THE NARRATIVE CONSTRUCTION OF BREAST CANCER: 
A COMPARATIVE CASE STUDY OF THE SUSAN G. KOMEN FOUNDATION 
AND NATIONAL BREAST CANCER COALITIONS’ CAMPAIGN STRATEGIES, 
MESSAGES, AND EFFECTS 

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This dissertation entitled

THE NARRATIVE CONSTRUCTION OF BREAST CANCER:
A COMPARATIVE CASE STUDY OF THE SUSAN G. KOMEN FOUNDATION
AND NATIONAL BREAST CANCER COALITIONS’ CAMPAIGN STRATEGIES,
MESSAGES, AND EFFECTS

BY

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The goal of this research is to reveal the connections, contradictions, tensions, and paradoxes inherent in the narratives of breast cancer created by the Susan G. Komen Breast Cancer Foundation and the National Breast Cancer Coalition by exploring three research questions:

Q1: How do the Susan G. Komen Breast Cancer Foundation and the National Breast Cancer Coalition perform a narrative of breast cancer at their respective events?

Q2: How are these performed narratives shaped by the cultural and historical context of breast cancer awareness in the United States?

Q3: How do these performed narratives shape current breast cancer awareness in the United States.

In addressing these questions, the historical and cultural roots of breast cancer campaigns in the US are addressed, as well as current narrative health communication scholarship. The organizational stories are told through ethnographic thick descriptions and analyzed using Goffman’s Frame Analysis to reveal narrative structure, cultural and historical themes, and speculate about the future of breast cancer awareness efforts in the US. This study serves as a record of events, a model of culturally and historically based narrative research, and a demonstration of how narrative theories can extend beyond the scope of a
single author and explain collective authorship as well. Reframing narrative scholarship in this way expands on current theories and offers a new perspective for analyzing the ways that we communicate about health-based narratives.

Approved:

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 CHAPTER ONE

BREAST CANCER CAMPAIGNS IN THE UNITED STATES

Prologue: Discovering Pink Ribbons

Clipped to my refrigerator is a white slip of paper with a large, official-looking number on it - 496. This was the race number from my first “Race for the Cure” 5 kilometer run/walk. The Race for the Cure is a fundraising event sponsored by the Susan G. Komen Breast Cancer Foundation. I keep it because it represents several firsts for me: The first time I enjoyed running. The first time I entered a race. The first community event I attended after moving to the small town of Nelsonville, Ohio. And, the first time I witnessed the selfless passion of many Race for the Cure participants who demonstrate through physical effort the degree to which they care about fighting breast cancer. As one woman said, “if my sister can go through chemotherapy, there’s no reason I can’t run up that hill.” It was at that moment I realized that this was more than just a race.

The small, local Race for the Cure that I witnessed that morning in the summer of 2001 made me realize the power breast cancer awareness campaigns have to influence us personally and shape our perceptions and emotions regarding this disease. Breast cancer awareness is inescapable: Komen’s Race for the Cure events draw more than one million participants annually to their 5K fitness run/walks (About Komen: Facts and Figures, 2002). Beyond special fundraisers, our daily lives are saturated with pink ribbons and cause-related marketing ranging from lids on Yoplait yogurt containers to pink KitchenAid mixers. Countless women’s magazines also take up the cause, as well as television programming like The Oprah Winfrey Show, and Murphy Brown. We are
inundated with messages that tell us not only to keep thinking about breast cancer, but *how* we should think about breast cancer.

The magnet that holds my Race for the Cure number to my refrigerator is a constant reminder of the forces that shape our thinking. The magnet bears a picture of a pink bulldozer pushing dirt and a caption that says: “[Not just ribbons]” (brackets in original). It is an ad for the National Breast Cancer Coalition (NBCC), reminding us that “pushing in the right direction” is what it takes to eradicate breast cancer. This magnet is important, because it represents the critical shift in thinking that led me to this research project.

When I first discovered the NBCC’s website, I believed that this organization worked against all the good that the Komen Foundation was doing. Their position paper rejecting the promotion of breast self-examinations, and NBCC pictures of women on Capitol Hill holding picket signs that read: “forget the pink, use the ink” were evidence that the NBCC enacts a radically different form of breast cancer awareness than Komen. I wanted to know why. Why can’t these organizations work together? Why can’t they align towards common goals? Why would anyone challenge the Komen Foundation? As I learned more about the NBCC, I discovered a very different sort of selfless passion. Rather than being driven by the very visible marketing that makes Komen successful, the NBCC is fueled by a grassroots advocacy effort and strong national network of affiliated organizations who fight breast cancer as a political cause as much as a personal one. The success of this organization is unparalleled: NBCC’s lobbying efforts have contributed to an eight-fold increase in federal breast cancer research since the Coalition’s inception in
The Coalition argues that breast cancer awareness in the United States isn’t just about ribbons. To look beyond the universal pink ribbon symbol that has so literally and figuratively put a bow on breast cancer, is to discover that breast cancer awareness in the U.S. is a story characterized by underlying controversy, division, and confusion.

What began as a research agenda focusing on the success of the Komen Foundation and their popular Race for the Cure has evolved into a critical inquiry into the intentions and effects of the two largest breast cancer non-profit organizations in the United States: the Susan G. Komen Breast Cancer Foundation and the National Breast Cancer Coalition. Although these organizations share a common vision of a future free from breast cancer, their paths toward this future are greatly divergent. The varying histories, strategies, rhetoric, and goals of Komen and the NBCC shape the ways we understand and react to breast cancer. The efforts of these organizations have focused attention on breast cancer, but have also created discrepancies that are confusing and at times disturbing.

The goal of this research is to reveal the connections, contradictions, tensions, and paradoxes inherent in the narratives of breast cancer created by the Komen Foundation and the NBCC. Through this context of breast cancer awareness, it will also be possible to explore the theoretical ramifications of the connections, contradictions, tensions, and paradoxes of narratives in general, thereby contributing to our understanding of how we co-construct and enact narrative ways of knowing. By examining the narrative lens through which we see and think about breast cancer, we can better understand the effects
that mass communication has on how we communicate interpersonally about the issue and how we behave given our understanding of breast cancer. There are more than campaigns and money at stake in the narrative construction of breast cancer: there are the lives of those with breast cancer, the medical staff helping them, and the friends and family supporting them. The narrative that shapes their perceptions of breast cancer will also shape their emotions, conversations, and medical decisions. As Walter Fisher argues, humans are essentially narrative beings, and narrative is so essential to us that we should think of ourselves as homo-narrans, storytellers (1984; 1990). While the specific salience of narratives will be discussed in forthcoming sections, their influence and importance are essential to the study of health communication. In order to fully understand how we communicate about breast cancer, it is necessary to study breast cancer as it has emerged historically, contextually, and at times very deliberately. This leads to three research questions:

Q1: How do the Susan G. Komen Breast Cancer Foundation and the National Breast Cancer Coalition perform a narrative of breast cancer at their respective events?

Q2: How are these performed narratives shaped by the cultural and historical context of breast cancer awareness in the United States?

Q3: How do these performed narratives shape current breast cancer awareness in the United States?

Toward these goals, this first chapter will focus on defining the breast and breast cancer, provide an overview of the history of breast cancer and breast cancer campaigns
in the United States, and discuss the contemporary position of breast cancer as both a public and private health issue.

The Breast and Breast Cancer

Men and women are aroused by it, artists represent it, poets apostrophize it, babies are nourished by it, fashion and commerce fetishize it – and disease afflicts it. All of these responses to the breast, including the last one, are conditioned, if not wholly determined, by the culture in which they operate. The breast attracts so much attention and is a site of conflict for so many of society’s values and beliefs that it often seems not to belong to a woman at all. (Leopold, 1999, p. 1)

Women’s breasts require very little introduction given the cultural obsession that surrounds them in the United States. As icons of sex and fashion, the breasts first and foremost function in infant nourishment is more of an afterthought than an initial one. In order to understand the forthcoming discussions of breast cancer, detection methods, and treatments, it is necessary to move beyond the cultural obsession and discuss the biology of this organ. Given the availability of detailed medical and scientific descriptions of the breast, what follows is intended as a basic overview to aid readers in the context of this conversation. Resources such as Our Bodies, Ourselves (Our bodies, ourselves for the new century: A book by and for women, 1998), or Dr. Susan Love’s Breast Book (Love, 2000) should be consulted for more comprehensive information.

Understanding the Female Breast

It is important to note that breasts are as unique and individual as each woman. Thanks to the same genetic variation that provides us with unique faces, we also have
differing shapes and sizes of breasts. Thus the qualifier “normal” is as inappropriate for labeling breasts as it would be for labeling something like hair color and texture.

**Anatomy**

The female breast is composed primarily of fat and breast tissue. The actual tissue of the breast consists of the ductal system and lobules that produce milk following childbirth. As described by Love, each breast contains six to nine ductal systems that culminate in an equal number of ductal openings in the nipple:

…the ductal system, like a tree, breaks up into little branches, which go all the way to the back of the breast. These branches are the ducts. Leafing out at the end of each branch are the lobules, which make the breast milk and then send it through the ducts to the nipple. Each ductal system is independent of all the others; each one creates milk separately. They coexist, but they don’t connect with one another. (p. 10)

The layers of fat, or adipose tissue compose roughly one third of the breast’s volume. These layers surround the breast tissue and reside on the pectoralis, or chest muscle, behind which are the ribs.

The little muscle that the breast contains is located in two places. There are muscles in the nipple that when contracted make the nipple stand out. There are also very tiny muscles around the lobules that aid in delivering milk.

Breasts contain arteries, veins, nerves, and lymph vessels, which are an important site in the detection of cancer. The lymphatic system, particularly the lymph nodes, are responsible for providing nourishment to cells and for clearing away cellular waste.
including cancer cells. “Lymph nodes function as filters to trap bacteria or foreign substances so that they will not be poured into the bloodstream. If there is severe infection, the lymph nodes proximal to the site can become enlarged because they are filled with the bacteria that are being destroyed by the lymphocytes there” (Burke, 1985, p. 186). When a breast is afflicted with cancer, “it is crucial to identify which lymphatics and which lymph node is draining a particular area of the breast so that the correct lymph nodes can be removed and examined for signs of cancer” (Love, 2000, p. 7). Lymph vessels from the breast drain to nodes in the armpit, nodes just above the collarbone and nodes just under the breastbone (Hirshaut & Pressman, 1992).

Although the primary function of the female breast is to produce milk to feed an infant, however Love does note that human females are unique as compared to other mammals, because they are the only mammals to develop breasts before they are necessary for feeding young. Additionally, “humans are the only animals who are actively sexual when we’re not fertile. This suggests that our breasts have an important secondary function as contributors to our sensual pleasure” (p. 12).

**Development**

Breast tissue begins growing during the sixth week of fetal development with the formation of the milk ridge from the under arm area to the groin. “In humans, this ridge disappears except for the area on the chest that will form a pair of breasts. In other mammals, the ridge will continue to form multiple pairs of breasts” (Our bodies, ourselves for the new century: A book by and for women, 1998, p. 605). Breast tissue begins changing with the onset of puberty. In girls, ovaries will begin to produce estrogen
one to two years prior to beginning menstruation, or menarche. Estrogen triggers the growth of breast cells and preliminary formation of the ductal system. Both Love and *Our bodies, ourselves* describe breast development as beginning with a firm bud of tissue that will grow and expand as the breasts continue to form. If this bud of tissue is removed or damaged, the breast will fail to develop.

Throughout puberty, the ductal system, the surrounding fatty tissue, and the fibrous tissue that supports the breast called stroma continue to grow until the breasts reach their fully developed size. According to *Our Bodies, ourselves*, most growth will occur in early puberty, some growth will continue at a slower rate through the teenage years.

Following puberty, the stroma and glandular tissue [the ductal system and lobules] of the breast continue to respond to estrogen and progesterone during the menstrual cycle, with growth and fluid retention at amounts that may be barely noticeable for some but painful for others. In early adulthood, the stroma is thickly branching. Most of the lumpiness felt during this time is due to these firm clumps of glandular tissue supported by the dense stroma and surrounded by soft fat. (*Our bodies, ourselves for the new century: A book by and for women*, 1998, p. 605)

In a purely technical sense, breast tissue must experience all stages including that of childbirth and milk production for the mammary tissue to be fully mature and functional. (Love, 2000; Riordan, 1999)
Lactation

A woman’s body begins preparing the breasts for lactation early during the pregnancy. During the first half, nipples enlarge and become more erect, estrogen causes the ductal system to grow and proliferate and progesterone promotes lobule growth in preparation for milk production. After these first sixteen weeks of preparation, the breasts will lactate even if the pregnancy does not continue. For this second part of the pregnancy, the breasts are in lactogenesis, stage 1, which is characterized by the capacity to secrete milk and resultant breast enlargement as secretory cells develop and begin accumulating fat droplets. Lactogenesis, stage 2 is triggered by delivery and the absence of the placenta. During the pregnancy, the placenta produces estrogen and progesterone that prohibit the pituitary gland from releasing prolactin, the hormone that triggers milk production. With the delivery of the baby and placenta, the levels of estrogen and progesterone drop and prolactin is released in order to produce milk. The secretory cells in the lobules extract water, lactose, amino acids, fats, vitamins, minerals, and other substances from the mother’s bloodstream and converts them into milk which is stored in the ductal system and eventually extracted through the nipple. Lactogenesis, stage 2 ends in the initial days following birth when milk production transitions from being hormonally controlled, to being demand controlled by milk removal. The supply-demand response matches prolactin and milk production to milk extraction and lactation will continue as long as a woman breastfeeds her infant. (Riordan, 1999)
Aging

As women age, breast density changes as the breast tissue decreases and levels of fat increase. During the adult years when breast tissue is dense, it is very difficult to screen for cancer with mammography because cancerous tissue is equally dense – all tissue appears the same on the x-ray. Given these equal densities, ultrasounds and biopsies are better detection methods for women in their 20s and 30s when breast density is highest. (Society, 2004b) Mammograms are more useful for detecting breast lumps when the breast has lost some density, typically occurring in a woman’s 40s or 50s and during menopause. With menopause there are significant hormonal changes – most notably a reduction in the amount of estrogen produced by the ovaries – and this also influences the composition of the breast. “Once you’re in menopause, the breast tissue goes away, and there are usually only a few strands of it left. However, women vary in the proportion of breast tissue remaining after menopause. And if they take hormone replacement therapy their tissue may remain as dense as it was, or may even become more dense” (Love, 2000, p. 125).

Through the lifecycle, the female breasts change significantly. Understanding these changes and basic breast biology contextualizes the effects of breast cancer. The next section will discuss cancer in general and as it applies to the breast and women in particular.

Cancers of the Breast

Cancer is caused by chemicals in the air we breathe, the water we drink, and the food we eat. Cancer is caused by bad habits, bad working conditions, bad
government, and bad luck – including the luck of your genetic draw and the
culture into which you’re born. (Proctor, 1995, p. 1)

According to the American Cancer Society (ACS), “cancer is a group of diseases
characterized by uncontrolled growth and spread of abnormal cells” (Society, 2004b, p. 1). The ACS estimates that 1,368,030 new cancer cases will be diagnosed in 2004 and
about 563,700 Americans will die from cancer this same year. Cancer is second only to
heart disease in cause of death in the United States.

Understanding breast cancer requires a basic understanding of cancer in general. Many of the issues that divide the Komen Foundation and the NBCC are philosophical
and definitional disagreements and so it is important to possess a working knowledge of
the terminology and biology. The next section will provide an overview of cancer in
order to familiarize readers with these concepts. More comprehensive discussions of
genetics, cancer, and biology are available from The American Cancer Society, Dr. Susan
Love’s Breast Book, and Cancer Wars: How politics shapes what we know & don’t know
about cancer by Robert N. Proctor.

Biology of Cancer

Cancer begins with the smallest essence of our being – our DNA, or
deoxyribonucleic acid. Simply put, DNA is the genetic blueprint contained in every
living cell. Love (2000) explains DNA with a cookbook metaphor: DNA consists of pairs
of nucleotides that form a chain of patterns called genes, much like letters form words.
Genes are like recipes that are organized into chapters, or chromosomes. All of the
chromosomes together form the cookbook, or genome that contains all of the information
needed to make a human being. When cells divide to reproduce, the DNA is duplicated so that each cell will have an identical copy of all of this information (Davey & Halliday, 2001).

During this process, a cell may not produce an identical copy of its DNA and instead produces a mutated version. Love (2000) explains that some mutations are harmless, like the mutation that results in freckles, but others lead to illness or cancer. One way that an individual can develop cancer, explains Proctor, is when it is inherited: “passed from generation to generation via the DNA contained in the fertilized egg that gives rise to an embryo” (1995, p. 223). Proctor argues that genetic inheritance accounts for few cancers and that most are the result of exposure to a carcinogen that triggers a gene to function abnormally.

