of medical discovery.

The image of the imminent cure has been around since the 1930s and continues to the present day. The following statement, appearing at the end of the National Cancer Institute’s (NCI) Breast Cancer Progress Review Group report in 1998, could have been written at any time between 1930 and the present:
The past two decades of painstaking research and substantial national investment have yielded major advances in our ability to care for women with breast cancer and for those at risk . . . by charting the course and implementing the recommendations described in this report, the nation will take the next crucial steps toward the ultimate goal of removing the threat of breast cancer from the lives of women and their families.46

This statement contains the standard optimism and priorities—basic biology, diagnosis, and treatment. In other words, scientists have made progress and, with increased funding in the right areas, will soon find a solution. As Susan Sontag noted, if cancer is a “killer,” the only appropriate response is a “fight” or a “crusade” against it. For almost a hundred years, this fight has continued and the repeated announcements of imminent victory are reminiscent of government pronouncements in times of actual war.47

The media also emphasize the position long taken by organizations such as the American Cancer Society that breast cancer mortality rates are declining due to both early diagnosis and improved treatment options. This information is presented as unvarnished truth, when the story is more complicated.48 If the cure for cancer involves early diagnosis and constantly improving medical intervention, this creates a dilemma for women. On the one hand, the newly diagnosed woman is expected to acquiesce in the face of medical expertise. The long-standing tradition of male surgeons possessing unquestioning authority over subservient and unknowing female patients still holds sway, even in an era where many women have entered medicine, including surgery. On the other hand, women feel considerable pressure to take charge of their interactions with doctors and to stay informed about treatment innovations.

Rachel Carson knew more about her disease and its progress than most women at the time. Yet she knew little compared to today’s patients. In the modern era, the widespread availability of books, articles, and other materials and the ready accessibility of the Internet mean that doctors no longer have a monopoly on information about breast cancer. For example, typing the word “tamoxifen”—until recently the most widely used hormone treatment for breast cancer—into the search engine
Google produced 2,420,000 hits. Many patients educate themselves about every aspect of their illness including diagnosis, types of malignancies, stages of the disease, treatment options, and support services. They engage their doctors with long lists of questions and use medical language with ease.

This readily available information, coupled with trends in the medical profession, in particular the proliferation of malpractice suits, has had a profound impact on doctor-patient relationships. In theory, at least, doctors must now educate patients about tumor type and stage of development and explain the resulting treatment options. As a result, the doctor no longer possesses all the wisdom about the patient’s needs; rather, doctor and patient are partners.

Doctors’ increased concern for patients’ rights can be partially explained by the growth of the health promotion movement. This movement has its roots in the nineteenth century, when health activists like William Kellogg promulgated the idea that the right diet could improve health. However, it grew rapidly in the last few decades in reaction to the long-accepted, conventional medical/scientific model of “Doctor knows best.” Now the focus is on prevention and on personal responsibility for health. The health promotion movement’s image of breast cancer is well represented in women’s magazines. Titles such as “The Nine Top Ways to Prevent Breast Cancer,” “Your Best Self-Defense against Breast Cancer,” or “The Anti–Breast Cancer Diet” have clearly communicated the message that by eating right, exercising, staying thin, and taking special action when risk is high, women can keep breast cancer at bay. This is also underscored in popular health books.

Twenty years ago, Marshall Becker complained that the rising health promotion movement was leading to a situation where patients were being blamed for getting sick, that is, for having a disease-inducing lifestyle. Susan Yadlon has even argued that the dominant discourse around breast cancer assigns women personal responsibility for getting the disease, especially by eating the wrong diet. While this is not the only message in the media, it is a common one, and it has been influential, even though Susan Sherwin has noted that there is a lack of concrete evidence that diet, especially the level of dietary fat, makes a difference.
The implication of this message is that those who get breast cancer have not taken personal responsibility and therefore have failed at protecting their own health. Among the most commonly emphasized failures are poor diets, lack of exercise, excess weight, smoking, alcohol consumption, and high stress.

