No shrinking violet: Rose Kushner and the rise of American breast cancer activism

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INTRODUCTION

When 45-year-old Maryland journalist Rose Kushner felt an "elevation" in her left breast in 1974, she immediately began to research the topic of breast cancer. What most surprised her was that physicians continued to use a dramatic operation, the radical mastectomy, to treat most cases of the disease. Even worse, Kushner believed, was the routine use of the "1-step" procedure in which surgeons, having obtained a biopsy specimen mid-operation that proved positive for cancer, then performed immediate radical breast removal on the anesthetized woman. By 1975, 1 year after being diagnosed, Kushner had become America's most prominent breast cancer activist.

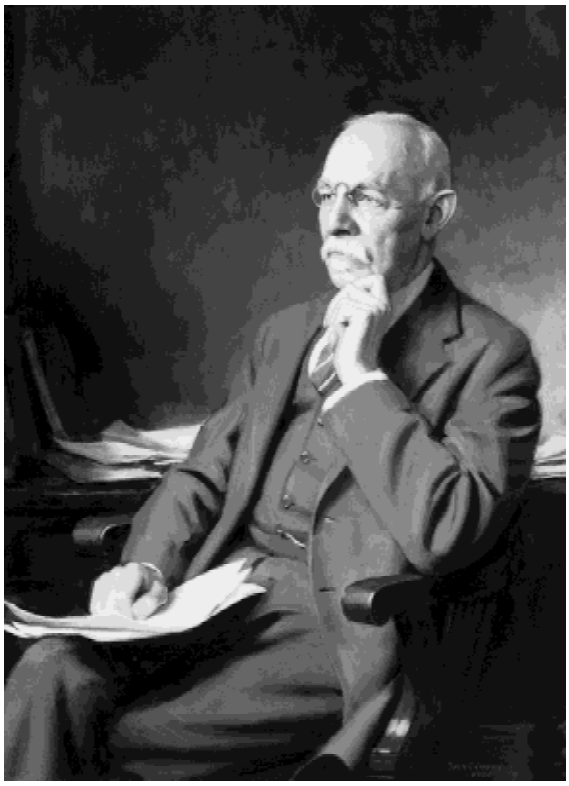
Modern breast cancer organizations have achieved remarkable success in publicizing the disease and raising funds. Revisiting Kushner's history illuminates the choices these groups have made and underscores the ongoing challenges they face.

THE RISE OF RADICAL SURGERY

Since the early 1900s, the treatment of choice for breast cancer had been the radical mastectomy, popularized by famed surgeon William Halsted. Halsted had argued that an operation aimed at removing the breast, the underarm lymph nodes, and both chest wall muscles underlying the breast was most likely to cure breast cancer.[1]

Although such a drastic procedure made sense when cancers were large and likely to have spread beyond the breast, by the 1970s, women generally came to their physicians with smaller, presumably more localized malignancies. A few renegade surgeons had thus begun to favor less extensive operations that preserved the muscles and, at times, even the breast. Some also advocated a 2-step procedure that separated diagnostic biopsy from treatment. Critics such as George Crile, Jr had "gone public," writing books designed for women.[2] So had a few breast cancer patients who had declined traditional treatment.[3] But the 1-step radical mastectomy remained the choice of most surgeons.

The first decision that Kushner made in 1974 was to refuse a 1-step procedure. Second, if she turned out to have cancer, she planned to decline a Halsted radical mastectomy. Yet, Kushner was unable to find a physician amenable to her plan. Ultimately, she convinced her family surgeon to perform only a biopsy. When the specimen tested positive for cancer, he berated Kushner for not having agreed to a 1-step procedure.[4] Next, having decided that she wanted a modified radical mastectomy, which would preserve her chest wall muscles, Kushner again had great difficulty finding a willing surgeon. When she finally did, the operation revealed a 1-cm cancerous lesion.[4]



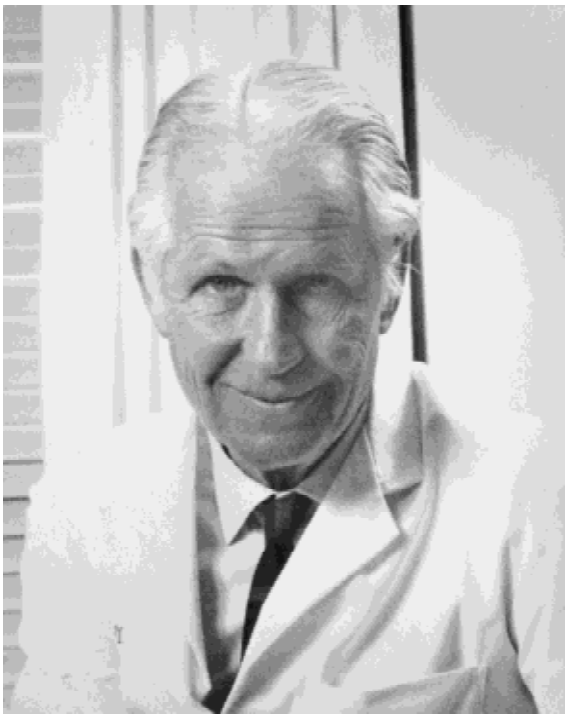
Alan Mason Chesney Archives

William Halsted, shown here in a 1932 painting by Thomas C Corner, popularized extensive operations to fight breast cancer