In either circumstance, the development of cancer is a multistage process that requires a series of mutations to occur before genetic sequencing is sufficiently altered to lead to problematic growth. A cell containing mutated DNA must also survive a variety of genetically programmed “checks” in order to continue replicating and further mutating. One such check involves enzymes called repair endonucleases, which monitor and correct for mutated DNA. If damage is too substantial to be repaired, the repair endonucleases will prevent the cell from dividing and cause it to engage in a programmed cell death called apoptosis.

Only the mutation of specific genes will result in cancer. Oncogenes are genes that permit cancer cells to divide and multiply, however several oncogenes must be activated before they will lead to cancer. Similarly, there are also anti-oncogenes that act
as tumor suppressors. These genes monitor cell growth and will engage apoptosis if oncogenes, mutations, or defects are detected (Davey & Halliday, 2001). If a mutated cell sustains these processes, it still may not result in cancer:

To become cancer, a cell needs more than the ability to divide and grow out of control. Noncancerous, benign tumors can also do that. What is ultimately crucial is the capacity to invade outside of their own normal territory. The cells in any given area are tightly attached to each other, forming a natural guard against invasion. So for a cell to break outside of its own area and into another requires special qualities (Love, 2000, p. 202).

This process of metastasis explains how cancer is able to move throughout the body and infect multiple organs and sites. This is why it is important to detect cancer quickly. The rapid growth of cancer cells into tumors is not only invasive in its original site, but potentially invasive to the rest of the body. Cancerous tumors have the potential to inhibit organ functioning, redirect blood supply, and sap the body of nutrients, but also to metastasize and pose great risk to an individual. Medical professionals assess cancer and its spread throughout the body by a descriptive process called staging. The American Cancer Society explains the TNM staging process that is often used to classify breast cancer:

A cancer’s stage is based on the primary tumor’s size and location in the body and whether it has spread to other areas of the body. A number of different staging systems are used to classify tumors. The TNM staging system assesses tumors in three ways: extent of the primary tumor (T), absence or presence of regional
lymph node involvement (N), and absence or presence of distant metastases (M). Once the T, N, and M are determined, a stage of I, II, III, or IV is assigned, with stage I being early stage and IV being advanced. (2004b, p. 3)

*Breast Cancer*

In order to classify breast cancer, physicians often use the TNM staging assessment but additional distinctions describe the cancer in relation to the surrounding breast tissue. A majority of breast cancers, roughly 86 percent according to Love, start in the ducts while a much smaller percentage start in the lobules at the end of the ducts. The origin of the cancer identifies it as either ductal carcinoma or lobular carcinoma. If the cancer has spread beyond the duct or lobule, it will be classed as invasive ductal or lobular carcinoma. “If the cancer is not invasive, it will be called intraductal carcinoma or ductal carcinoma in situ, or lobular carcinoma in situ or even noninvasive carcinoma” (Love, 2000, p. 328). Additional classifications further identify specific variations of the breast cancer and distinguish it as aggressive or slow growing.

*Detection of Breast Cancer*

Before a tumor develops in the breast, genetic testing can provide an indication of future risk and genetic predisposition towards cancer. The presence of the BRCA1 or BRCA2 genes doesn’t necessarily guarantee that breast cancer will develop, but these genes do indicate a heightened risk. As explained by the National Institutes of Health: National Human Genome Research Institute:

[BRCA1/BRCA2 are] the first breast cancer genes to be identified. Mutated forms of these genes are believed to be responsible for about half the cases of inherited
breast cancer, especially those that occur in younger women. Both are tumor suppressor genes. (2005)

*Treatment of Breast Cancer*

While genetic testing is becoming increasingly common, when detecting and treating breast cancer, physicians typically rely on other methods. Biopsy has long been used to extract tissue from lumps in order to provide a sample for analysis. Biopsy methods have varying levels of invasiveness ranging from fine-needle aspiration (a syringe is used to extract cells from a lump) to core-needle biopsy (a core tissue sample is obtained via syringe-like tools) to the most invasive, an excisional biopsy (the entire lump is removed while the patient is under general anesthesia) (*Our bodies, ourselves for the new century: A book by and for women*, 1998). Information gained from the biopsy analysis is paired with information from mammograms, x-rays, sonograms, or other breast-imaging methods and a treatment course will be determined.

Like other cancers, breast cancer can be treated locally, at the site where cancer developed, and systemically, throughout the entire body. Often, a physician will treat it both ways. The four most standard ways of treating breast cancer are a combination of local and systemic methods. Surgery and radiation are localized methods for treating cancer within the breast. Chemotherapy and hormone therapy are systemic methods for treating metastatic breast cancer.

Historically, mastectomy, the surgical amputation of a breast, has been the procedure of choice for breast cancer treatment. In the United States, Halsted’s disfiguring and debilitating radical mastectomy stood alone as standard treatment for
breast cancer from the early 1900s through the mid-1970s (Olson, 2002). Radical mastectomy is the removal of the breast tissue and skin, the underlying chest muscles, and the surrounding lymph nodes. Following a lengthy recovery, women were left with a scarred and concave chest, little if any movement in the adjacent arm, and lymphatic swelling to cope with in addition to the loss of a body part.

Dr. William Stewart Halsted, for whom this procedure is named, was the first professor of surgery at Johns Hopkins Medical School during the 1890s. Although he did not invent the radical mastectomy, he systematized it and by teaching it to a legion of new surgeons, Halsted and his students made the radical mastectomy a standard of practice for decades to follow. This, in spite of the fact that only 12 percent of Halsted’s patients who survived the surgery lived more than 10 years post-mastectomy (Leopold, 1999). By current standards, it is shocking to see such poor success rates – especially attributed to the surgeon credited with such expertise in mastectomy – and it is a wonder that surgeons became and remain to be integral to breast cancer treatment.

Looking back through the history of women’s health in the United States, the rise of surgeons as breast cancer specialists can be attributed to a variety of circumstances. In colonial America, women provided health care to their families as part of their domestic responsibilities. Weisman (1998) explains that as health care providers, it was largely women who fueled the Popular Health Movement of the mid-1800s, a social movement that educated the public about illness prevention, hygiene, and self-help. Health care options outside the home were diverse and included physicians, herbalists, bonesetters, Hydropathologists, homeopaths, and botanists, as well as midwives, who in addition to
assisting in childbirth, also attended other women’s health needs. Economic competition between the regular physicians and the sectarians resulted in action from both sides. The reformers of the Popular Health Movement, white middle-class women, sectarians, laypersons, and some physicians fought to keep health care from being controlled by physicians they viewed as elitist. The physicians responded to competition by founding the American Medical Association (AMA) in 1847 and excluded sectarians and women from membership. Although the Popular Health Movement and its supporters brought attention to women’s health, the AMA’s efforts to professionalize physicians claimed control over American health care for good.

Through the late 1800s and early 1900s, women’s health care became men’s domain as the AMA established a specialty in gynecology in the 1870s and took over the roles traditionally held by midwives. During this time, the number of female physicians was increasing, but because they were excluded by the AMA, female physicians were also excluded from advanced educational opportunities and from practicing in most hospitals. The dominance of male physicians, the new professionalism of medicine, and the role of women in society all contribute to the rise of the surgical solution. In her study on the history of breast cancer treatment, Leopold (1999) explains that breast tumors were typically regarded by women as shameful and often hidden until pain or rupture necessitated medical care. If she chose to visit a doctor at all, she would be more likely to describe her condition to the physician rather than have him physically examine her breast. Even when physicians made efforts to treat breast cancer by “purging and bleeding, the compression of the breast with lead plates, the direct application of
calamine, goat’s dung, arsenic and zinc chloride pastes” and other failed remedies, breast
cancer could not be cured (p. 24). Leopold suggests that because physicians were
incapable of treating breast cancer, they began to ignore it and as the AMA and
physicians specialized and defined their boundaries, female breasts were left behind.
Even gynecologists rejected the breast and through ignorance and inexperience, women’s
doctors failed to diagnose any breast conditions at all.

The one medical specialty to not reject the breast, was surgery. The
predominantly male medical establishment viewed breasts as disposable appendages that
could be amputated if diseased. Cancer was regarded as a local rather than systemic
disease, and as no other treatment was effective, physicians often turned to surgeons to
perform mastectomies for patients who had exhausted all other options. With the arrival
of Halsted and the proliferation and systemization of the radical mastectomy, surgery
became the only option (Leopold, 1999).

Halsted’s radical mastectomy dominated breast cancer treatment through the
1970s, when women began demanding that more humane options be developed. Current
treatment options and surgeries designed to conserve the breast, or at the very least, to
preserve a woman’s options for reconstructive surgery have rendered the radical
mastectomy largely obsolete. Today’s breast conserving procedures include: lumpectomy
(a lump and a small amount of surrounding tissue are removed); partial mastectomy (the
cancer, surrounding tissue and some lymph nodes or muscle lining are removed); and
quadrantectomy, (surgical removal of a cancerous quarter of a breast including some
skin and lymph nodes). In spite of breast conservation efforts, varying levels of
mastectomy may occasionally be the best option. A total or simple mastectomy is the removal of the breast and often some lymph nodes. A modified radical mastectomy is removal of the entire breast, surrounding lymph nodes and the lining over the chest wall muscles (Brinker & Winston, 2001).

Surgical procedures are often accompanied by radiation therapy, which Olson (2002) claims was first employed as a breast cancer treatment by Richard Ludlum in 1886. Soon, scientists like Marie and Pierre Curie began studying the effect of alpha, gamma, and beta rays on human tissue. Olson describes the power of their discovery and research:

When human cells – normal as well as malignant – are exposed to those rays, they are ionized, becoming unstable. The rays bombard atomic structures, dislodging electrons and disheveling genetic material, and killing the cell during mitosis, or the division cycle. Because cancer cells divide so rapidly, they exist more frequently in a state of mitosis and are more vulnerable. They tend to die before normal cells. Exact dosage is key. Physicists must supply enough alpha, beta, and gamma rays to kill the cancer, but not enough to destroy normal cells. For the first time, doctors did not have to rely on surgery alone. (p. 89)

Radiation has become a refined and complex science since the beginning of the 20th century, but its basic principles are still what make it an effective cancer treatment today. As a method for killing fast-growing cells, it may be used before surgery in order to shrink a tumor, or following surgery to ensure that no cancer cells remain at the site of the growth. Risk of recurrence can be greatly reduced when radiation is paired with
surgery. For instance, a lumpectomy alone could have as high as a forty percent recurrence rate, whereas with radiation the recurrence risk lowers to about ten percent (Brinker & Winston, 2001).

Chemotherapy and hormone therapy are cytotoxic systemic types of treatments that work to kill cancer cells directly. Much like radiation, these treatments can be used prior to surgery to reduce tumor size and as post-surgical, or adjuvant treatments to kill cancer cells that may remain in the body – either at the site of surgery, or as a result of metastasis. Chemotherapy involves the administration of chemicals, either orally or intravenously, that prevent fast-growing cells from dividing. A common side effect of chemotherapy is that fast-growing non-cancerous cells are also prevented from dividing, resulting in hair loss, low energy, nausea, amenorrhea, anemia, and susceptibility to infection. The side effects of hormone therapy are less severe, but this treatment is only effective for specific types of cancer that rely on hormones like estrogen or progesterone for growth. Hormone therapy blocks the body’s production of these hormones, thereby preventing cancerous cells from growing (Brinker & Winston, 2001).

Mastectomy, radiation, and chemotherapy, also known respectively as “slash, burn, and poison” to breast cancer advocates like Dr. Susan Love and Roberta Altman and others, reflect significant medical advancements in cancer treatment, but also medical uncertainty in cancer treatment. Love argues this uncertainty is apparent in the overuse of chemotherapy. Because we cannot predict who will be helped by chemotherapy, we poison the majority to save the minority. Similar arguments exist regarding the overuse of radiation and the occurrence of more mastectomies than necessary given less radical
surgical options (Altman, 1996). Since we have not yet discovered a cure for cancer, the best alternative medical science has given us is to cut it out, burn it out, and poison it out of our bodies and hope it doesn’t come back. Given these options, it is no wonder that organizations like the Komen Foundation and the NBCC generate such support and work so tirelessly for improved research into cancer causes and treatments. Until more options become available, varying combinations of the four standard treatment methods are currently used to treat breast cancer and continue to be refined and improved through medical research. Much of what we now know about treating breast cancer comes to us through the efforts of early activists pushing science forward. By looking back at breast cancer through history, we can learn a great deal about our current conceptions of this disease.

**Historical Overview of Breast Cancer Campaigns**

*The American Society for the Control of Cancer*

The earliest organized effort to inform the American public about cancer began in 1913 with the formation of the American Society for the Control of Cancer (ASCC, renamed American Cancer Society in 1945). Responding to newly available statistics citing a rise in cancer deaths, a small group of surgeons, gynecologists, physicians, and laypeople founded the ASCC and established a set of axioms that would shape their efforts and dominate cancer awareness for much of the century. The three axioms are:

1. Cancer is at first a local disease.

2. With early recognition and prompt treatment, the patient’s life can often be saved.
3. Through ignorance and delay, thousands of lives are needlessly sacrificed.

(Lerner, 2001, p. 30)

The ASCC translated these axioms into a breast cancer campaign that championed the radical mastectomy. Echoing the advertising boom of the 1920s and the social shame generated by campaigns addressing personal hygiene (or lack thereof), the ASCC’s campaign relied heavily on fear appeals. Women’s breasts were no longer the taboo topic they once had been and consumer culture was quick to identify an ideal body type and a variety of products to help women achieve it. Primed by a sense of bodily inadequacy and imperfection, “the relentless undermining of women’s self-esteem left them ever more vulnerable to the belief that breast cancer was just another flaw in their makeup, a flaw that, like all others, they alone were responsible for repairing” (Leopold, 1999, p. 161). Although a radical mastectomy might render the achievement of the ideal body type forever out of reach, the ASCC reminded that it was certainly preferable to death.

In 1929, the ASCC published a pamphlet entitled, “What Every Woman Should Know About Cancer” which advised women to have a physical examination once a year, but also capitalized on the traditional gender role of women as family and community caretakers. The pamphlet encouraged women to distribute copies to her friends and family, to make sure that they were informed about cancer, and to make sure that they had the best medical attention. Leopold notes that the ASCC had no trouble finding volunteers among middle to upper class women recently liberated by birth control, dress reform, and voting rights (1999).
To further promote their message of early detection, the ASCC officially organized their volunteers into the Women’s Field Army (WFA) in 1936. With a one dollar enlistment fee, the 100,000 members recruited in 1936 also became the primary fundraisers for the ASCC. The WFA spread the ASCC’s messages through social networks, the first cancer prevention clinics, lectures, exhibitions, fair booths, newspapers, magazines, and billboards. The women of the WFA caused considerable concern among the still male dominated medical profession. Informed women posed a challenge to the medical authority traditionally afforded to physicians. With more knowledge, women asked more questions and in the eyes of physicians, they became troublesome patients (Leopold, 1999). The public awareness created by the WFA brought national attention to cancer that would further challenge the authority of physicians. In 1937, with the support of the WFA and the ASCC, Congress passed the National Cancer Institute Act to establish the National Cancer Institute and provide funding and coordination for cancer research. The act was opposed by the AMA, who cited concern over government involvement in medical research (Altman, 1996). The WFA faded into the larger structure of the ASCC/ACS through the mid-1940s, but with a peak membership of two million spanning 39 states, it is argued to be the most important source of breast cancer information for women in the first half of the twentieth century (Leopold, 1999).

The dominance of early detection

Throughout the 1940s, the message of early detection grew stronger as medical advancements allowed for a greater clarity to emerge in awareness campaigns. Until now,
women had been advised to have an annual physical or consult a doctor about suspicious lumps in order to detect cancer early. As the Pap smear, the breast self-exam, and mammography were developed, women could now be advised to take specific action.

In 1943, George Papanicolaou published, “Diagnosis of Uterine Cancer by the Vaginal Smear.” The Pap smear, as it came to be known, was groundbreaking in terms of women’s cancer in that it offered a simple and reliable method for detecting cervical cancer in its earliest stages. For the next few years, Papanicolaou continued his research and the Pap smear gained slow support among the medical community. During these same years, it had come to the attention of some ASCC volunteers, most notably Mary Lasker, that the organization provided no support for cancer research. In 1945 Lasker spearheaded a reorganization of the ASCC that involved a turnover in leadership, a shift in goals towards professional fund raising, and a name change to American Cancer Society (ACS). As insistent as ever in promoting early detection, the postwar ACS took up the cause of the Pap smear and by the 1950s had launched national promotion campaigns (Lerner, 2001). The ASC’s adoption of the Pap smear set the stage for the adoption of other early detection methods and made it easy to cluster women’s cancer detection into a recommended annual exam.