Almost any woman can find reasons to blame herself for her illness and to think that lifestyle changes could prevent a reoccurrence. Best-selling books testify to this. Bernie Siegel’s *Love, Medicine, and Miracles* has described the “typical” personality profile of those who get cancer as “compulsively proper and generous people . . . because they put other people’s needs ahead of their own” but who “are giving love only in order to receive love.” Adding that “there are no incurable diseases, only incurable people,” Siegel described “exceptional” patients who cured themselves by their determination to fight and to embrace healing techniques. Magazine articles have made the same point with titles such as “Boost Your Immunity: The Seven Traits That Keep People Healthy,” “A Woman of Valor,” or “Think Yourself Well.” Only one article, of those that I analyzed, acknowledges a lack of empirical evidence that the causes of breast cancer lie in the mind.

In addition to emphasizing personal failure, the health promotion model reinforces women’s personal responsibility for recovery. The patients’ rights movement and the women’s health movement have further promoted this idea by demanding that patients be given access to complete information about their illnesses and that patients should participate in treatment decisions. And the replacement of the radical mastectomy with less drastic surgery, in conjunction with the use of radiation, chemotherapy, and hormones, means that women no longer face one all-powerful surgeon but a team of doctors, each of whom may offer choices. This has increased women’s sense of involvement in decision-making about treatment.

The idea of patients as partners has created its own problems for women. The easy availability of masses of information, often coupled with separate decisions at each doctor’s office, makes decisions more confusing. Much of this information is highly technical, and women must struggle to understand, let alone decide on, the options open to
them. Furthermore, in spite of the rhetoric of patients’ rights, many doctors do not treat breast cancer patients as partners. Instead, they may resist what they see as intrusions on their expertise. This is especially true for male physicians, who are particularly likely to be patronizing to women patients. The percentage of women physicians has increased; in 1970, women constituted less than 8 percent of physicians in the United States but were almost 25 percent by 2001. However, they are concentrated in general medicine and in specialties such as obstetrics, gynecology, and dermatology. Even as late as 1999, only 21 percent of surgical residents were women compared with 67 percent of obstetrical and gynecological residents. A woman diagnosed with breast cancer will have exclusively female physicians only if she puts considerable effort into doing so. Among the ninety-six women I interviewed, over two-fifths had an all-male team of doctors and only four women had an all-female team. The rest had teams of mixed gender; in most cases, one woman was on a team with two or three men.

Much has been written about the ways in which problems faced by Westerners have been increasingly medicalized. This has happened in part because of the tendency of the medical profession to increase its sphere of influence. In addition, the respect accorded medicine leads groups to want their problems to be designated as medical problems and thus treatable. This idea of medicalization is closely associated with Peter Conrad, who has described numerous concerns—overeating, alcoholism, hyperactivity—that once were seen as behavior problems but now are treated as medical conditions.

Clearly breast cancer did not have to struggle for inclusion in the illness lexicon. However, some writers have expanded Conrad’s arguments to focus on the medicalization of women’s bodies. Emily Martin, who first propounded this viewpoint, and other writers have taken the position that women’s bodies are increasingly seen as pathological and that female functions formerly viewed as normal—menstruation, reproduction, menarche—are now viewed as medical conditions requiring expert intervention and management. The resulting sense of bodily estrangement has led women to view their bodies as in need of constant surveillance and to anticipate that things might go wrong, particularly with
those body parts that are exclusively female. Thus women feel under
great pressure to check their breasts, to subject themselves to regular
examinations, and to fear for their futures. Furthermore, as Nora Jacob-
son has shown, with the introduction of breast implant techniques, a
whole industry has emerged involving plastic surgeons, manufacturers
of implants, and complicit women. This industry has helped change a
woman’s breast into an idealized version of itself.