While recovering, Kushner turned her journalistic skills to writing about breast cancer, both her own experiences and her research. Kushner believed that every woman deserved to know 3 things: that the 1-step radical mastectomy, already rejected by many physicians outside the United States, was outdated; that cancer specialists, not general surgeons, provided superior care; and that women needed to acquire medical knowledge, participate in decisions, and challenge their doctors.[4]

TAKING ON THE MEDICAL PROFESSION

In making these claims, Kushner thoroughly upset the apple cart. Her personality fit this task. Outspoken and direct, Kushner boldly criticized the medical profession in newspapers, on television, and ultimately, in a book.[4] Attending medical conferences as a journalist, Kushner would rise in the back of the room and question the data



Cleveland Clinic Foundation Archives

George Crile, Jr advocated separating diagnostic biopsy from operative treatment of cancer of the breast

that doctors were reporting. She also charged the American Medical Association with "hiding important information from the public."[5]

Not surprisingly, many physicians believed Kushner's behavior was appalling. Although the authority of the mostly male medical profession was under fire by the mid-1970s, physicians still commanded considerable respect. To be challenged publicly by a layperson—especially a woman—was an affront. At a symposium in 1975, physicians on a panel with Kushner implied that she was fabricating information.[6] Kushner's book, another doctor stated, was a "piece of garbage."[7]

Kushner was also rebuked by the physician-dominated American Cancer Society, which still favored radical surgery for women with breast cancer.[1] She frequently criticized the society's "Reach to Recovery" program, which provided counseling for mastectomy patients about postoperative rehabilitation. Kushner believed that this focus discouraged women from learning about treatment options before surgery. She was also dismayed that, in a "free and democratic society," Reach volunteers needed a surgeon's permission before visiting a patient.[8] Challenging established organizations, Kushner was more outsider than insider during these years.

In this sense, Kushner was a product of her times. Mainstream institutions across America were under siege in the 1970s as the civil rights movement coalesced with efforts to stop the Vietnam war. In covering Vietnam as a journalist, Kushner had become particularly offended by what she believed was the arrogance of the military and government officials directing the war effort.

Meanwhile, feminists were angrily challenging male domination of society. By the early 1970s, this critique had spread to medicine. Terming most male physicians "condescending, paternalistic, judgmental, and noninformative,"[9] the growing women's health movement urged women to actively participate in their health care. Although the initial focus of the movement was on childbirth, Kushner's attack on the 1-step radical mastectomy exemplified this type of feminist critique. By making inappropriate treatment decisions on anesthetized women, physicians were silencing women with breast cancer. One such woman, Kushner claimed, was Betty Ford, whose breast cancer was diagnosed in 1974. When told that President Gerald Ford had decided that his wife should receive 1-step radical surgery, Kushner wrote that this event "has got to be engraved somewhere as the all-time sexist declaration of no-woman rights."[10] As a way to help women, she established the Breast Cancer Advisory Center, which provided information to thousands of patients.

FROM OUTSIDER TO INSIDER

Yet, even as Kushner fought to change the system, she avoided appearing too extreme. She peppered her presentations with self-deprecating comments, characterizing herself not as a patient activist, but a "Yiddish humorist." Kushner constantly sought to build bridges. For example, after taking on physicians, she would invariably write them letters, not backing down, but perhaps apologizing for her zeal. Rather than writing off the conservative American Cancer Society, she worked with sympathetic officials to spread her views.

Perhaps the best example of Kushner's moderation was her response to more radical feminist critiques of medicine. Many women's health activists in the 1970s belonged to grass-roots organizations that advocated broad social and political change. This agenda at times included substituting lay female health providers for gynecologists.[11] In the case of breast cancer, these critics charged that male surgeons were "mutilating" uninformed women.[12] Kushner had little tolerance for such language. Men undergoing treatment of prostate cancer, she noted, received similarly disfiguring procedures. "As for the accusation that mastectomies are male-chauvinist inventions created to butcher women," Kushner wrote, "militant Women's Libbers should drop the charge."[13] She also disapproved of breast cancer activists who openly displayed their mastectomy scars as a political statement.