The breast self-exam (BSE) was developed by radiologist Alfred Pompa in 1948. His original home movie demonstrating the technique with a woman volunteer was professionally reproduced with funds from the NIH and mass distributed around the United States. The ACS became an enthusiastic supporter of BSE as an early detection method and also helped promote it beginning in the 1950s. BSE critics like Dr. Susan
Love and NBCC argue that by the time a tumor is palpable during a self-exam, it has likely been growing for several years and may have already spread to other parts of the body. Leopold points out that this is not new knowledge and breast cancer researchers in the 1950s knew that BSE would not catch tumors early enough to effectively treat them (1999). Unfortunately, BSE fit well with the popular message of early detection and the underlying theme of personal responsibility rather than the shortcomings of medicine. A message that Leopold argues, tells a woman that a cancer diagnosis is her own fault for not acting sooner or in the right way. With the refinement of mammography in the 1960s, women finally had a scientifically based breast cancer screening method. Mammography can be used to detect lumps long before they can be felt and pinpoint them within the breast. Although a significant advancement, mammography is still a less than perfect screening method in that tumors may be missed, especially in young women, and exposure to radiation may actually cause cancer in limited cases (Love, 2000).

**Women speak out**

In the 1950s, traditional assumptions about breast cancer began to be questioned at a number of levels. First, tumor biologists like Bernard Fisher began to understand breast cancer as a systemic disease rather than a local one. In light of this new theory, early detection and the standard radical mastectomy needed reconsideration as both relied on the idea that if cancer was detected and cut out of the body early enough a patient was cured (Leopold, 1999). Second, surgeons led by George Crile began to question the universal acceptance of the Halsted radical mastectomy and the institutions that promoted it as a woman’s best and only option. Crile was the most outspoken critic of the “bigger
better” surgical approach to breast cancer and argued for surgeons to make the best recommendation for each individual patient rather than insist on unnecessarily extensive surgeries for the sake of tradition. And third, women finally gained a powerful voice in the breast cancer forum and began to ask questions, organize, and take action.

When women like Terese Lasser, whose efforts are described below, began talking to other women about their experiences with breast cancer, a revolution in women’s health care began to take shape. As Olson (2002) describes, Lasser and others not only questioned the nature of breast cancer, they questioned medical science, and the surgeon-patient relationship as well:

In 1952, after feeling devastated by a radical mastectomy at Memorial Sloan-Kettering, [Terese Lasser] founded Reach to Recovery, a support group of mastectomy survivors dedicated to assisting women who had recently undergone surgery. Lasser began visiting mastectomy patients while they were still in the hospital, discussing the whole range of emotional and physical issues with them, including sexuality, breast prostheses, fashion, and exercises to reduce the swelling from lymphedema. Some surgeons banned Lasser from the halls of Memorial, but she defied them, showing up unannounced. On more than one occasion security police had to escort her from the hospital. At M.D. Anderson Hospital in Houston in 1956, one surgeon complained: “Keep those women off the floor! They are interfering with the physician-patient relationship and I’ll not have it!” But Reach to Recovery – women talking to women about breasts, sexuality, and cancer – was an organization whose time had come, and chapters
sprouted throughout the United States. In 1969, the American Cancer Society officially assumed direction of Reach to Recovery, and by the 1980s three of four mastectomy patients were receiving visits. (p. 120)

Interestingly, the ACS website effectively erases the grassroots efforts of Terese Lasser and claims to have launched the Reach to Recovery program in 1969 (Society, 2004a). By erasing Lasser, the ACS also erases the controversial origins of the Reach to Recovery program and the tremendous efforts women made to talk to other women. In spite of the ACS’ efforts to clean up the image of Reach to Recovery, the program has been criticized by Rose Kushner for belittling the decision making authority of women by requiring a surgeon’s permission to receive a visit from a volunteer (Lerner, 2001). Audre Lorde has also criticized the program for erasing the evidence of breast cancer from women’s bodies with prostheses and promoting a patriarchal and heterosexual standard of attractiveness (Lorde, 1980). Today, the program is still under the direction of the ACS and not only offers post-operative visits, but pre-operative visits as well to help women understand their treatment options (Society, 2004a).

At the time when Lasser was organizing one of the very first breast cancer support groups, the United States was on the verge of the Women’s Health Movements. Traditional gender roles were challenged by the wartime opportunities for women to work outside the home and challenged again postwar when women were expected to return to domestic work inside their homes. Leopold (1999) argues that through the 1950s and 1960s American women grew increasingly discontent with their social status until the rallying cry of Betty Friedan’s *The Feminine Mystique*, published in 1963 helped women
to identify their discontent and launch the Women’s Health Movement as well as the second wave of feminism. Friedan led women to question their sexuality and reproductive roles as wives, mothers, and housekeepers and ultimately, to demand greater control over their lives and bodies. As women rallied for (among other things) birth control and then abortion rights through the 1960s breast cancer remained a concern, but failed to emerge as the chief concern of the Movement until the 1970s. Several key events led to breast cancer becoming an issue of national importance and recognition.

To begin with, 1960 had brought about the very first discussion regarding informed consent between doctors and their patients with the landmark *Natanson v. Kline* case. As told by Ellen Leopold (2004) based on court documents and interviews with Natanson family members, Irma Natanson was diagnosed with breast cancer in 1955. At this time there were a variety of new treatments for cancer that seemed promising but remained untested like cobalt radiotherapy. Trial and error of these methods often occurred with actual human patients and unfortunately Irma Natanson was among the first to undergo cobalt radiotherapy, which resulted in disastrous consequences. Natanson was left permanently deformed. Among her post-treatment ailments: permanent unhealing burns, loss of one lung, loss of use of one arm, amputated fingers, destroyed ribs, and more than 20 plastic surgeries. Faced with mounting medical bills, Natanson sued her doctor, John R. Kline for failing to inform her of the hazards of cobalt radiotherapy treatment.

“The legal case that ensued, *Natanson v. Kline*, was a landmark in many respects. For perhaps the first time in a public arena, the case exposed, quite literally, the horrific
damage done to woman’s bodies by prevailing breast cancer treatments” (p. 2). Natanson won the case and the Kansas Supreme Court set the precedent for informed consent: “that physicians had ‘the obligation…to disclose and explain to the patient in language as simple as necessary the nature of the ailment, the probability of success or of alternatives, and perhaps the risks of unfortunate results and unforeseen conditions with the body’” (p. 2).

Throughout the 1960s women fought for more and more power over their bodies and their rights as health care consumers: particularly the right to have an abortion. During this decade, an underground group of women known collectively and individually only by the generic moniker, “Jane” grew active in Chicago and helped women secure safe, private, and affordable abortions (Baumgardner & Richards, 2000; Weisman, 1998) and defied laws still declaring the practice illegal. Women continued to reach out to other women with the formation of groups like the National Organization of Women (NOW) in 1966, and the National Association for the Repeal of all Abortion Laws (NARAL) in 1969. By 1973, Roe v. Wade was handed down and women were legally guaranteed the right to an abortion, another significant advancement in the Women’s Health Movement.

In 1970, one of the most influential groups of the Women’s Health Movement, the Boston Women’s Health Book Collective, first published Our Bodies, Ourselves and offered women carefully researched information on women’s health – including breast cancer. Our Bodies, Ourselves told women that the ‘personal is political’ and gave them the knowledge to understand their bodies, take charge of their health, and challenge medical assumptions (Our bodies, ourselves for the new century: A book by and for
The book gave women the information they needed to exercise their right to choose, especially when it came to breast cancer and the traditional “one-step” procedure “in which the surgeon would immediately perform a radical mastectomy if the intraoperative frozen section revealed cancer” (Lerner, 2001, p. 146). In spite of *Natanson v. Kline*, women were still asked to consent to the “one-step” prior to surgery and would enter the operating room not knowing if they would wake up with two breasts or not. *Our Bodies, Ourselves* encouraged women to ask questions and to ask for options less devastating than the “one-step” procedure.

In the spirit of the personal being political, several women were influential in the passage of the 1971 National Cancer Act. Mary Lasker and the ACS argued that a war on cancer was just as important as the war in Vietnam and deserved equivalent attention and funding (Lerner, 2001). Ann Landers also inspired a massive Congressional letter writing campaign when she wrote in her column that if the United States could put a man on the moon, then surely it could find a way to cure cancer (Olson, 2002). Nixon officially launched a national “war on cancer” in his State of the Union address and support of the National Cancer Act which allocated $334 million annually to the National Cancer Institute for cancer research (Lerner). The prominence of the war metaphor is especially interesting in that it emerges once again in relation to an actual war as it did during the early efforts of the ASCC and WFA. Additionally, and in some ways ironically, the war metaphor achieved literal status when the Department of Defense Peer-Reviewed Breast Cancer Research Program was established in 1992 and the Department of the Army was allocated a $210 million budget for the program (NBCC, 2003b; Weisman, 1998). I will
reserve analysis on the war metaphor and the metaphors favored by Komen and the NBCC for forthcoming sections. With respect to the current conversation, it is important to draw attention to the historical consistency of the characterization of cancer as a war and the frequency with which this metaphor has been linked specifically to breast cancer.

One way that this war has been fought is through personal battles and the stories women tell of them. As breast cancer became a national issue and women began to talk to each other about their experiences, women also began sharing their breast cancer stories publicly. The first woman to do so was Shirley Temple Black, a former child movie star and then a Representative and Ambassador to the United Nations. Black found a lump in her breast in 1972 and rather than follow her doctor’s recommendation for a traditional “one-step” procedure, Black became an active and informed participant in her treatment decisions. She took several weeks to review current literature on breast cancer treatments before consenting to have a biopsy – and only a biopsy. She maintained that the decision to have a mastectomy was hers not the surgeons, and she would make it after hearing the results of the biopsy. The tumor that was removed was malignant and again, Black took her time to review her options and make an informed decision. She rejected her doctors’ recommendations for a radical mastectomy and agreed instead to a simple mastectomy and the removal of a few lymph nodes. None of the removed tissue showed any signs of cancer cells. Black published the details of her breast cancer story in *McCall’s* magazine in 1973. She received over 50,000 pieces of mail praising her courage in her treatment decisions and in sharing her story with other women (Lerner, 2001; Olson, 2002).
Thanks to Black’s initial effort, 1974 became the year of the breast cancer narrative and marks a turning point for breast cancer awareness in the United States. Personal stories give names, faces, lives, and emotions to disease and breast cancer suddenly gained context as women wrote and read about the daily challenge of facing breast cancer.

When First Lady Betty Ford faced surgery following the discovery of a breast lump during a routine physical, she insisted that the public be fully informed about her condition and her decisions. In spite of current research finding simple mastectomies to be equally as effective as radical mastectomies, Ford’s doctor recommended a “one-step” procedure of biopsy and, in the case of cancer, an immediate radical mastectomy. Ford agreed and cancer cells were detected during her biopsy resulting in the radical mastectomy of her right breast (Lerner, 2001).

Whereas Black had been the first public figure with breast cancer, Ford was the first First Lady with breast cancer and the media coverage of her treatment and recovery was universal front-page news. Her story sparked an increase in mastectomy appointments, and also sparked the attention of journalist, Rose Kushner. Kushner had been diagnosed with breast cancer June, 1974 and engaged in extensive research prior to making treatment decisions. Her research led her to conclude that the Halsted radical mastectomy was an outdated operation and the “one-step” procedure was unnecessary and inadvisable. Like Black, Kushner insisted on an initial biopsy and when cancer cells were found, had to hunt down a surgeon who would agree to perform a modified radical mastectomy leaving the pectoral muscles intact. Kushner wrote about her experience for
the Washington Post and criticized the medical community’s devotion to Halsted. After learning that Betty Ford had chosen to undergo a “one-step” and possible radical mastectomy, Kushner tried to contact the White House to encourage the First Lady to consider other treatment options. Her efforts went largely unheard, as she was told that the President [sic] had already made his decision. Kushner felt that an enormous education and information gap existed when women, including the First Lady, were faced with breast cancer treatment decisions and in her extensive efforts to bridge the gap became the first nationally known breast cancer advocate (Kushner, 1984; Leopold, 1999; Lerner, 2001; Olson, 2002).

In 1975, Kushner published, *Breast Cancer: A Personal History and Investigative Report*. According to Leopold:

Kushner’s book was really the first attempt to use a personal narrative of breast cancer as a springboard to a much broader discussion. A memoir, a comprehensive handbook, and a manifesto all rolled into one, it opened up an extraordinarily rich debate. (1999, p. 234)

By familiarizing herself with medical literature on the topic, Kushner presented an articulate and informed argument for a “two-step” procedure separating biopsy from mastectomy, thereby giving women a voice in controlling their own destinies. She also criticized the medical establishment for being overeager to operate and driven by economic incentives rather than patient needs. Her book was met with considerable controversy but nonetheless established the groundwork on which today’s breast cancer activism is built. As Lerner explains:
What most set Kushner apart from other critics of physicians was her inclination and ability to debate actual medical topics….she learned the literature and then aggressively challenged the knowledge of medical professionals….by the late 1970s Kushner was on the payroll of the National Cancer Institute, reviewing grant applications and revising literature written by cancer specialists. (2001, p. 180)

Kushner’s work and her premature death from breast cancer in 1990 at age 60 served as the inspiration for like-minded activists to establish the National Breast Cancer Coalition in 1991.

Shirley Temple Black, Betty Ford, and Rose Kushner are just three of the many women who shared their stories during 1974 and made a powerful contribution to breast cancer awareness. Among them were also Betty Rollin, a news correspondent for NBC, whose book, *First, You Cry*, provided the first discussion that acknowledged issues of appearance as being important to the recovery and healing process (Lerner, 2001). Audre Lorde’s, *The Cancer Journals*, was also published in 1974, giving much needed voice to African American women, and to lesbian women (Leopold, 1999; Lorde, 1980).

By the end of the 1970s, the ACS, NIH, and the *New England Journal of Medicine* had all backed research citing the Halsted radical mastectomy as unnecessarily aggressive, scientifically unfounded, and outdated. The “two-step” procedure separating biopsy and subsequent surgery also gained support from the medical community, as did reconstructive surgery and breast implants.
These roots of breast cancer advocacy reveal how formative early efforts shaped breast cancer awareness and paved the way for the advocacy organizations of today, especially the Komen Foundation and the NBCC – organizations that both owe their existence to early activists, but who also are significant voices in continuing the dialogue on breast cancer.

The Arrival of The Komen Foundation and the NBCC

Following the success of the breast cancer activists of the 1970s, there was still no organization in existence that focused exclusively on breast cancer. This would change, however when in 1982, Nancy Brinker established the Susan G. Komen Breast Cancer Foundation and forever changed the landscape of breast cancer awareness in the United States.

The story of the Komen Foundation is told by Brinker in her book, *Winning the Race: Taking Charge of Breast Cancer* (Brinker & Winston, 2001). Brinker explains that she was an assistant couture buyer at Neiman-Marcus in Dallas, Texas when her sister, Susan Komen was diagnosed with breast cancer in 1977. Komen’s treatment was reflective of the current debates within the medical community and the treatment of breast cancer: she was diagnosed and treated by a family physician and her surgery, a subcutaneous mastectomy which leaves the skin in tact but removes all underlying breast tissue, was performed by a general surgeon. An oncologist was never consulted.

When Komen found a second lump in her breast five months after her mastectomy, the sisters went to the Mayo clinic where they were told that the cancer had metastasized and she was unsuccessfully treated with radiation. Komen then consulted
the M. D. Anderson Cancer Center in Houston, Texas where she could be closer to
Brinker during treatment. At M. D. Anderson, she was identified as a Stage 4 cancer
patient and given an aggressive treatment plan of chemotherapy and radiation. She was
also given a 25 percent chance of survival.

During this time, Brinker had also found breast lumps and was worried about her
own health as well as her sisters. All three of the tumors she found were benign, but
Brinker had experienced enough through both her sister’s struggle and her own to fuel a
desire to try and change the state of breast cancer treatment. As she explains, her sister
had grown frustrated by long delays in uncomfortable waiting rooms:

She was more concerned with the treatment of the patients; but my concern was
the treatment of the disease. I was outraged that more hadn’t been learned to help
my sister. “Nan,” she said, ‘as soon as I get better, let’s do something about this.
You can find a way to speed up the research. I know you can. And I want to fix
up this waiting room and make it pretty for the women who have to be here. This
isn’t right.” (Brinker & Winston, 2001, p. 33)

In 1980, after fighting breast cancer for three years, Susan Komen died.