Like other aspects of medicine, medicalization has resulted not only
from doctors’ expansionist tendencies but from patients’ desires for the
best that medicine can offer. However, this has not always been a smooth
relationship. Medicalization can be both empowering and repressive to
women, depending on the relationship they have with their doctors.
Frequently, patients’ desires for involvement in decision-making have
collapsed with autocratic doctors. This has sometimes led to resentment
about doctors, which is reflected in women’s magazines to a surprising
degree. In clear, nontechnical terms, readers have been told that they
must select carefully, since some doctors mask incompetence with
authority. Doctors’ reported failures have included saying “not to worry
about a small hard spot in your breast because it hasn’t shown up on
your mammogram,” prescribing mastectomies where lumpectomies are
appropriate, claiming “You’re too young to have breast cancer,” per-
forming breast exams improperly, not warning that fertility treatments
increase breast cancer risks, and not informing women that mammograms
may produce false positives. With these stories of doctors as ordi-
nary mortals, the media demystify the practice of medicine. Yet simulta-
nuously, they exalt biomedical science with miraculous tales of medical
breakthroughs.

If women feel ambivalent about organized medicine, they sometimes
pursue alternative treatments. Magazines abound with stories of women
who have aided their recovery with techniques such as hypnotherapy,
visualization, or Chinese medicine. So popular have these “fringe”
methods become that mainstream hospitals now offer information ses-
sions and classes on alternative practices. One hospital in suburban
Philadelphia even opened a wellness center with furniture and facilities
arranged according to feng shui principles.
Most of the cultural images of breast cancer in women’s magazines evoke individual pathologies and treatments as opposed to risk factors that are beyond individual control. In recent years, however, some activists have taken the position that breast cancer is a disease outside an individual’s control or personal history. Breast cancer, these advocates have argued, is produced by modern industrial life, particularly by pollutants and pesticides, and the cure for cancer involves government action and even a restructuring of social life. Proponents of this view, first articulated in the 1960s by Rachel Carson, have interpreted its relative lack of attention from the media as resulting from the corporate pressures of industry, the medical profession, and university researchers. In this model, the disease’s “cause” is not to be found in the individual woman or her history, but in the environmental toxins she cannot avoid because they are all around her. Genetic traits or other risk factors may increase a woman’s potential for breast cancer, but the trigger is a sick society bent on profit without regard for its citizens’ health. This image is at odds with the medical community’s view, where the emphasis is on finding a cure rather than on promoting prevention. In the late 1980s, the director of the National Institutes of Health, Harold Varmus, stated that “You can’t do experiments to see what causes cancer. It’s not an accessible problem. It’s not something that scientists can afford to do.” When prevention has been discussed, it has been usually at the level of the individual woman rather than of society as a whole.

Women’s magazines pay little attention to the idea of breast cancer as anything other than an individual pathology. A lone story on estrogen in *Self*, in 1994, noted the high rate of cancer on Long Island and included information on environmental estrogens, but such stories are rare. However, in recent years, both the National Cancer Institute and the Environmental Protection Agency have started to collect epidemiological data on incidence in an attempt to measure which pollutants might be to blame for breast cancer’s apparent increase. This is a difficult task relying on possibly spurious ecological correlations, but pressure from environmental activists and from some breast cancer activists to undertake this type of research has pushed government agencies forward. A number of recent books on breast cancer have argued that environmental toxins...
account for an increase in the rates.\textsuperscript{75} Several of these books are by breast cancer survivors with a history of political activism.

Some activist organizations have taken a militant position on breast cancer and the environment. Most notable among these is the San Francisco–based organization Breast Cancer Action, whose Web site states that, in spite of massive research funding for cancer ("$23 billion"), "Environmental factors have been largely ignored by science as possible explanations for the escalation of the incidence of breast cancer."\textsuperscript{76} Taking the existence of a breast cancer epidemic for granted, Breast Cancer Action has argued that if breast cancer is to be contained, exposure to toxins must be reduced. And at the international level, the Women’s Environment and Development Organization has made breast cancer and its environmental connections into a central issue. This organization has held two world conferences on breast cancer, and each included numerous sessions on the environment.