Kushner's greatest triumph came at the 1979 National Institutes of Health (NIH) conference on breast cancer treatment, where a consensus panel concluded that radical mastectomy was no longer appropriate; smaller operations, often combined with radiotherapy, chemotherapy,

or both, provided equivalent survival with less disfigurement. But it was Kushner, the panel's only layperson, who single-handedly convinced her colleagues to include a statement rejecting the 1-step procedure. Separating biopsy from operation, she successfully argued, empowered women to make informed decisions.

Shortly thereafter, President Jimmy Carter named Kushner as the first lay member of the National Cancer Advisory Board. She had earned this honor by her advocacy, outspokenness, and scientific knowledge of breast cancer. Indeed, by the early 1980s, Kushner was reviewing NIH grant applications. She was pleased with her new ability to work within the system, where she believed she could create change most effectively. "A maverick no more," Kushner quipped. "I'm a full-fledged member of the Establishment."[14]

Kushner's insider status also became apparent through her growing relationship with Bernard Fisher, a surgeon whose randomized trials had rendered radical mastectomy obsolete. Kushner had become a convert to Fisher's strategy of performing rigorous studies. In so doing, her earlier skepticism regarding physician expertise was replaced with an increasing faith in the value of properly obtained scientific knowledge. Fisher, in turn, came to respect the woman who had so often interrupted his presentations or his sleep. Kushner and Fisher became a team in the 1980s, recruiting women for clinical trials and lobbying Congress for funding.

But by this point, Kushner knew she had terminal breast cancer. In 1981, she had discovered a lump near her scar, connoting metastatic disease. She refused chemotherapy, which she believed was too toxic,[15] opting for treatment with tamoxifen. A few days before her death in 1990, she was on the phone promoting legislation to cover screening mammograms. Kushner was 60 years old when she died.

MODERN BREAST CANCER ACTIVISM

In 1991, a group of activists formed the National Breast Cancer Coalition, which drew on earlier women's health advocacy and AIDS activism of the late 1980s. Coalition members argued that breast cancer research was grossly underfunded, given that the disease was the most common nondermatologic cancer in women. The coalition set up shop in Washington, DC, and made lobbying for research money its prime goal. "Women have declared war on breast cancer," the coalition's president Frances Visco proclaimed, "and [Congress] had better find a way to fund that war."[16]

Breast cancer activists raised money to fight the disease with great success in the 1990s. Government allocations for breast cancer research, $75 million in 1989, now total $600 million annually. Private foundations have also raised hundreds of millions of dollars for biomedical research and early detection programs. Breast cancer activists have forged relationships with industry, which has funded studies of diagnostic and therapeutic methods.

In working for change within the system, modern breast cancer activists have followed the strategies that Kushner stressed in her later years. They have built a highly professional advocacy movement,[17] supported randomized trials of screening and treatment regimens, and raised consciousness about a feared disease. Happily, these efforts seem to be paying off. The death rate from breast cancer, stable for decades, is finally declining.[18]

Despite these successes, critics—both outside and within the movement—have questioned how breast cancer advocacy has evolved. Funding for research, some argue, should not be determined by who yells loudest. Focusing on single diseases pits one medical condition against another.

Other critics claim that intensive lobbying for breast cancer research has deflected attention from broader strategies to improve women's health. That is, the fight against breast cancer has become "overmedicalized."[19] Early grassroots feminist health activism, sociologist Sheryl Ruzek states, stressed a social model that considered how "women perceive[d] health risks in the larger context of

Harvey Kushner

Rose Kushner fought tirelessly on behalf of women with breast cancer

their lives."[20] Promotion of women's health thus entailed not only preventing disease but also improving housing, education, and economic resources. In contrast, modern efforts to address breast cancer among disadvantaged women stress access to new technologies. Similarly, breast cancer prevention strategies encourage healthy women to take potentially dangerous pills, such as tamoxifen, rather than to pursue healthier lifestyles.[21]

One reason for this development, more radical women's health activists fear, is that the breast cancer movement has become "co-opted"—overly dependent on funding from pharmaceutical companies and other corporations.[17] Such alliances, ecologist Sandra Steingraber alleges,[22] both compromise objectivity and discourage scrutiny into possibly carcinogenic substances that industry releases into the environment. As activist Barbara Brenner writes, true conquest of breast cancer will require "understanding and eradicating the causes of the disease."[21]

CONCLUSION

It is tempting to ask how Kushner might have responded to this debate. Having laid the basis for a professional breast cancer movement, she would no doubt be pleased by its accomplishments. Yet Kushner always feared the complacency that followed when "vested interests" achieved too much success. As early as 1976, she analogized the war on cancer to that conducted in Vietnam. "I am well aware," she stated, "of what our bureaucracy—military or medical—can do when there is a lot of money to be earned by the combination of government and industry."[23] It will be the challenge of modern breast cancer activists to continually scrutinize their strategies and, when necessary, question dogma, as Kushner did so successfully.[1]

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