Following her sister’s death, Brinker describes herself as haunted by the need to
fulfill her promise to her sister. Uncertain of how to begin, she took the advice of her
husband and capitalized on her Nieman-Marcus marketing experience and fund-raising
experience from various charities and founded her own charity for breast cancer research.
Brinker proceeded to research breast cancer, call upon her personal network for support
and formed the Susan G. Komen Breast Cancer Foundation in 1982 with the mission “to
eradicate breast cancer as a life-threatening disease by advancing research, education, screening and treatment” (p. 78).

Through the 1980s, smaller breast cancer support and fund-raising groups would form, but none grew to be as well known or as successful as the Komen Foundation. Komen, with its popular Race for the Cure events was making significant financial contributions to breast cancer research, but made no efforts towards changing public policy. Breast cancer activism was still largely the domain of Rose Kushner and other politically minded women. When Kushner died in 1990, her legacy inspired activists representing a variety of separate breast cancer organizations to work together in forming the National Breast Cancer Coalition, officially established in 1991. The initial founders included: Dr. Susan Love, an author, teacher, surgeon, and well respected breast cancer authority, and Susan Hester, director of the Mary-Helen Mautner Project for Lesbians with Cancer, a volunteer organization dedicated to helping lesbians with cancer, as well as their partners, and caregivers. Love and Hester were soon joined by Sharon Green of Y-Me, a toll-free national hotline of peer counselors, Ann McGuire of the Women’s Community Cancer Project, a network of cancer survivors who provide support and community resources, and Pam Onder of the Greater Washington Coalition for Cancer Survivorship, a peer support organization. Together, these women formed the NBCC as an umbrella organization representing the interests of more than 180 breast cancer advocacy groups in the United States (Lerner, 2001; Love, 2000; Olson, 2002). By some accounts, Nancy Brinker was also included in the initial discussions that led to the
formation of the NBCC, but bowed out prior to establishing an affiliation (Klawiter, 1999). Currently, these organizations have no common affiliation.

The three goals that guided the formation of the NBCC were: “(1) increasing research funding, (2) increasing access to screening and treatment for all women, and (3) increasing the role of women in health policy decisions” (Olson, p. 259). The NBCC continues to work toward these goals as a successful and well-respected breast cancer lobbyist and activist organization.

Chapter Summary

This chapter introduces my research project and situates it within the scientific and historical context of breast cancer awareness in the US. An overview of the biology and physiology of the female breast and breast cancer, the history of breast cancer campaigns, and an introduction to the Komen Foundation and the NBCC provide the rationale for three research questions:

Q1: How do the Susan G. Komen Breast Cancer Foundation and the National Breast Cancer Coalition perform a narrative of breast cancer at their respective events?

Q2: How are these performed narratives shaped by the cultural and historical context of breast cancer awareness in the United States?

Q3: How do these performed narratives shape current breast cancer awareness in the United States?

Succeeding chapters explore these questions in further detail to broaden our understanding of how we communicate about breast cancer in and through the narratives performed by Komen and the NBCC.
Chapter Two is a review of literature on narratives of health communication. This chapter focuses on the work of Erving Goffman in establishing a framework through which narrative may be interpreted as a performance. Three contexts of narrative performance are discussed: individual, medical, and societal. While the societal context will be the main focus of this investigation, other contexts are discussed as they present an undeniable influence on the social context, and may emerge in the ethnographic narrative and final analysis. Chapter Three is a review of the ethnography as a method of inquiry and of the narrative analysis procedure. The ethnographic data will be presented in Chapter Four. This chapter will include thick descriptions of both the Susan G. Komen Foundation’s Race for the Cure and the National Breast Cancer Coalition’s Annual Advocacy Training Conference. Finally, Chapter Five will present the results and conclusions. This chapter will include a systematic analysis of the performance framework established in Chapters Two and Three and offer a comparison of the resulting picture of breast cancer that is performed by these two organizations.
CHAPTER TWO
PERFORMANCES AND CONTEXTS OF NARRATIVE INQUIRY

The Power of Stories

A year-long series of articles published in 1999 in *SELF*, a women’s health and fitness magazine, sparked my interest in studying breast cancer. The series, entitled “Diane’s Diary,” appeared as one to two page excerpts from model Diane Erickson’s diary as she battled breast cancer. Erickson had been *SELF* magazine’s first cover model and when she returned to *SELF* in 1999 it was to share her breast cancer experience – from diagnosis to treatment – with *SELF* readers. Her unfolding story captivated me and each month I turned to her article first to read about her progress. Through her candid diary entries, readers learned about Erickson’s hopes and fears, her decisions, her family, her strategies for coping, and how breast cancer forever altered her life.

As December approached, I wondered if the year-long series would be extended so that readers could continue following Erickson’s story. Shockingly, with no warning that her prognosis was dire, the December issue announced Erickson’s death with a tribute in place of her diary, she had died several months earlier. I had no idea until that final article of just how emotionally invested I had been in Diane Erickson’s story. I was deeply saddened by her death and troubled by the questions left unanswered by her diary. Through her story, I found a connection to breast cancer that compels me to continue seeking out breast health information and resources and to conduct research and participate in advocacy efforts for the eradication of this disease.

In the midst of those advocacy efforts in the spring of 2003, I discovered a more personal connection to breast cancer. I learned through my mother’s cousin that my great
aunt is a breast cancer survivor – a family history I hadn’t heard about before. Perhaps relatives assumed I already knew – after all, I was familiar with some of her story including a chemotherapy mishap that left her deaf and an eventual marriage to her doctor. From my perspective, her story is not a breast cancer story. Rather, it as a story of extraordinary circumstances and their consequences and outcomes, not a story of initial causes. Discovering a family history of breast cancer confused me. How do I reconcile a research agenda inspired by the narrative of a stranger with my newfound family connection? Should I continue to explain my study of breast cancer as a response to the experiences of others, participation in a Race for the Cure, and a fascination with the popular media’s obsession with this disease? Or is my research now in honor of my family and great aunt?

As I struggle to position myself within my own narrative of breast cancer awareness and scholarship, I am reminded of Mead, who wrote, “All selves are constituted by or in terms of the social process, and are individual reflections of it” (1934, p. 201). The narrative of breast cancer that guides my understanding of this disease is indeed a reflection. The social influences that have helped author it include the stories of women like Diane Erickson and my great aunt and the collective stories of organizations like the Komen Foundation and the NBCC and my participation in their fundraising and advocacy efforts. The academic influences that have helped me comprehend this narrative construction are equally reflective and compelling: communication scholars have had a great deal to say about narrative ways of understanding health and illness: who authors these stories, what they mean, and what we can learn from them. This
chapter serves to both position my work within this larger academic landscape of narrative communication scholarship, and to identify the niche where my research can make a unique contribution to the field. Toward this end, this review of literature will begin with an overview of health narratives in context, beginning with the individual, then the medical community, and finally ending with the social community where organizations like Komen and the NBCC fit. Organized contextually, it is possible to trace not only the progression of the field, but also the progression of narrative construction. While this specific project is most concerned with the context of community, there is considerable influence from the other contexts that must be acknowledged as vital components of the narrative process. Without the individual voices of their members, and the continued efforts of the medical community, Komen, the NBCC and their respective stories would not exist.

The second part of this chapter will focus on the work of Erving Goffman as a tool for analyzing these narratives as they are performed within the social community. Goffman’s emphasis on a theatrical metaphor suits this project well as the stories told by these organizations are often staged for public viewing and involve a great cast of characters to be told. Goffman’s simple, yet elegant, system for classifying the structures present in these narratives makes for an ideal tool for comparison and analysis.

Finally, this chapter will re-connect with the historical conversation in chapter one to introduce the origins of Komen and the NBCC. This introduction will set the stage, if you will, for the following thick descriptions of each organization’s key event and the narrative analysis to follow.
Narratives of Health and Illness

Even when caused by a toxin, by a microbe, or by the dysfunction of an organ, illness is a fluid process that changes as we change, enigmatic, insubordinate, subjective. It captures bodies, minds, and emotions, remains at its deepest level inaccessible to language, and alters under the influence of non-medical events from divorce to climate change. What biomedicine finds hard to recognize or to accept is that different observers – patient, spouse, doctor, pastor, insurance provider, hospital administrator, epidemiologist, to name a few – examining the same illness from their separate perspectives will observe different aspects of its truth. (Morris, 1998, p. 5)

Illness can be an all-consuming, all-changing presence in our lives. Narrative scholar Arthur Frank (1995; 2000) argues that one reason we have such a difficult time coping with illness is that it disrupts the routine of our lives. Becoming what he calls a “wounded storyteller” is a painful process – and typically not a process in which one has volunteered to engage. To Goffman, the presence of illness might represent a new frame of reference that overshadows all others, forcing an actor to re-evaluate his or her role in all other performances. For example, women facing breast cancer may experience role uncertainty when faced with the array of options for understanding her illness that are offered by the medical community, family and friends, support organizations like Reach to Recovery, and media portrayals. This plurality of comprehension has been described as postmodern illness.
Postmodern illness, as described by Morris, is “situated at the crossroads of biology and culture” and encompasses the experience of the patient (p. 71). It is illness inscribed with multiple voices and, depending on the voice narrating, inscribed with very different perspectives as well. This conception of postmodern illness serves as a basis for describing three contexts in which illness is performed: the individual self, the voice of medicine, and the social community. These contexts reflect the three natural divisions that I found to emerge from my review of narrative health communication literature. The next sections will further elaborate on the contexts of performance by focusing on each of the three categories starting with the individual self, followed by the voice of medicine and social community respectively.

Narrative and the Individual Self

Charles Taylor has argued “that we cannot but strive to give our lives meaning or substance, and that this means that we understand ourselves inescapably in narrative” (1989, p. 51). As we author our lives, we are influenced by our surroundings – friends, family, media, authority figures, and especially other stories. Yet as much as we look outside ourselves for solace and advice, and occasionally co-authorship, ultimately we must turn inside to seek the meaning and substance that will help each of us to perform a self that is consistent with our own self concept and which will allow us to keep progressing through the larger story of our lives.

Illness is an intensely personal element of human existence that regardless of its specifics often debilitates an individual both psychologically and physically. Because our sense of self is in many ways a reflection of this Cartesian mind-body dualism, illness can
cause a great disruption by challenging existing perceptions of selfhood. Many scholars (Frank, 1995; Hunter, 1991; Hydén, 1997; Polkinghorne, 1988; Smith, 1993; Sontag, 1977) have echoed this concern, arguing that illness often forces an individual to rearticulate a narrative of self in order to include the new reality of illness. Making sense of illness in one’s life is certainly not an easy task. Narrative scholar, Arthur Frank (1995; p. 57) has written considerably on this subject and has devised a well-respected taxonomy of narrative types that characterize the ways in which individuals incorporate illness into their lives with three narrative types - restitution, chaos, and quest.

Restitution narratives. The restitution narrative, according to Frank, “has the basic storyline: ‘Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again’” (p. 77). In this type of narrative, the self remains intact as it existed prior to illness. Illness does not become the new reality for this storyteller, it is a digression from it, but life will return to normal at some point. Certainly for many of the more typical physical discomforts – colds, sprains, headaches, bruises, and the like - this is a very appropriate choice as the self likely will not be largely affected by these temporary interruptions. Even for more chronic ailments, narrating an unaltered self has value: the restitution narrative provides an individual with future goals and makes it possible to believe in the effectiveness of health care. This is a narrative of hope.

The restitution narrative can also be one of denial, which by contemporary American standards (and the standards of contemporary American armchair psychologists) is considered to be problematic. Refusal to alter one’s self image to account for illness may be the result of denying the illness. In this sense, the restitution
narrative reflects the staunch individuality that is often typical of American and other Western cultures: “Our unfortunate belief in the strength of the individual self, rather than a more communitarian model of interaction, depicts disease as an individual rather than social phenomenon” (Fitts, 1999, p. 14). Occasionally famous athletes who have overcome disease are depicted in this light. This is certainly the case for cyclist, Lance Armstrong whose battle with prostrate cancer is typically portrayed as man alone against disease. The community of doctors, teammates, and family that surrounded him during his cancer treatment has disappeared and instead his recovery is attributed to his strength of character and strength of person alone (Armstrong & Jenkins, 2000).

In another sense, the restitution may reflect a more spiritual rather than physical change of self. An individual may decide that regardless of the circumstances of illness, he or she can still choose how to live life. In the case of my great aunt who lost her hearing during chemotherapy, this change in her health may be an unexpected physical hindrance, but her spirit remains as strong and joyful as ever.

The realities of recovery are complicated, which makes this narrative type a very complex one. Frank notes that this narrative is the preference of American culture. It is unsurprising that a culture of consumerism perpetuates an optimistic narrative that believes in the power of medicine, science, money and perseverance to cure all. These cultural values explain why Frank’s second narrative type is so very frustrating for an ill person and his or her audience.
**Chaos narratives.** Chaos narratives, as Frank describes them are in many ways anti-narrative:

Chaos is the opposite of restitution: its plot imagines life never getting better. Stories are chaotic in their absence of narrative order. Events are told as the storyteller experiences life: without sequence or discernable causality. The lack of any coherent sequence is an initial reason why chaos stories are hard to hear; the teller is not understood as telling a “proper” story. But more significantly, the teller of the chaos story is not heard to be living a “proper” life, since in life as in story, one event is expected to lead to another. Chaos negates that expectation. (p. 97)

As an emergent narrative, Frank reminds us that one of the worst things we can do to a storyteller is deny him or her chaos either by not listening or by imposing structure to what we hear and rushing a person through a very necessary process. There are times our lives do not make linear sense and as an ill person struggles to maintain a sense of self amid the chaos and confusion, the difficult job of the listener is merely to honor the experience rather than step in as a co-author.

Echoing Frank’s description, Boje (2001) has also described a chaotic state that he terms antenarrative. Boje argues that narrative is a necessarily retrospective retelling of events in which we reflect back to see or assign order and structure that allows for a narrative to be told. Prior to this time though, we are engaged in the “flow of lived experience” (p. 3). Frank and Boje believe that chaos or the antenarrative is a postmodern condition in which the self is in many ways lost in the confusion. As Boje explains:
The postmodern condition of fragmentation and simulation makes coherence problematic. There is no whole story to tell, only fragments, which even with retrospective sensemaking cannot find a plot that will make the fragments cohere. Instead a wandering audience chases storylines on multiple and simultaneous stages. (p. 5)

For individuals experiencing chaos, this antenarrative condition is not of their choosing, nor is it desirable. The chaos of illness does not prevent a person from trying to find a narrative that fits. According to Goffman, we will still work to try and assign a meaningful frame of reference until we find one that fits. Chaos, however, prevents an individual from being able to find any narrative. Without narrative structure, it is impossible to take advantage of the predictive elements that we gain through narrative comparison. Without any idea of what the future will hold, it is hard to know what sort of support to request, or as a caregiver, to provide. For family and friends, caring for someone experiencing chaos requires exceptional patience as everyone is asked to withhold authorship in exchange for uncertainty.

*Quest narrative.* According to Frank, the quest narrative is different from the other two types in one way – it is the only narrative performance in which the individual facing illness claims the experience as uniquely his or her own. Whereas the restitution narrative is performed for us by the medical establishment, placing science as the main hero and the narrator as subordinate, and chaos absorbs the narrator too completely to allow for a coherent story to emerge, the narrator of a quest narrative is the central focus.
Quest stories meet suffering head on; they accept illness and seek to *use* it. Illness is the occasion of a journey that becomes a quest. What is quested for may never be fully clear, but the quest is defined by the ill person’s belief that something is to be gained through the experience. (p. 115)

Through the journey of illness the self is rearticulated, emerging stronger as a result. Authoring illness as a quest demonstrates a great deal of security in one’s sense of self and a unique faith in life’s lessons. For caregivers, it may be difficult to understand the faith that an ill person might inscribe into a quest narrative, but it also relieves them of the ambiguity that often accompanies illness. Friends and family can incorporate the quest into their story of illness as well, so that everyone involved might learn and grow. Regardless of recovery, the quest narrative returns purpose to the self during times of ill health. Recovered alcoholics, for example, often use their experiences to become motivational speakers. By demonstrating the lessons learned as a result of their drug use, they hope to help others avoid making the same mistakes. The value of the quest is finding peace in the fact that you cannot change your past, but you can change your future.