Breast cancer is not the only disease where activist and expert interpretations of data have led to a struggle over the meaning of scientific evidence. In his study of leukemia in Woburn, Massachusetts, Phil Brown demonstrated how activists forced the debate over the relationship between a toxic water supply and higher than average levels of leukemia. And Steven Epstein has documented the ways in which AIDS activists questioned the scientific basis of clinical trials in testing the efficacy of AIDS drugs.\textsuperscript{77}

So women with breast cancer face competing images as they struggle to understand what is happening to them. Each image is gendered in important ways. Women know that breast cancer can lead to death, but they may also believe that women should put aside their own fears and focus on what will happen to their families should they get seriously ill or even die. Individual women may reject this theme of sacrifice, but it resonates loudly in our culture and in the media. Patients must put their faith in the ability of doctors to cure them, yet they also receive loud messages that they themselves are responsible for getting well. And they may question themselves about how they allowed cancer to happen. Women are responsible for the health of themselves and their families, and to get too sick to be the family caregiver is to fail miserably at this task. Even
those who deny the truth of this cultural mandate are not indifferent to it. Neither are women who distrust the medical profession indifferent to its power and authority. Finally, for some women, their diagnosis confirms the sorry state of society and the lack of power women face in trying to create change.

Women diagnosed with breast cancer not only struggle to understand and respond to the crisis but typically must make difficult choices among an array of options. In the majority of cases the tumor is small, and women may choose between two surgical procedures: a mastectomy or a lumpectomy plus radiation. In some cases there is no choice; the size and type of tumor necessitate a mastectomy. When treatment involves a mastectomy, decisions must be made about breast reconstruction.

Depending on a woman’s age and the type and stage of her tumor, a further series of decisions involve chemotherapy. Sometimes women are given a choice about whether or not to undergo chemotherapy; in other cases, doctors strongly recommend or even insist on it. When women have chemotherapy, doctors often present options about type. In addition, while women who have lumpectomies are prescribed radiation, it may also be recommended for mastectomy patients, especially where there is extensive lymph node involvement.

To further complicate matters, new treatments appear frequently. There have been recent changes in, for example, the preferred method of diagnosis, the order of surgery and chemotherapy, and the chemotherapy protocols. One of the most difficult decisions has been whether or not to take hormones, and here too recommendations have changed. In the past, the hormone of choice was tamoxifen. Tamoxifen is generally taken for five years, and its unpleasant and potentially dangerous side effects make it controversial, especially for premenopausal women, as it typically puts them into menopause. More recently, the dominance of tamoxifen has been challenged by a new set of hormones—aromatase inhibitors—taken either in conjunction with tamoxifen or instead of it.

As a result of the constant treatment changes, it is not uncommon for a woman who seeks a second or third opinion to receive more than one set of treatment recommendations. So how do women who have just received the devastating diagnosis of breast cancer work through their
choices? As Sherwin has noted, while women’s health activists fought hard for the right of patient autonomy in decision-making, this right assumes that patients are independent agents and in control of other aspects of their lives and that they feel entitled to have opinions.79 Furthermore, the information necessary to understand and to make a decision is highly technical, and most women start out ill-equipped to make decisions that may have life or death consequences. In addition to learning about tumor size and type, women must learn about their lymph nodes and the meaning of lymph node involvement. They learn that some of their treatments are intended to minimize chances of a recurrence in the breast while others lessen the chance of metastases. Many treatments have dangerous side effects, and it is not easy to weigh the health benefits of treatment against these. Women who have mastectomies must not only decide whether or not to undergo breast reconstruction but also, if they choose to undergo it, what type to have.