Quest narratives are by their very nature compelling, which is why Frank argues that these are the stories of illness that are most often published as memoirs, manifestos and automythologies. Because these authors view their experience as having a greater purpose, they seek to share them. Role modeling may be one goal for these authors, but many also seek to invoke change. This is especially true in the case of breast cancer. As Sharf explains:
Personal stories of breast cancer have raised social awareness, destigmatized the disease, and been key in creating significant changes in health policies. Legislative allocations, medical standards of care, and scientific research priorities have all been altered by women’s storytelling about breast cancer. Shifts in policy influenced by powerful illness narratives have been mainly positive, but sometimes compelling stories can lead to undesirable outcomes as well. (2001, p. 213)

According to Sharf, the powerful pathos of the quest narrative has accomplished a great deal of good in terms of breast cancer awareness. She warns, however, “individual stories should not be taken as scientific proof” (p. 217). Since not everyone is able to perform their illness as a quest narrative, the concern is that only the most charismatic and engaging stories are heard. Perhaps it is the stories that aren’t heard are the ones that require the most attention in terms of legislative action and health policy.

*Performing the narrative of the individuals self*. As a context of performance, the individual self contributes a valuable perspective on health and illness. Through Frank’s restitution, chaos, and quest narrative types, it is clear that every single experience of illness is personal and unique.

Health communication scholars have widely studied individual narratives of health and illness and there is certainly merit to this sort of research. Critics of this work however, echo some of the concerns raised by Sharf. As Frank’s most vocal critic, Paul Atkinson (1997) agrees that the narrative voice is privileged with an authenticity greater than other authorities. This valorization breeds skepticism and disempowers the medical
community’s voice as it pits readers against medical practitioners. This leads to his second concern that personal narratives are told without regard for context and are celebrated rather than analyzed. In keeping with Sharf’s concerns, narratives void of context should not be celebrated as representative. Atkinson warns, “what we cannot afford to do is to be seduced by the cultural conventions we seek to study” (p. 341). While as communication scholars, we should indeed study the ways individuals make sense of their illness experiences, we should not do so at the expense of thoughtful analyses.

*Narrative and the Voice of Medicine*

As a site of narrative performance, the voice of medicine is fraught with paradox. Medicine is required to name, define, identify and describe the conditions that ail us, while being warned to not assume authorship over a patient’s story. Even though the voice of medicine is constructed by a community of researchers, HMOs, and a regulatory agencies, it is most often attributed to medical practitioners, specifically doctors. Far from being unusual, doctors represent their field of knowledge in much the same way other professionals do. They have specialized knowledge we rely on and serve as a medium between our needs and the technical information required to fulfill them. Just as we would turn to mechanics, attorneys, and librarians when we need help with cars, law, and gathering information, we turn to doctors for help with the human body. While we expect expertise from any of these professionals, we expect more from doctors – we expect guarantees. Lupton (1994) credits these expectations to a societal reverence given to doctors for their many years of training and dedication to the care of others. Doctors
are afforded with a legitimate position of power that makes it difficult to not allow them some sort of role in the narratives of our lives.

In response to this paradox, health communication and medical scholars who research doctors and narrative have focused much of their attention around two central questions: is there a place for narrative in medical practice, and whose performance is privileged in a medical encounter?

Finding a balance. The first question is a question of medical ethics. How should a doctor balance the subjective elements of a patient’s story and the subjective interpretation of that story with the objective principles of science? Or, “how…can we square the circle of upholding individual narrative in a world where valid and generalizable truths come from population derived evidence?” (Greenhalgh, 1999, p. 324).

The narrative based medicine series authored by Greenhalgh and other physicians (Elwyn & Gwyn, 1999; Greenhalgh & Hurwitz, 1999; Jones, 1999; Launer, 1999) provides a valuable perspective for understanding how the medical community has addressed narrative ways of knowing in doctor-patient interactions. The authors of this series argue that narrative and its subjectivity are essential to medical practice. When humanity is maintained, both doctors and patients benefit, one by listening and learning, the other by being heard. Greenhalgh and Hurwitz criticize practices that train doctors to de-value the act of listening:

At its most arid, modern medicine lacks a metric for existential qualities such as the inner hurt, despair, hope, grief, and moral pain that frequently accompany, and
often indeed constitute, the illnesses from which people suffer. The relentless substitution during the course of medical training of skills deemed “scientific” – those that are eminently measurable but unavoidably reductionist – for those that are fundamentally linguistic, empathic, and interpretative should be seen as anything but a successful feature of the modern curriculum. (p. 50).

The authors of this series argue that narrative is a lost art in the practice of medicine that should be re-introduced. Taking a medical history is already a narrative request. By examining how a story is told, diagnostic medicine can be a more interpretative process. Focusing on narrative allows for a blending of patient experience and objective medical knowledge to co-author a solution that satisfies both doctor and patient: a problem solving approach rather than a prescriptive one. Narrative based medicine is ethical, necessarily patient-focused requiring doctors to appreciate the patient as the author of his or her own illness experience.

*Whose narrative is it?* Much of the rationale for using narrative also addresses the question of authorship. Privileging patients’ stories is an ethical medical practice. In her writings on doctors’ stories, Hunter (1991) expresses a similar ethic in shifting authorship away from doctors and towards patients. She argues that doctors often have a mistaken sense of authorship through the medical interview and diagnosis. While co-authorship might be a useful way of conceiving the goals of the interview ultimately, “co-authorship accords the physician a much too central role in the life drama of the person who is ill. It is interpretative work that the physician is doing, not original composition” (p. 11).

Doctors can only understand illness indirectly – through the narrative of the patient who
lives the daily performance of it. Illness narratives therefore, educate the medical community.

Privileging the patient’s stories in doctor-patient interactions is unquestionably valuable, but the medical community must also tell stories of illness. Illnesses must be categorized, described, and defined so that diagnostic models can assess and treat patients. Doctors must assign a name to suffering and recommend a course of treatment and outcomes, and so they assume some authorship. While an experience of illness is absolutely individual, we need the medical community to help us author that experience. Susan Sontag (1977) and Deborah Lupton (1994; 1995) argue that the language and metaphor used to refer to diseases like AIDS and cancer “has a direct effect upon the way in which ill people deal with their condition and the ways in which others treat them” (Lupton, 1994, p. 57). The pervasiveness of the war metaphor, especially with respect to cancer as discussed in chapter one, positions the ill person as a soldier in a scripted battle. More parties than the medical community construct illness metaphors (certainly the media rarely passes on a sensational metaphor) and these metaphors do often shape our experiences. Our interest in privileging the narrative of the patient is a response to the insistence of an illness metaphor to force an illness experience into a predictable pattern, to the accessibility of health information, to the rise in alternative medicines, and to the plurality of frames presented by postmodern illness. Unfortunately, I fear this response might vilify and mute the voice of medicine entirely. Collaboration between a doctor and an ill person must occur, or I suspect we would find ourselves facing antenarrative states of chaos far more often.
**Narrative and the Social Community**

Communication scholars argue that community is essential for constructing and maintaining the self (Dewey, 1916; James, 1977; Mead, 1934; Rothenbuhler, 1998, 2001; Shepherd, 2001; Taylor, 1989). Through community – and most simply, communication – we come to know ourselves and to have purpose and place in the world. “Disease and injury creates a break between the individual and the community which compromises the individual’s status within the community as well as the integrity of the self as a ‘product’ of social interaction” (Hester, 1998, p. 371). Just as illness forces a re-articulation of the self, a break with one’s community also leads to a loss of self.

While community might be broadly characterized as the social network of people with whom an individual regularly communicates, my intention in identifying the social community as a narrative context is to highlight how social communities act as unique and powerful authorities.

*Community as author.* Communities organized around illness are unique by their very nature of having illness as their central focus. As explained by Cartwright (1998):

> In many areas of political organizing, alliances, however uneasy, have been forged across genders, classes, professions and cultures. What is new here is not what counts as community or coalition, but the fact that the crisis of illness, and not an aspect of shared identity in the conventional sense is the basis for alliance. (p. 120)

Illness communities take a variety of forms: support groups, awareness groups, lobbyist organizations, and fundraising organizations to name a few. True to Cartwright’s claim,
the membership of these communities is unique in that were it not for the crisis of illness, these communities would fail to form. Brought together at a time when individual identities are fragile and traditional communities cannot accommodate all the needs of a person experiencing illness, the illness communities collaborate the illness experience in order to author a common narrative for the community. For the members of that community, the goal in organizing might be to reclaim the illness experience, or “to rewrite the master narrative, to tell a different story” (Trethewey, 2001, p. 216). In this sense, an illness community can be a very positive and empowering community for its members.

While some illness communities engage in a private performance limited to its immediate membership, other communities share their narrative with the larger public. Often, the intentions justifying the creation of a public narrative are good ones: to raise awareness, to share community, to invite identification. Storytelling organizations, however, face a number of challenges to their identity as the membership struggles to tell their collected stories while at the same time managing the myriad new voices that reshape the narrative: “Stories in organization are self-deconstructing, flowing, emerging and networking, not at all static” (Boje, 2001, p. 1). As the stories change, so does the community: “the socially constructed organization appears objective and independent of its creators. Actors orient to organizations through their language use and treat them as objects with realities of their own” (Fairhurst & Putnam, 2004, p. 9). In this sense, the illness community becomes an entity capable of original authorship. Consider the story of the book, Our bodies ourselves for example. The original authors of the Boston Women’s
Health Book Collective (BWHBC) who collaborated in 1973 to write the very first edition had to accept that as the popularity of their project grew, new editions needed to include new authors and perspectives that differed from their original vision (Our bodies, ourselves for the new century: A book by and for women, 1998). As the membership grew, the BWHBC changed from a group of women telling the stories that each individual found important to an organization that currently acts as a unified original author with a common vision.

**Uncharted territory.** Within the communication literature, there has been growing interest in studying how illness narratives are constructed by organizations, which is largely uncharted territory in narrative health scholarship. Identifying narratives authored by organizations is far easier than plotting their construction. As Lupton (1994) explains, “theory in health communication is too often limited to individualistic models of knowledge and behavior, whereas the cultural (and less easily measurable) dimensions of health communication are frequently ignored” (p. 57). This is an opinion shared by Sharf and Vanderford (2003) as well as Van Maanen, Manning, & Miller (1988). Conducting this sort of research is more challenging, but well worth the effort: “By studying how illness is socially constructed, we examine how social forces shape our understanding of and actions toward health, illness, and healing” (Brown, 1995, p. 34). Further, “it is crucial to understand how values, beliefs, and norms associated with health, illness, and medicine are affected by interaction with mass-mediated messages” (Kline, 2003, p. 558). By valuing narrative context as much as narrative, we learn how each author is also a performer and an audience and how narrative frameworks shape one another.
Win some hearts and close other minds. One goal of this project is to examine the narrative construction of breast cancer as performed by the Susan G. Komen Breast Cancer Foundation and by the National Breast Cancer Coalition. While these organizations address the same illness, they enact very different, and very successful, narratives – in part due to their different audiences. As Charmaz explains (1999), “any story must fit the audience if it is to be heard. The same story told the same way may win some hearts and close other minds” (p. 375). Because each organization performs and maintains a very well-defined narrative of breast cancer, Komen and the NBCC have bifurcated the breast cancer community into loyal followers of the narrative of awareness and the narrative of advocacy. Further examination of these differences requires a vocabulary that will allow the various and unique dimensions of collective narratives such as these to be labeled and compared. Goffman’s theatrical metaphor of narrative performance provides such a vocabulary.

Narrative as Performance

Goffman’s approach to understanding and analyzing the social world begins with the individual examining his or her environment. Just as the field of health narrative scholarship has focused on contexts from one to many, so does Goffman. He begins with the assumption that in any given situation individuals face the question:

“What is it that’s going on here?” Whether asked explicitly, as in times of confusion and doubt, or tacitly, during occasions of usual certitude, the question is put and the answer to it is presumed by the way the individuals then proceed to get on with the affairs at hand. (1974, p. 8)
The question is answered by assigning a definition, or a frame to the situation at hand. Goffman explains that a frame is a principle of organization that governs events, much like a story or a narrative. Frames are composed of strips, or “any arbitrary slice or cut from the stream of ongoing activity” (1974, p. 10). For example, opening a can of cat food, transferring it into a small bowl, placing it on the floor and calling, “kitty, kitty, kitty” is a strip that would bring to mind the frame most of us know as feeding the cat.

**Frameworks**

Frame analysis is the examination of the organization of experience, and in many ways is the central element of Goffman’s metaphor. It is the process an individual engages in to make sense of, identify, and label the multitude of strips that are encountered in daily life. It is the way that we determine the plot line of the story that we are engaged in and understand how to act, or what might happen next. We use frameworks to make sense of both very simple and very complex life circumstances. We may assign the frame of feeding the cat without a second thought, whereas determining a frame to explain times of ill health may require a great deal of thought and time. Frame analysis is also a process that we use to compare frameworks or stories in order to understand the differences between strips that may look similar, such as jogging for recreation and running to escape danger or poisoning the body to harm versus poisoning the body to heal, as in the case of chemotherapy. Goffman addresses these differences in his discussion of primary and secondary frameworks.

**Primary Frameworks.** A primary framework is a meaningful rendering of a scene or strip. It allows the individual to identify, locate, perceive, predict, and label concrete
occurrences as defined by its terms. Goffman argues that primary perspectives are available to all members of a society and consequently affect the participants in the framework, but the bystanders and onlookers as well. He claims that ascribing a framework is such an ingrained reaction that a mere glance often affords an individual with a sense of prior happenings and a good idea as to what will happen next. These primary frameworks may be either natural or social.

“Natural frameworks identify occurrences seen as undirected, unoriented, unanimated, unguided, ‘purely physical’” (1974, p. 22). An individual cannot continuously guide the outcome of a natural framework. Like the state of the weather, the process of aging, or the length of a day, we can adapt and respond to these natural frameworks, but we are incapable of reversing or stopping them. Our health may be considered a natural framework in that we can certainly respond to and treat circumstances of injury and infection, but we cannot outright prevent these things from happening to us. Certainly throughout history, cancer has continued to be a disease we cannot fully control or cure and as much as we would like to believe differently, it remains in most ways to be a natural framework.

Social frameworks, on the other hand, provide background understanding for events that incorporate the will, aim, and controlling effort of an intelligence, a live agency, the chief one being the human being. (1974, p. 22)

A social framework is a guided doing in which motive and intent contribute to occurrences and outcomes. Exercising, watching a movie, or spending time with friends are all social frameworks. When it comes to illness, prevention and treatment methods
are essentially products of human motive and intent and are social frameworks we employ to maintain productive health.

In Goffman’s terms of primary frameworks then, the efforts of the Komen Foundation and the NBCC provide a bridge of explanation between natural and social events. At the most basic level, their depiction of breast cancer provides the public with possible frames to define an experience with this disease. Beyond defining, Goffman describes a variety of secondary frames that we might use to further describe or narrate life events:

Secondary Frameworks. Secondary frameworks are variations of primary frameworks. A secondary framework is activity patterned on one primary framework that is actually something quite else. A child’s scavenger hunt is a secondary framework derived from the primary framework of hunting and gathering food, for example. Komen’s Race for the Cure is a secondary framework that, among other things, masks the primary social framework of fundraising. Goffman labels this process of transcribing and transforming primary frames into secondary ones as keying and identifies five general categories of keys: make-believe, contests, ceremonials, technical redoings, and regroundings. Understanding and analyzing an event as it has been keyed tells us a great deal about the ways that we choose to organize our experiences.

The first key, make-believe is characterized as an imitation, or run-through of another original activity. The purpose of make-believe is simply the intrinsic satisfaction of the fantasy, daydream, or playfulness. Dramatic stagings are a sort of make-believe and Goffman notes that while make-believe frameworks often allow for a certain
acceptable voyeurism, as in the way a theater set often allows an audience to view a character’s private living space, social standards still determine frame limits in rendering certain activities inappropriate or too private for all audiences (p. 56). Illness is frequently keyed as make-believe in movies and television shows and when depicted carefully, this secondary frame can serve a very useful educational purpose in that we gain knowledge without having to literally experience the reality. As audience members though, we are not always aware of what is accurate and what is not, the entertainment business is, after all, just that and liberties may be taken to ensure entertainment value. I am reminded of just how much emotional damage a dramatized medical inaccuracy can cause when I think of a friend whose mother died of a rare and rarely treatable brain tumor. Not long after she died, a character on a popular medical drama was diagnosed with and miraculously cured of the very same brain tumor. My friend was angry and hurt that the characters on this television show were apparently an exception to the statistical and medical realities that his family had struggled with for so long. When reality is keyed as make-believe, there is always the risk of perpetuating a false reality. Having experience with a primary framework can make a secondary keying like this one quite painful, while for others with a less defined frame, it may appear quite hopeful: make-believe is not wrong, but it is fiction. We are usually willing to accept inaccuracies in the name of entertainment because we have other sources for gathering accurate information. Even so, we often blur the boundaries between our sources of fact and fiction and find we’re faced with conflicting frames and a need for a decision. Clearly, when it comes to frames that have great personal relevance, this has the potential to be very confusing.
A second type of keying is contests. Most sports fall into this keyed framework as they represent a controlled and modified display of aggression based on a more literal framework of fighting. This framework is intended to produce a winner(s) and loser(s) and contains clear and definite limits to denote appropriate behavior. Our U.S. Government’s historically recurring “war on cancer” comes to mind as a contest keyed on the primary elements of suffering citizens, medical research, and accessibility to health care. Certainly, the Komen Foundation’s Race for the Cure is another obvious contest in which we declare anyone who has made a donation and runs or walks the 5K as a “winner” in the “fight” against breast cancer, and for that morning at least, this disease is the loser. Victory is sweet and we very often key times of ill health as contests. Whether it takes the public form of money for research, or the personal form in which perseverance, white blood cells, and a good attitude go to battle against infection, we like to cheer on a winner. We also like to have an explanation when things don’t go as planned: cures aren’t found, a friend continues to suffer, or somebody special dies. When illness is keyed as a contest, we can quickly make sense of these events by explaining them as a good fight against a stronger enemy and even though our anticipated winner has lost, we maintain the labels of good and bad, right and wrong. With this, we can begin to see how secondary frameworks may overlap to collaboratively key a primary framework like health or illness: contests can contain elements of make-believe to help us make sense of the fight and understand the competing elements. Think of how many times you’ve seen the process of reproduction animated to depict sperm cells as trash-talking sprinters on their way to woo the oh-so-sexy but sassy egg cell (or maybe I’ve just
seen Disney’s version one too many times). Make-believe can also prime us with
depictions of illness that will help prepare us for the contest and the events that could
unfold – positive or negative, recovery or not. These first two secondary frameworks are
similar in that they help us to make sense of the events in our lives: they present options
for understanding and variation on literal experience. This is not to say that they are
entirely optional or obvious, but we understand them as secondary because they are about
life unlike the frames to follow which are secondary because of their placement in the
context of life.

Ceremonials are secondary frameworks based on rituals. “Social rituals such as
marriage ceremonies, funerals, and investitures are examples. Something unlike ordinary
activity goes on in them, but what goes on in them is difficult to be sure of” (p. 58). Like
a make-believe frame, there may be elements of a ceremony that are scripted, but
important differences distinguish between the two: Only certain individuals have scripted
roles as a ceremony is not a simulation of actual life, it is instead intentionally
consequential and revolves around a specific deed or doing. As Goffman explains, “a
play keys life, a ceremony keys an event” (p. 58). We often use ceremonials to mark
important life events. Those who have faced a major illness often recognize an
anniversary and commemorate the date that marks the defeat of an ailment. In much the
same way, the Komen Foundation includes a survivor’s ceremony following each Race
for the Cure that honors women who have survived breast cancer. Events like this are
highly scripted and quite rich with symbolism. Komen’s ceremony, for instance, releases
white doves to recognize women who did not survive breast cancer. These social rituals
serve to mark passages of time and turning points at which something significantly life altering takes place.

The fourth key, a technical redoing, occurs when an actual strip of activity is performed out of context. Included in this framework would be practice sessions, dry-runs, rehearsals, and training. For example, in order to get a driver’s license, an individual must key actual driving situations as technical redoings. Parallel parking must be rehearsed in parking lots with big orange cones before a new driver will face the situation on a street with other cars and drivers. Goffman explains that technical redoings are bound by certain unavoidable framing limits: the keyed scenario will likely account for far more challenges than an individual will encounter in the real environment and will never be able to reproduce the actual conditions of performance. Nonetheless technical redoings are a critically important framework in terms of learning and experimenting. Diane Erickson, whose story was discussed at the beginning of this chapter, engaged in technical redoings when she was preparing for chemotherapy: she visited a professional stylist to be fitted for a wig before she lost her hair so that she could learn how to put it on, care for it, and see how it would feel. She even brought her young daughter along to try on wigs with her which demonstrates nicely how one event can be framed differently by two people – a technical redoing for the mother is framed as make-believe for the daughter, but helps both cope with the pending reality of cancer treatment side effects.

The final key is regrounding which is unique compared to the rest of the keys in that it is primarily actor-focused rather than context-focused. “What is involved is the performance of an activity more or less openly for reasons or motives felt to be radically
different from those that govern ordinary actors” (p. 74). For instance, a restaurant reviewer would rekey the frame of dining out to accommodate his or her responsibilities to evaluate and report on the food, service, and atmosphere at a restaurant. Ordinary diners may make similar observations, but likely will not be publishing their opinions in a magazine or newspaper for example. As an ethnographer, my attendance at the Race for the Cure events and the NBCC Advocacy Conference would be considered a regrounding as I was performing the dual role of researcher and participant whereas most everyone else was likely there to solely participate.

Performances

Frameworks are valuable in that they provide an individual with a sense of context and a reference for a situation. In other words, the framework tells the story that the actors are engaged in. After identifying a frame, be it primary or secondary, the next challenge becomes presenting oneself appropriately within the narrative, or joining the scene. Goffman extends his metaphor to account for individual behavior and the performance of daily life.

Personal Fronts. For the individual, Goffman explains, all of life is a performance in which you play yourself. He argues that we develop individual conceptions of who we should be and strive to live up to those roles until they become second nature. This process of “finding yourself” is essential for finding a place in society and relating to others: “We come into the world as individuals, achieve character, and become persons” (1959, p. 20).
The role that we present publicly is referred to as a front. It includes gender, age, appearance, speech patterns, gestures, expressions, and health as discussed earlier. One’s personal front is also reflective of societal values and circumstances (p. 22). Goffman compares our personal front to an on-stage persona: we maintain a certain appearance, cue others by adopting varying manners of behavior, and act within a setting that supports our character. In order to balance out our public life, we also have a private life, backstage. Backstage is where we are allowed to shed our personal front and pause from our performance in order to relax (p. 113). Changing out of work clothes and into casual clothes after returning home, or backstage, might be a familiar example.

Frontstage and backstage behavior can be a careful negotiation when our health is concerned. It’s not unusual for an ill individual to keep quiet about an ailment in his or her frontstage, or public persona and maintain a certain normalcy in those relationships. Conversely, at home or backstage where one might typically relax the performance, he or she will instead put on a brave face for the sake of others and thus never get the break that the backstage is supposed to provide. In some ways then, the functions of the front and back stage may reverse themselves to account for an illness that is not of public knowledge, or an individual may seek a new backstage in the form of a support group where a group of peers can collectively let down their guard and honestly express themselves.

Performance Teams. Often, performances are more about the accomplishment of a task than about individual expression and consequently require a team of actors to work together. Goffman calls these performance teams and explains that they are often
characterized by the presence of a single director guiding the performance (p. 97). Additionally, “one over-all objective of any team is to sustain the definition of the situation that its performance offers,” explains Goffman (p. 141). In other words, teams define and perform frameworks. Both the NBCC and the Komen Foundation function as performance teams: a corporate office serves as a director to guide the goals and activities of the membership and that membership in turn wholeheartedly supports the overall cause.

Maintaining a definition requires a team to engage in information control with members of the audience, or non-team members. Goffman refers to any sort of information management as secrets and identifies five different types of secrets that teams employ to keep a frame functioning as intended: dark secrets, strategic secrets, inside secrets, entrusted secrets, and free secrets. Although the term “secret” implies a sort of divisive and underhanded strategy taking place, the term should be thought of as neutral and merely descriptive of an activity that could be positive or negative.

Dark secrets consist of “facts about a team which is knows and conceals and which are incompatible with the image of self that the team attempts to maintain before its audience” (p. 141). For example, an energy company that advertises pollution free power sources may conceal that it is partially owned by a large petroleum company whose products obviously pollute the environment. Or a family may conceal a member’s use of medicinal marijuana with the hope of avoiding legal trouble.

Strategic secrets are those that a team is aware of, but conceals to prevent premature audience adaptation. Computer companies, for instance, go to great lengths to
maintain the secrecy of new product development from their competitors. Strategic secrets differ from dark secrets in that dark secrets may be intended to stay secret forever. A strategic secret is intended to be revealed at a certain point, and early disclosure presents a disruption to the strategy, but not significant damage to reputation (p. 142). News of breakthroughs in medical research are often kept strategically secret until conclusive results are drawn. Premature disclosure can mislead the public and interrupt the research process, possibly causing irreparable damage.

Third are inside secrets. These may include dark or strategic secrets, but mostly consist of knowledge that makes one an insider. “Inside secrets give objective intellectual content to subjectively felt social distance” (p. 142). If you worked for a website, you would have access to the code and databases that make the site run. The details of this information are restricted to team members or employees only, but its existence is not a closely guarded secret. At the NBCC Advocacy Conference the lobbying objectives were considered insider information. Knowledge of our collective mission gave a sense of camaraderie to the group that helped bind us even closer.

In addition to secrets about our own teams, we occasionally have access to secrets about other teams. One such type of knowledge is entrusted secrets. “This is the kind which the possessor is obliged to keep because of his relation to the team to which the secret refers” (p. 143). For example, it’s not uncommon for spouses to discuss work issues when they are at home and backstage. The details of these conversations are usually understood to be confidential – their relationship to one another and consequently to the other’s respective professional team ensures a confidence when it comes to these
entrusted secrets. Certainly also, when teams collaborate there are shared secrets. The NBCC’s partnership with Avon, or Komen’s relationship with Ford Motor Company must lead to shared knowledge for both sides of the partnership as these are relationships built on trust and mutual benefit.

Should you come to know another team’s secret but lack any relationship to the team, this is a free secret. Disclosure of a free secret will do no harm to oneself or one’s relationships, but a team will often try to persuade the possessor that the knowledge is entrusted (p. 143). For instance, if you notice your neighbors setting up party supplies and realize that they are throwing a surprise party for an absent roommate, your neighbors might persuade you not to give away the surprise by inviting you to the party.

_Dramaturgical Analysis_

For the purposes of examining how breast cancer awareness is performed, Goffman’s theatrical metaphor provides a tool for labeling and then comparing the various aspects of performance. Furthermore, as Goffman explains:

> The dramaturgical perspective…can be employed as the end-point of analysis, as a final way of ordering facts. This would lead us to describe the techniques of impression management employed in a given establishment, the principal problems of impression management in the establishment, and the identity and interrelationships of the several performance teams which operate in the establishment. (p. 240)

In the establishment of American breast cancer awareness there is certainly a great deal of impression management to explore in the narratives performed by the Komen
Foundation and the NBCC. These narratives are performed in the context of the social community but influenced by the performances of individuals and medicine. To further articulate how these organizations function as authors, at this point I will continue my description of Komen and the NBCC and the events through which they perform their narratives of breast cancer.

Contexts of Performance: Komen Foundation and the NBCC

_The Susan G. Komen Breast Cancer Foundation._

The Komen Foundation is best known for its Race for the Cure events. As Brinker explains:

To achieve our mission fully, we needed to raise the public’s awareness of breast cancer and the life-and-death issues that went with it. We weren’t creating another charity; we were creating a movement. That meant Komen needed a mechanism to carry its message to every town and city in America. We needed to recruit our own messengers of hope. That is how the Komen Race for the Cure was born.

When I came up with the idea of the Race, everybody – I mean everybody – thought I was crazy. Even my mother. Women wouldn’t go out on a Saturday morning to run in a sweaty race through town, they argued. But I was undeterred. (Brinker & Winston, 2001, p. 75)

Race for the Cure events follow a standard format regardless of location. Races are held early on a weekend morning on a 5-kilometer race-course that is certified by the USA Track and Field, the national governing body for running and walking events. Participants receive event t-shirts and race numbers – pink for breast cancer survivors and
white for all others. They are also encouraged to wear “In memory of” or “In celebration of” signs in order to dedicate their efforts to somebody who has faced breast cancer.

While the main event is the race, there are a significant number of post-race events that participants also engage in. Race winners are announced for varying age, gender, and survivorship categories and in a special ceremony in which white doves are released, women are recognized by years of post cancer survival through the National Breast Cancer Survivor Recognition Program. Race festivities continue throughout the morning as participants visit the sponsors area where companies including Yoplait, American Airlines, Ford Division, Johnson & Johnson, the Kellogg Company, New Balance Athletic Shoe, Quilted Northern Ultra, Silk Soymilk, RE/MAX, and Zeta Tau Alpha Fraternity set up information booths to hand out complimentary food, beverages, and promotional material (2004).

What started as a local event in Dallas, Texas with 800 participants in 1983, has grown to be the largest series of 5K runs and fitness walks in the world. In 2004 alone, 1.3 million participants are expected to cross finish lines in over 100 U.S. cities, raising over $87 million dollars (The Susan G. Komen Breast Cancer Foundation 2002-2003 Annual Report, 2004). The Foundation’s mission is “to eradicate breast cancer as a life-threatening disease by advancing research, education, screening, and treatment” (About Komen: Facts and Figures, 2002). Although the Komen Foundation sponsors a number of other fundraising activities (Sing for the Cure, Cook for the Cure, Clean for the Cure, Virtual Race for the Cure, Lee National Denim Day, and others), Komen is best known

A very specific story of breast cancer guides Komen and the message at Race for the Cure events. This is a story of faith in medicine, early detection and hope. It sings the praises of survivors and finds cause for celebration in their lives. While the Komen Foundation has been praised for its breast cancer education and positive message, it has also been criticized for being middle-class, white, and aligned with pharmaceutical companies like AstraZeneca, who originally declared October to be National Breast Cancer Awareness Month (NBCAM) in 1984 as a marketing campaign. Since then, NBCAM events have become a major focus for the Komen Foundation. Many see AstraZeneca’s promotion of breast health as deeply problematic because in addition to producing the best selling cancer drugs currently used to treat breast cancer, they also produce herbicides that are known to be carcinogenic (Klawiter, 1999; Pezzullo, 2003). It is argued that Komen’s affiliation condones the production of cancer and the current treatment options and ignores questions of causality and the effectiveness/appropriateness of current treatments (Ehrenreich, 2001). In light of the hugely successful marketing of breast cancer awareness via ad campaigns, pink ribbon related merchandise, and the Race for the Cure, Komen’s relationships to corporate sponsors goes largely unquestioned rendering it ever more important to study how breast cancer is narrated and performed by this organization.
The National Breast Cancer Coalition.

The NBCC is known largely for the coalition’s lobbying efforts and political credibility. In fact, in a recent study of the most influential groups in health policy, congressional staffers rated the NBCC to be one of the 25 most influential interest groups. The NBCC is the only group on the list both led by and composed of grassroots activists (Heaney, 2003). Since the coalition’s formation in 1991, the organization has remained true to its original goals:

To promote research into the cause of, optimal treatments and cure for breast cancer through increased funding, improved coordination and distribution of research funds and recruitment and training of scientists;
To improve access to high-quality breast cancer screening, diagnosis, treatment and care for all women, particularly the underserved and uninsured, through legislation and change in the regulation and delivery of breast health care;
To increase the involvement and influence of those living with breast cancer in the areas of legislation, regulatory processes and all aspects of clinical trial design, including access to clinical trials. (NBCC, 2004b)

In 1992, the NBCC held its first ever Advocacy Training Conference, an event that has become one of NBCC’s largest and most visible annual events. Currently, the NBCC has hosted 12 Annual Advocacy Training Conference and Lobby Day events in Washington D.C. At the most recent, 2003 conference, more than 600 attendees were present for the three days of training and research panels and the final day of lobbying on Capitol Hill (NBCC, 2004a). The efforts of these conferences have made significant
differences in health care policy relating to breast cancer. As a result of the first
conference, NBCC president, Fran Visco presented President Clinton with a petition
containing 2.6 million signatures to represent the 1.6 million women living with breast
cancer and the 1 million that would be diagnosed within the coming year. As a result of
this petition, Clinton committed to a National Action Plan on breast cancer that has aided
the increase in federal breast cancer research funding from just over $100 million to more
than $800 million (Stabiner, 1997).

The NBCC and its advocates were also a leading advocate for the passage of the
National Breast and Cervical Cancer Treatment Act in 2000. This law ensures that low-
income women have access to screening and treatment of breast and cervical cancer
through Medicaid funds and federal funding. NBCC advocates are credited with the rapid
statewide adoption of these funds and for gaining the participation of all 50 states by
2004.