In most cases there is no particular urgency to decide on the course of treatment, yet women feel tremendous pressure to decide quickly. They perceive untreated breast cancer to be a killer, so they want treatment to start as soon as possible. This pressure is in part a result of medical and media messages that cancer diagnosis and survival cannot tolerate delay.80

While they are processing this new information and making these terrifying decisions, women must sort through the various faces of breast cancer and make sense of their diagnosis. At the same time, they must decide whom to tell and how to tell them. And there are other struggles: whether or not to continue working, whether or not to go for second opinions, whether or not to use alternative treatments and if so which ones, and the biggest struggle of all: how best to cope with chemotherapy and radiation.

These decisions and struggles form the basis of what many women experience as a journey through cancer treatment and recovery. This journey has a number of stages, not always the same, and each brings its own set of issues. Patricia Kaufert has described each stage as “another rite in the passage from being the ‘well’ woman to being this other woman, the cancer patient.”81 And all women must decide how well informed they will become, and how involved they will be in their treatment.
The first stage in the breast cancer narratives of the women I interviewed involved their beliefs and practices before diagnosis. This often included accounts of their ideas about cancer and their history of self-examinations and mammograms. The second stage was diagnosis, starting with an account of how they found out something was wrong. To make sense of their diagnosis, most women created a theory about why they had developed cancer. At diagnosis, patients not only want to know the name of their disease, they want to understand its cause. In her sample of working-class women in Scotland taken over twenty years ago, Mildred Blaxter discovered that they viewed cancer as a random fate. It is most likely a testament to the increased optimism about cancer treatment that almost all the women in the current study had a theory to explain why they got cancer.

Once diagnosed, women had to decide what to do next—whether to seek second opinions and whether to obtain treatment at a local hospital, a comprehensive cancer center, or a teaching hospital. And they had to decide about the myriad of possible treatments. These decisions did not occur in a vacuum. While some women gave priority to helping those around them, others who had expected their loved ones to provide support had not received it and felt outraged that it was not forthcoming. Next, women had to undergo difficult and debilitating treatment. With breast cancer, it is usually the treatment and not the disease that makes the patient ill. Going through treatment involved dealing with side effects and coping with the consequences of treatment such as hair loss and weight gain.

Finally, after cancer treatment was over, women had to get on with their lives. They also had to live with increased feelings of vulnerability caused not only by the events they had lived through but also by fears of reoccurrence or metastasis. Furthermore, some were permanently disfigured after surgery. Some experienced significant weight gain. These, in turn, had profound implications for intimate relations. After treatment, in facing the future, women had to decide whether to stay focused on breast cancer in some way or to try and put their illness behind them. Some remained involved with breast cancer as activists and volunteers, while others tried to go back to the lives they had lived before diagnosis.
Either way, many saw themselves as permanently changed psychologically. Such women needed to feel that their illness was not completely in vain but had had a profound and generally positive effect on them as individuals.

At each stage of the journey, the various images of breast cancer portrayed in the media were important in helping women I interviewed frame the issues. And just as these images varied, these women’s views about their treatment did also. There were two major dimensions to this: their attitudes toward biomedicine and the extent to which they wanted to take charge of the decision-making.

A majority of women believed in the message that, in the modern world, biomedicine works miracles. They thought that they had the best doctors, and they saw medical science as their salvation. These were women who supported the extension of medical authority into more and more areas of life. Adele Clarke and colleagues have described an extension of medicalization that they call “biomedicalization.” This involves the commodification of health and the use of ever-expanding technologies and treatments. Women who believed in biomedicine wholeheartedly embraced this notion of ever-expanding medical miracles.

However, some of the women I interviewed had more critical views of biomedicine; they did not completely trust doctors or the medical establishment, and in some cases not at all. Such women sought alternatives or supplements to the established health care system when they were diagnosed with breast cancer. And many felt critical of their treatment by the medical system, describing insensitivity, insults, and even incompetence. This finding that some women were ambivalent or hostile is similar to that of Martha Balshem in her study of cancer and community. Many of Balshem’s working-class respondents did not accept the biomedical explanations for cancer that they were given. This division between those who embraced biomedicine and those who looked outside can be understood by viewing medicine as both a resource to people facing serious illness and as a constraint on coming to terms with the deeper meaning of the illness.