The success of the NBCC is due in part to the annual Advocacy Training
Conferences. Though only attended by a fraction of the Coalition’s total membership, the
men and women who do attend are dedicated activists working hard for change.
Additionally, many attendees represent a larger constituency from their home state and
voice collective concerns in Washington D.C. In exchange, these representatives will
share conference information with their groups when they return home, thereby
supporting the network that makes the Coalition as strong as it is. In the 2003 Conference
program, Coalition president, Fran Visco provided this explanation of the event:
The National Breast Cancer Coalition Fund (NBCCF) convenes this Conference each year to bring together individuals who are new to the issue as well as old-timers who are well versed in strategies needed to achieve our goals. As you will see as you look through this program, workshops and plenary sessions focus on current, often controversial, burning issues affecting breast cancer. Also included are sessions designed to teach you what you need to know to become an effective advocate with members of the government, the research community and the media. (NBCC, 2003c)

Conferences follow a standard format from year to year: The conference is held each spring in Washington D.C. beginning over a weekend and ending on a Tuesday with scheduled Congressional visits. The days leading up to the Lobby Day are filled with a full schedule of plenary sessions, which are panels and speakers presented for the entire body of attendees; workshop sessions, which are small interactive sessions attendees can elect to attend throughout each day; and a variety of award luncheons and training sessions for the lobbying to follow.

Individuals at the conference attend either at their own expense, or with financial assistance from their local NBCC affiliate organization or NBCC directly by means of scholarships. The cost of attending the 2003 conference was $75 for conference registration plus travel, hotel, and food (NBCC, 2003c). The conference fee covers all materials necessary for the conference, transportation to and from Capitol Hill for lobbying, and the variety of refreshments and luncheons provided throughout the weekend. Because this event is held only once annually and requires an investment of
time and money, the individuals who elect to attend, do so with great purpose and conviction and take their role as a breast cancer activist very seriously. Perhaps because of this, pink ribbon related paraphernalia is generally avoided at the conference and occasionally scorned for being too commercial. Instead, these activists are concerned with learning as much as possible from the scientific experts, legislators, and researchers who present throughout the weekend and lobbying effectively both at the Lobby Day and afterwards with their home organizations.

Chapter Summary

This chapter first identified narrative as a site of performance by reviewing the theories of Erving Goffman and the framework for dramaturgical analysis that his work provides. Because the narratives performed by Komen and the NBCC are part of a larger context of health narratives, I reviewed current communication scholarship relating to narratives of health and illness performed by the self and the medical community in addition to the social community where these organizations are best situated. To bring the historical conversation that began in chapter one up to the current date, and to further identify the specific narrative contexts to be explored, this chapter ends with a description of the Komen Foundation’s Race for the Cure event and the NBCC’s Annual Advocacy Training Conference and Lobby Day. The next chapter outlines the ethnographic method of inquiry and the Goffman-based procedure for analysis.
CHAPTER THREE

METHOD OF INQUIRY

Simply put, “ethnography is a written representation of a culture” (Van Maanen, 1988, p. 1). It is a method and a perspective of research that privileges the lived experiences of others as sources of knowledge worthy of documentation, translation, and interpretation. In much the same way that Goffman, discussed in the prior chapter, encourages us to ask, “what’s going on here?” and interpret the frameworks and performances of daily life, the role of an ethnographer is also to discover what indeed is going on in a given context.

Goffman’s notion of frameworks is closely mirrored by noted ethnographer, Clifford Geertz’s (1973; 1979) discussion of cultural webs. Geertz explains that humans are suspended in webs of cultural significance that we, ourselves have had a hand in spinning. Thus, ethnography is an interpretive search for the meanings within the webs. It is a process of taking “experience-distant” bits of meaning that occur in a cultural context – the rituals, customs, and ideas, for example – and “sorting out the structures of signification” (1973, p. 9). This sorting out process creates an inscribed or written “thick description” in which the ethnographer works to make “experience-distant” cultural contexts, if not entirely “experience-near,” then at least accessible and understandable for an outside audience. Geertz emphasizes that as an interpretative tool, ethnography can’t provide all the answers to our questions: research, existential, or otherwise. Rather, the value of ethnographic study is “to make available to us the answers that others, guarding other sheep in other valleys, have given, and thus to include them in the consultable record of what [humanity] has said” (1973, p. 30). In terms of this research project, the
value of using ethnography to study Komen Foundation and NBCC events is in the resultant thick descriptions. By observing and recording the performances, i.e. the answers, that these organizations offer one historical and cultural landscape of breast cancer awareness in the United States, new depth is possible in terms of analysis and our comprehension of the communication that takes place.

The following sections of this chapter will address the method of ethnographic research, provide a detailed discussion of my process of fieldwork and artifact gathering, and finally outline the procedure used to analyze the data.

The Practice of Ethnography

Ethnography is an intensely personal method of research. Few other methods require such physical, emotional, contextual, social, and academic commitment. As such, there are a number of practical considerations that must be made, but first and foremost, philosophical considerations must be addressed. At some point, an ethnographer must enter the field and venture into the unknown alone. Goffman (1989) especially espouses the value of the lone ethnographer entirely immersed in the cultural experience. Without an advisor or mentor to turn to, it is critical for an ethnographer to possess a comfortable familiarity with a few select scholars in order to have a mental reference when questions arise. Two of the most influential scholars I took into the field with me were Dwight Conquergood and Erving Goffman.

The Role of the Researcher

Both Conquergood and Goffman recognize the physical nature of ethnography. As Conquergood explains, “ethnography is an embodied practice; it is an intensely
sensual way of knowing. The embodied researcher is the instrument” (1991, p. 180). He argues for an ethnographic practice that involves committed interaction, shared time together, and a level of participation that blurs the boundary between observer and observed. Other scholars have categorized this as the “complete participant” role and warn against a loss of objectivity (Lindlof, 1995). Conquergood maintains that this sort of radical empiricism is essential to ethnography and only by engaging so completely in the experience can we shift ethnographic writing from reports of information to discussions of actual communication.

Goffman (1989) echoes Conquergood’s call for embodiment and adds that,

By subjecting yourself, your own body and your own personality, and your own social situation, to the set of contingencies that play upon a set of individuals…you’re empathetic enough – because you’ve been taking the same crap they’ve been taking – to sense what it is that they’re responding to. To me, that’s the core of observation (p. 125).

Goffman does caution that this sort of participant-observation fieldwork requires a balance: It is important to make friends, but not be so friendly that you are unnatural. It’s equally important to be observant, but not so observant that you are unfriendly, and so forth. He says that the best sign of a good ethnographic experience occurs when you are able to forget about being a researcher and settle into the natural rhythms of the group – this is a sign that you have penetrated a group in the right way and are a part of the communication process.
In keeping with the ideas of embodied ethnography, I became a complete participant in the Race for the Cure events and the Advocacy Training Conference that I attended. For my first Race for the Cure, I ran weekly in preparation for running the five kilometers. I attended the Race as any other participant would – I paid the registration fee, wore the race t-shirt and number, laced up my running shoes and joined the crowd. The physical exertion, the emotional involvement, and even the bee sting I suffered at the end of the race allowed me to embody the role of participant and be a part of the race in a way that standing on the sidelines never would have allowed. Other than the volunteers at the medical tent, there’s little opportunity for substantial interaction at an event like this and I was able to maintain my anonymity as a researcher and blend in as any other participant might.

For my second Race for the Cure, I chose to walk with a pair of friends and experience the race from a slower perspective. Since many participants choose to walk with small groups of friends or family, my experience, aside from the academic banter that occurs when two communication scholars and a sociologist get together anywhere, was quite typical. As we wound through the streets of downtown Houston, hot, thirsty, and sweaty in our Race t-shirts, we blended in with everyone else and became a part of the event.

I used a similar strategy to embody the role of a participant at the NBCC Conference. I became an NBCC member, I applied for a scholarship, I drove alone from Ohio to Washington, DC, and I shared a hotel room with another conference attendee. At the conference, I was open about my research, but I also chose to identify myself as an
activist-academic – a term that I feel best explains my desire to conduct social activism through my capacity as a scholar. By labeling myself as an activist first and an academic second, I hoped to also convey my commitment to the purpose of the conference and not merely to a research agenda, as my efforts to learn and to lobby were, and continue to be, sincere and serious rather than merely a means to an end.

At the Conference, I spent much of my time with a group of women who were also from Ohio. I was welcomed to their group as a friend, but also as an ally – because I was the only representative from my Ohio congressional district, I was almost immediately asked to speak with certain legislators during the lobby day. By declaring myself an activist, making friends, and taking on the responsibility of lobbying, I experienced not only all of the events of the conference, I also experienced the physical fatigue of four full days of intense learning. I listened to the stories that my new friends told about their experiences with breast cancer and their reasons for attending the Conference and shared in their emotions. I felt anxious and nervous when I had to meet with legislators or their assistants and request their support for cancer conscious public policy. As an ethnographer, I allowed myself to embody the experience of the NBCC conference.

Fieldwork

The tradition of ethnographic fieldwork that guided my study grew out of the sociological fieldwork conducted by The Chicago School of Urban Ethnography in the 1930s. Van Maanen (1988) credits The Chicago School with shifting the focus of ethnography from the anthropological norm of studying remote and far-away places to a
more sociological practice of examining the city around you. This sort of “backyard” ethnography encouraged scholars to engage in direct participation with these cultures and to use ethnography to expose the subcultures that help shape our daily contexts. In this sense, it is more descriptive than explanatory and seeks to tell the “real story” and offer evidence for reform rather than provide a basis for comparison.

Sociological anthropology, in the tradition of the Chicago School, also informs the writings of Conquergood and Goffman. Conquergood (1991) argues that by studying remote cultures, ethnographers privilege their perspective from the periphery rather than the experience one might have from within a culture. He suggests that ethnographers recognize their role as a co-participant both influenced by and influencing the production of culture in the field. This perspective repositions the ethnographer in a way that allows for “a rethinking of identity and culture as constructed and relational, instead of ontologically given and essential” (p. 184). Further, he argues that, “borders bleed as much as they contain” (p. 184) and in order to capture the multiple influences that shape a specific culture, we have to look out as well as look in. According to Conquergood then, the process of defining the field of study must be one that includes more than the literal site at which observation occurs. Goffman (1989) echoes this, saying that deep familiarity grows out of extended affiliation in the field, not just time spent with the culture one is studying, but time spent becoming familiar as well. Goffman recommends ethnographers spend a year or more in the field.

Sources of data. Following these traditions, I choose to be broad when defining my field of study. My ethnographic field includes the Cleveland 2002 Race for the Cure
held in Cleveland, Ohio on September 28, 2002; the National Breast Cancer Coalition Fund Annual Advocacy Training Conference held in Washington D.C., May 3-6 2003; and the Houston 2004 Race for the Cure held in Houston, Texas on October 2, 2004.

During the two years that span these events, I also spent considerable time studying Komen’s website at www.komen.org and studying the NBCC’s website at www.stopbreastcancer.org, and frequently printed sections of interest to my study. In addition, I also studied the sites of other organizations like Y-ME National Breast Cancer Organization, National Association of Breast Cancer Organizations (NABCO), the American Cancer Society (ACS), Centers for Disease Control (CDC), and National Institute of Health (NIH) in order to verify and supplement information from Komen and the NBCC.

I collected and read pamphlets, literature, newsletters, and advertisements from both Komen and the NBCC. As a member of the NBCC, I received information on a regular basis regarding breast cancer related legislation, upcoming events, and opportunities to take action.

To familiarize myself with the greater context of breast cancer in the United States, and the position of Komen and the NBCC within this landscape, I read books, magazine and newspaper articles, and research articles regarding breast cancer information, history, and commentary. I read until I found I was no longer encountering any new information or arguments and then continued to read to check for accuracy and depth.
Although my field is defined expansively, the focus of my study remained all the while to be the specific events hosted by Komen and the NBCC. By thinking broadly and continuously studying the surrounding context of these events in a reflexive manner, my perspective more fully captured Conquergood’s call to see the blurred borders of culture and Goffman’s call for lengthy engagement.

**Field Notes.** Lindlof (1995) describes field notes as the evidential foundation linking field observations to the written ethnography. He describes notes taken in the field as being either scratch notes or head notes. Scratch notes are written accounts taken in the moment of the details of the event. Head notes are written accounts transcribed from memory immediately following time spent in the field. He notes that a combination of these two note-taking methods is ideal, as it allows for a greater depth and breadth of information available. Lindlof advises that field notes of all types should include as much detail as possible and should address a question that echoes Goffman, “what’s going on here?” By first establishing notes regarding the “who, what, when, and where” concerns, the answers as to “why” can then emerge.

Following Lindlof’s recommendations, my goal when taking field notes was to collect as much information as possible regarding the narrative performance of breast cancer at Komen and the NBCC’s events. Toward this end, I found that different variations on my method were appropriate for the varying contexts I was studying.

At the Race for the Cure events, I documented my experience with a digital camera and a minidisk recorder. The camera allowed me to capture scenery, participants, and significant presentations or displays throughout the event, and the minidisk allowed
me to capture my own voice and thoughts as well as any information presented over public address systems. Following the events, I also transcribed my head notes as typed up field notes.

At the NBCC Conference, I took copious scratch notes throughout the conference. Most of my notes correspond directly to the conference program in which all of the speakers, their credentials, and their topics of discussion at the conference were listed. I used the digital camera to take a few pictures, but the majority of my information was derived from scratch notes in the field, head notes transcribed immediately after leaving the field. I did not use the minidisk recorder at this event because all of the sessions were recorded and made available for sale at the conference – I purchased two recordings of sessions I attended so that I could review the information for later analysis.

Data Analysis

Geertz (1973) writes that, “analysis, then, is sorting out the structures of signification” (p. 9). Before an ethnographer can sort, the story of the culture under study must first be told. This process of sifting through, organizing, and finally telling the story of the data is what Geertz calls a thick description: it is at once rich and specific and represents an ethnographer’s best effort at providing an accurate picture of a culture. My thick descriptions of the Komen Race for the Cure and the NBCC Advocacy Conference will be presented in the following chapter. These thick descriptions will then be analyzed using Goffman’s narrative paradigm as outlined in chapter two. In my analysis, I will systematically identify the performance features of each organization and event as
outlined by Goffman, and then compare and contrast the resulting conclusions in a thorough discussion organized around each of the three research questions:

Q1: How do the Susan G. Komen Breast Cancer Foundation and the National Breast Cancer Coalition perform a narrative of breast cancer at their respective events?

Q2: How are these performed narratives shaped by the cultural and historical context of breast cancer awareness in the United States?

Q3: How do these performed narratives shape current breast cancer awareness in the United States?
CHAPTER FOUR
ETHNOGRAPHIC DATA
Thick Description of the Race for the Cure

On September 28, 2002, I ran in my first Race for the Cure in Cleveland, Ohio. At this time, I had started researching the Komen Foundations campaign success, but I had not witnessed a large-scale Race for the Cure event. I attended the race in Cleveland to run and to experience the Race for the Cure just as any other participant might. On October 2, 2004, I attended my most recent Race for the Cure event in Houston, Texas. This time, I walked as a researcher, well-versed in breast cancer politics and the criticisms directed at the Komen Foundation. As I walked, I was mindful of my role as an ethnographer and the need to check perceptions, make observations, and take field notes along the way. I was equally mindful of my role as a participant and as a caring human woman and found myself as in Cleveland, emotionally moved in powerful ways by the thousands women, men, and children who walked and ran for breast cancer that morning. This thick description of the Race for the Cure will be a blending of perceptions from both races, supplemented by news coverage, Komen web site data, and my own field notes and recordings.

The race day events that I witnessed in Cleveland and Houston, follow a schedule that is relatively consistent across Race for the Cure events. Participants arrive at the race site early on a Saturday morning. Hundreds of participants are standing and talking while waiting to start walking or running. Some people are still registering for the race and collecting their race t-shirt and number, but most participants have these already. The t-shirts come in two colors – white is the most commonly seen shirt, which is given to all
participants who are not breast cancer survivors. Survivors, as they are called at the race, receive pink shirts and this makes them very visible among the sea of white shirts. Some people have chosen to personalize their shirts with things like fringe, pink ribbons, pins, or fabric paint. Many people personalize their shirts at the race by adding “in memory of” signs, or “in celebration of” signs provided by Komen. The signs are printed on bright pink paper and have space to write in names. Participants pin the signs to the back of their t-shirts.

Amid all of the pre-race activity, there is an opening ceremony. In Houston, the ceremony began with a volunteer singing, “On a clear day (you can see forever)” – a song made popular by Barbara Streisand. One of the friends I was walking with thought it was strange to hear this song (or anything for that matter) before the national anthem.