In addition to their attitudes toward biomedicine, the women I interviewed varied in the level of personal responsibility they took for their
own recovery. Some believed that, to get better, they must put themselves in others’ hands. Such women frequently had family responsibilities or personal fears that led them to minimize their own involvement and levels of learning. They were often intimidated by the medical establishment. Others felt they must make decisions themselves, usually with the aid of experts but never by deferring to another’s judgment without thorough consideration of the issue. This division is similar to that made by other researchers. In an Australian study, Deborah Lupton divided patients into consumers and passive patients, based upon their relationships to doctors. The former saw themselves as autonomous actors in making medical decisions, while the latter were more dependent on the doctors’ recommendations. In a study of doctor and breast cancer patient encounters, Tovia Freedman found that while some patients wanted doctors to tell them what to do, others wanted to believe they had made all the decisions themselves.

Christy Simpson has described three types of ideologies in talking about health and disease. While one ideology operates at the level of the social—that is how societies promote or inhibit the achievement of health—the other two take place at the level of the individual patient. They concern “the belief in technological and pharmacological solutions to problems of health and disease” and “the promotion of personal or individual responsibility for health.”

These two distinctions in types of response—attitudes toward biomedicine and level of personal involvement in decision-making—led me to identify four groups of respondents in my interviews. These groups help us understand the variations in women’s interpretations of the meaning of breast cancer and in their coping strategies. These four groups are described briefly below and in more detail in chapters 2 through 5.

Two groups put their faith in doctors, hospitals, and medicine. The first of these—the traditional responders—believed in biomedicine and also believed that the doctor knows best and should be deferred to. These women rarely questioned a doctor’s decision or recommendation. They often remained uncritical of their doctors, even as they told stories of less than stellar care. They learned little about their illness because
they found knowledge frightening and instead tried to get on with their lives with as few interruptions as possible. This was one of the two largest groups, comprising one-third of the women I interviewed.

The other largest group of responders—the biomedical experts—also believed in biomedicine. However, these women saw themselves as responsible for their own health and sought partnerships with their doctors rather than deferring to superior medical expertise. They obtained numerous second opinions in their quest to find the best experts, they read about all aspects of their disease, and they became conversant with the technical language of breast cancer. Biomedical experts were also one-third of the total sample.

In contrast to those who believed in biomedicine—whether in a traditional way or by becoming an expert—were two groups with less faith in its powers. The first of these, the religious responders, generally did what their doctors asked but believed that, if they were to get better, they must put their ultimate faith in God and not in doctors. So while they deferred to a higher power, this was a power outside the medical profession and, in these women’s opinions, superior to it. They used prayers, their own and those of others of similar faith, to help them safely through their illness. They found support in organized religion both while they were receiving medical treatment and afterward. This was the smallest group—just over 10 percent of the total sample.

A final group consisted of women who wanted to take charge of their own recovery but did not place great faith in doctors. While no one turned their backs completely on biomedicine, women in this group used alternative practices to supplement or replace some aspects of the standard medical treatment; thus they are called the alternative experts. They viewed doctors as dictatorial and often as in league with corporate capitalism in profiting from patients’ desperate needs. In looking outside their own individual behaviors to explain breast cancer, this was the only group that also embodied Simpson’s other health ideology—that of the social. They believed they were beating the medical system by taking their search for a cure elsewhere. They often chose to wholly or partly reject doctors’ recommendations. One-sixth of respondents fell into this category.
As can be seen from table 1, traditional responders were the most racially and ethnically mixed of the groups. Biomedical experts had an overrepresentation of Jewish women but only two African American women. The group most different in race and ethnicity from biomedical experts was the religious responders. While less than half of all black respondents were religious responders, almost all the religious responders were African American. Had I not made a decision to interview enough African American respondents to generalize about their experience, I would not have found this group. None of the religious responders were Jewish. This does not mean that Jewish respondents found no comfort in faith but rather that relying on faith first and foremost was not their main response. Finally, alternative experts were similar in race and ethnicity to biomedical experts.

In the following chapters, I expand on the differences among these four groups as we join the women I interviewed in their journeys through the land of breast cancer. We also see how many aspects of treatment differed for the women in these four groups. The stories of how these different groups of women made sense of their experiences are told to a great extent in the women’s own words. The stories follow Martin’s injunction that we need to provide a forum to show the variety of ways in which women understand their bodies and the meanings they give to the physical events in their lives.\(^9\) I should note that five of the women

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**Table 1  Response Groups by Race and Ethnicity**

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Traditional responders</th>
<th>Biomedical experts</th>
<th>Religious responders</th>
<th>Alternative experts</th>
</tr>
</thead>
<tbody>
<tr>
<td>White (not Jewish)**</td>
<td>19</td>
<td>21</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Jewish</td>
<td>5</td>
<td>9</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>African American</td>
<td>8</td>
<td>2</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>32</td>
<td>32</td>
<td>10</td>
<td>17</td>
</tr>
</tbody>
</table>

* Five interviewees had mixed responses, including the three with metastatic cancer, and so are not included in this tally.
** Includes one Latina.
were not easy to categorize into groups. Two had simultaneously tried many different responses and the other three had moved between categories at some point. These issues are discussed in the Conclusion.

Illness narratives take a particular form because the speaker is telling a story about a major disruption in her everyday life. While everyday accounts are easily understood by both speaker and listener, telling the illness narrative takes more work. It must be constructed in a way that makes sense to the woman and to her audience, and it must include previously unthinkable possibilities like imminent death. The sufferer has to categorize and explain the progress of the disease and its treatment as well as the ways in which it causes pain. In a study of rheumatoid arthritis patients, Gareth Williams found that the experience of chronic illness forced its victims to reconstruct events in order to explain how the illness happened at the particular moment in history and to reaffirm the belief in life as purposeful. The breast cancer survivors I interviewed needed to do this also.

The ways in which individuals talk about their illnesses tell us both about personal experience and about the cultural context in which the experience occurred. Culture shapes the experience of illness and gives it meaning. In analyzing the narratives of sufferers of TMJ, Linda Garro described patients as struggling because their illnesses deviated from an existing cultural model of how illness was supposed to progress and be understood. Women who have had breast cancer have a different experience. Unlike TMJ, their illness has enormous visibility and an established language that all understand.

The narratives about illness and sickness that appear in subsequent chapters tell the reader what the tellers wanted the world to hear. Many times, women commented that they agreed to an interview so I would share their stories with others. In her book on cancer and culture, Jackie Stacey has described such narratives as carrying a “health warning.” By this she meant that the reader should beware of “the certainties they promise” and “the truths they guarantee.” As Lucy Yardley argued in her essay on discourses of health and illness, we can only explain our experiences to ourselves and others by using the language and the human concepts that are accessible to us. A woman who tells the interviewer
about her breast cancer is engaging in impression management and
directing her responses to support the way she wants to present herself. Catherine Kohler Riessman illustrated this point by describing how a man
interviewed about divorce was able to structure the conversation in a way
that protected his masculine identity in the face of multiple sclerosis.

In the end, the reader has to make of these narratives what she or he
will. When the women I interviewed told me their stories, they most
likely had a larger audience in mind, at least some of the time. I as the
writer must necessarily change their stories by setting them in a context
and by selecting which voices and segments to recount. Many of these
women wanted their voices to be part of the public face of breast cancer.
Yet, while we need to accept that their narratives are a kind of story, we
should also realize that, to the narrators, they represent breast cancer’s
truth. I have tried to honor that truth in the pages that follow.