The master of ceremonies for the event, Dana Tyson, a local morning radio show personality, then announced that area Girl Scouts were now on stage holding the American, Texas, Girl Scout, and breast cancer flags and the same volunteer sang the Star Spangled Banner. From where I stood, nobody could see or even locate a stage and we were so crowded together that heading off to locate one would have been futile. We could see the starting line for the race, and hear clearly thanks to many elevated speakers, but the crowd around us made it difficult to see much more than this.

As we listened to the National Anthem, conversation died down and most people tried to turn toward the area where we suspected the stage to be. Dana Tyson then continued the opening remarks:
Today we celebrate the survivors of breast cancer. We pray for them: the women and the men who are now fighting the fight. We thank the caregivers out there, the family members who offer so much love and support. We’re so thankful to live in this great country with tremendous medical facilities, and talented doctors, (and we spoke to quite a few on ‘Sunny’ this week), the researchers as well who are bringing us closer every day to finding a cure for breast cancer. Until we find that cure we will continue to fight the disease like we do, and as we mark fourteen years of this amazing event, we are honored this year to celebrate those who have fought and have won. This is truly a race to celebrate all of you survivors. And if you look around you and you see the light blue Komen t-shirts, those are our volunteers. It would not be possible, with the countless hours that these volunteers have put in, to make this race possible. Thirteen hundred volunteers we would like to thank. And leading them, is one very special individual, please allow me to introduce the 2004 Race for the Cure chair, Vickie Matthews-Clark.

At this point, there was general applause and Vickie Matthews-Clark took the microphone and continued the opening remarks:

Thank you Dana, very much. We know in January we [challenged] everyone to put on a party and we were afraid nobody would come and look who’s here today! All of you! Thank you so much for coming! With thirty-three thousand participants including fifteen hundred breast cancer survivors, this is the signature fundraiser for the Komen foundation – the largest 5k run/walk in the world. Here in Houston, you are the biggest – you’re the biggest 5k run/walk! (Applause)
This race started twenty-one years ago with eight hundred participants and it’s grown over a hundred races with over one million participants throughout the world, including Germany and Italy.

The foundation was established by Nancy Brinker in 1982 in honor of her sister, Susan G. Komen for which this is named. It’s an international organization committed to fighting breast cancer as a life threatening disease through research, education, screening, and treatment. The battle can be won, and through the partnership of companies across the US and here in Houston, we’re able to spread the word about early detection and provide funds for research. In Houston we have the support of over eighty companies, and I see a lot of large groups from our sponsors! Yay, sponsors! Our diamond sponsors are Chevron, Compass Bank, Cordúa Restaurants, Sunny 99.1, the New Mix 96.5, KTRH 740, Texas area Ford dealers, the Houston Chronicle, Kroger, and Royce Builders. We would not be here without them. However, we have our wonderful presenting sponsors showing tremendous support…support, that would be our wonderful Reliant Energy, and the Lester and Sue Smith Foundation. Joining us today from Reliant Energy is Jim Robb, senior vice president of retail marketing for Reliant Energy. I’d like for him to say a couple of words.

At this point, Jim Robb, Lester Smith, and Sue Smith were all given a few minutes to thank everyone for coming and pledge their continued support to the fight against breast cancer. Then, Dana Tyson gave Jim Robb the “honor of firing the gun to start the races” and the first group, the competitive runners, were off. Dana Tyson
continued to cheer, encourage, thank people as she announced the starts of the consecutive races, the non-competitive runners, the walkers, and the Kids K – a one kilometer walk for families and small children.

As we made our way to the beginning of the race-course for the start of the 5K walk, the general crowding grew more oppressive as others did the same. It took several minutes for the momentum of the walk to pick up and for those of us who were half a block back or more from the pink tape starting line to actually begin walking. As we passed under the pink and black balloon arch that also marked the starting line, I finally located the “stage” and Dana Tyson – it was a small elevated platform about one story high just beyond the race start. By the time we passed it, Tyson had already launched three groups of runners and walkers and was obviously running out of encouraging words. It was relieving to walk beyond the reach of the speakers and her “go, go, go’s!” and fall in with the hum of the crowd. As we picked up momentum as a whole, the crowd thinned out some and we all had more room to move and to breathe in the Texas heat.

At the Cleveland Race for the Cure, the race started on the steps of the Rock’n’Roll Hall of Fame, and Lake Erie cast a cool breeze over the morning. Opening remarks were much the same as they were in Houston, but as a nod to the location, rock music played over loud speakers and could be heard for the first few blocks of the race-course that wound through downtown streets, specially blocked off for the event. For many of the twenty thousand participants, the shotgun start didn’t mean much – everyone started at the same time at this race and the starting line was packed with people for a
good block back. Anyone who was serious about running was probably at the head of it to avoid having to navigate through walkers. As this was my first 5K, I wasn’t familiar with how to position myself as a runner and I wound up at the back and had to navigate through endless walkers. As in Houston, it took several minutes for the momentum of 20,000 people, who were mostly walking, to reach the back of the pack and for the whole procession to begin its 5K (3.1 mile) journey though the streets of Cleveland.

As I ran through the streets of Cleveland, and wove my way though the walkers, I was able to get a sense of the great diversity of participants. I saw families with young children, large families with several generations present, groups of friends, and teams of walkers. About two thirds of the participants were female, the other third male and I saw people of all ages and ethnicities. A majority of participants appeared to be Caucasian, but I was surprised to see how many African American participants were at the Race, given criticism I’ve read to the contrary citing this event as being middle-class, Caucasian, and female. I would estimate African American participants made up about twenty percent of the total attendees. As far as physical appearance, some people looked athletic, most appeared to be in average physical condition, and there were a fair share of overweight participants. Were it not for the pink shirts, it would have been difficult to determine the survivors from the other participants: women in pink shirts appeared healthy and capable and looked no different from everyone else. And as I ran, I saw group after group walking and talking – nobody walked alone.

Walking through the streets of Houston provided a different perspective on the race participants. Walking gave me the time to focus on the participants around me and to
observe more carefully what they were like individually rather than holistically. I was particularly taken with the group of walkers immediately in front of us. About twelve people total, the “in celebration of” signs told their family story. An older woman, maybe in her 60s, wore a pink ribbon scarf around her neck, a pink ribbon themed charm bracelet, and the sign on the back of her pink Komen shirt read: “in celebration of ME!” With her walked a man about the same age, who wore a sign pinned to his white Komen shirt that read, “in celebration of my wife” followed by her name. Surrounding the couple were other family members, all wearing “in celebration of” signs that identified the walker by his or her relationship to the survivor. There were two sons, a daughter, a few in-laws, a few friends, and many grandchildren.

Watching this large family walk filled me with a series of mixed emotions. At first, I saw a family spending time together and thought about how neat it was that they all made time for this event. Then I saw a family supporting and honoring one special woman and thought about what gift this was to her, what a lesson in family support for the children, what a beautiful gesture of love for all. At the same time, I realized I was looking at a family that probably endured a great deal of pain and suffering as one member battled breast cancer and walking in celebration of her recovery may be serving a dual purpose: a symbol within the family that a struggle has ended, and a symbol from the family that breast cancer needs to end. Their presence at the Race for the Cure as an entire family represents a powerful display of endorsement for the Komen Foundation and its activities. Whether participants like these attend the race to mark personal
victories, or to actively support the Komen mission, 25,000 Texans are hard to ignore (Kliewer, 2004).

As we walked through the streets of Houston, I noticed other groups of walkers: families, groups of friends, and many business-sponsored groups. The participants reflected the ethnic diversity of Houston, although it appeared that a majority, perhaps half of the participants were Caucasian while the other half were African American, Hispanic, or of Asian descent. As in Cleveland, about two thirds of the participants were female and the other third male. Physical fitness levels varied with most people appearing to be about average.

Beyond the flurry of the starting line, the Race is fairly quiet. The route is monitored by Komen volunteers in blue t-shirts, who watch for injuries and hold mile number signs. Occasionally neighborhood residents step out on their porches or balconies to watch and wave at the passing crowds. There was one water stop, about halfway through the route where volunteers poured small paper cups of water. We found it interesting that there were only a few volunteers with trash bags after this and for the most part cups wound up underfoot on the street. One of my walking partners commented on the irony walking for a cause and yet neglecting civic pride and we wondered if and how the cups would be cleaned up.

The last half-mile of the Houston Race stretched down a long boulevard and anticipatory finish line excitement grew. Faint music became clearer, Komen volunteers increased and cheered on walkers, and race décor increased, most notably the “survivor salute flags.” Along the grassy median where we walked, some 150-200 tall wooden
spikes with printed “flags” stapled to them were poked into the ground about every six feet. The flags, available for purchase prior to the race, were customized with printed individual names and of course the Komen logo and pink ribbons. We saw a few groups stop at their flag to take pictures, or to pull it out of the display and carry it across the finish line. Here and there a flag had fallen over and a few had been propped back up against the occasional tree, most that had fallen stayed on the ground. It struck me as a little sad that there were no volunteers around to replace the fallen flags, and that no walkers were pausing to lend a hand. As I reflect on why I didn’t stop, I remember feeling tired and achy, eager to reach the finish line, pulled by the momentum of the crowd, and wary of what appeared to be splintery wooden posts. Perhaps other walkers felt like I did and allowed the circumstances of the event to overcome a normally obligatory kindness.

Truth be told, I didn’t just walk by the fallen flags because I was tired, I found the flags to be obnoxious and I didn’t feel like paying them any more attention than I already was by walking by and reading them. To me, the flags became a symbol to divide the haves from the have-nots. Each flag represented an additional $26 donation and a single individual. Unlike the “in celebration of” and “in memory of” signs handwritten and worn by participants, these flags were anonymous and aside from the differing names, they were otherwise identical and void of human connection. Their repetitive orderliness, paired with the lack of race day explanation made them feel like they were not a “race extra” as billed by Komen of Houston, but a race imperative and I wondered, do survivors who don’t find their name on a flag feel sad, forgotten, less important, or
unworthy? The friends I was walking with thought that there was a flag for every survivor at the race until I explained otherwise and I only knew because I scoured the Komen of Houston website for my research.

The finish line in Houston was much like the starting line – a thick strip of pink tape on the ground and a great balloon arch over it. In front of us, a group of walkers lined up arm-in-arm and stepped over the finish together while others took pictures. A man on an elevated platform read the names and times of survivors as they finished the race. Another group of volunteers made sure that each survivor received a pink rose after crossing the finish line.

Finishing the race in Cleveland was a much different experience. The last corner of the route revealed a downhill finish towards Lake Erie. What I found to be more impressive than the lake, however, was the great sea of pink created by the signs people wore on their backs, and the winding line of survivors in their pink shirts and hats as they were guided to a special “survivor’s lane” that lead out to a growing pool of women gathering for the survivor’s ceremony. The ceremony was celebratory in tone, but also very serious as the announcer recognized the years that women had survived past their breast cancers by inviting those with the most years of survivorship up on to a stage and working down through the years, until the women who were in their first year past cancer were invited to join their sisters on stage. Faces on the stage and in the audience were a mix of teary eyes and smiles. At the end of the ceremony, white doves were released to commemorate the women who had lost their lives to breast cancer.
In addition to the ceremony, the finish line was a general flurry of activity. There was a survivor’s tent where tables and chairs were set up and food was available. There was a medical tent, where I discovered a team of responsive and caring volunteer medical professionals following a nasty bee sting. The nurse who helped me told me that she volunteers at the Race for the Cure every year.

There also were tents and tables set up by many of the Race for the Cure’s corporate sponsors: Yoplait gave out yogurt; Kellogg’s gave out cereal; there were popsicles, fruit, water, and sports drinks available. Ford Motor Company was taking free pictures and handing out special bandannas, a group of chiropractors provided massages, and New Balance had a display of athletic shoes and laces with pink ribbons on them for sale. The general feeling was of celebration – after the seriousness of the 5K, the sponsor’s area offered an opportunity to eat, relax, and visit with one another. Everyone had at least one food item in his or her hands, most had a few as there were almost no places to sit and breakfast was on most everyone’s minds. I had a banana and a popsicle and browsed the booths with everyone else.

Contrary to what I had expected to find, there were no booths with breast health information at all at the Race for the Cure. The only health-related material to be found was distributed by Zeta Tau Alpha, a national fraternity for women: members handed out bookmark-sized sets of twelve pink ribbon stickers to put on a calendar as a reminder to do a breast self exam. Even this material had little information about the actual practice of the self exam and focused more on Zeta Tau Alpha’s relationship with the Komen Foundation. Additionally, the absence of a Zeta Tau Alpha tent or table gave the
impression that the members’ presence was less valuable than a corporate sponsor, or possibly not sanctioned by race coordinators.

The same was true for the Race in Houston. I came away with no information on breast health, cancer screening, or even political updates – surprising considering the proximity of the Race to the presidential election and that Houston is home to several major medical centers. Instead, I came away with my Race t-shirt and number, a bottle of water, a few achy joints, and a still hungry stomach. As I left the Race site with my friends, and participants began to head in their separate directions, I thought about the reach that the Komen foundation would have for the rest of the afternoon. Like the ever-growing concentric circles when a stone is dropped in water, the Race participants would diffuse from downtown, the center of Houston, and head back to their own neighborhoods, communities, and suburbs and probably tell others about their morning. I crowded onto the light rail train with other Race participants to get back to my home and an hour later when I walked to a nearby restaurant for brunch, there was a group of women in their Race t-shirts ahead of me in line. Even later that day when I was running errands, I saw a few more folks in their Race t-shirts out and about, demonstrating that the visual reach of Komen may be as extensive as the verbal reach. The next morning, when I opened the newspaper and found that the Race had made the front page of the city section – complete with a large color picture – I was reminded that our efforts the previous morning were meaningful and valuable to the community.
Thick Description of the Annual Advocacy Training Conference

On May 3, 2003, I joined women from across the United States and places as far as Estonia and Australia in Washington D.C. for the National Breast Cancer Coalition’s Annual Advocacy Training Conference and Lobby Day. My journey to this conference marked something of a turning point in my breast cancer research: I had discovered the NBCC several months earlier and had been regularly monitoring their website when I found the announcements about the conference. Because much of my previous work had focused on the Komen foundation, the NBCC conference presented an ideal opportunity for me to branch out as a scholar and gain some first hand experience in the more political side of breast cancer awareness.

Getting to the conference was a journey in itself. The NBCC has a scholarship fund for attendees with limited income. As a graduate student, the only way I could attend the conference would be with financial assistance and fortunately my application was accepted and my registration fee was waived along with my hotel expenses. I also received travel funds from Ohio University that covered my meals, additional conference materials not included in the registration fee, and gas for the seven-hour drive east from Ohio. Early in the morning on Saturday, May 3rd, I set out to cross the Appalachian Mountains and arrived in our nation’s capitol to learn, to lobby, and to experience advocacy in action.

Day one.

When I arrived at the Renaissance Hotel in Washington D.C., one of my first tasks was to find the registration table and check in for the Conference. On my way
through the hotel lobby I noticed several women carrying royal blue tote bags printed with the current NBCC conference title and dates. I followed them down an escalator where I found a set of tables with a huge royal blue banner declaring this to be the NBCC Annual Advocacy Training Conference registration center. At the table I received a name badge to wear throughout the conference and a blue tote bag of my own. It contained: a giant three-ring binder filled with the conference program, speaker biographies, an overview of the NBCC, all of the NBCC’s fact sheets and position papers, and all of the materials needed for the panels, workshops, and lobbying. My bag also contained information on the legislative process, information on the NBCC’s other training program: Project LEAD, and a notepad. This blue bag and giant notebook became my constant companions for the next three days, just as it did for other attendees. In fact, the blue bag became something of an amusing identifier for NBCC conference attendees: on the third day of the conference, after we’d spent enough time together to grow familiar with many of the other attendees, another conference was held in our same hotel that also handed out blue tote bags and there was suddenly a great deal of good natured confusion about who was with what organization and whom one should ask for directions. To add to the confusion, the other conference also had a medical focus and some of our session titles were so similar that a few people did wind up in the wrong room with the wrong group.

After the registration table, my next stop was the exhibit area where I discovered a table with NBCC staff, information on NBCC and related programs, questionnaires, information for attendees with leadership responsibilities, and a very popular table full of
NBCC merchandise. One of the most popular items for sale was a rectangular button with the NBCC logo in black and “stamped” diagonally across it was, “ACTIVIST” in bold red letters. There were also t-shirts, other buttons and pins, books, pens and pencils, bumper stickers, and magnets for sale, but almost nothing in pink or displaying a pink ribbon. I looked around the exhibit area and talked with the NBCC staff about the conference and the lobby day until about 6:00 pm when they needed to start packing up for the night and I realized I was tired from my long drive and hungry for dinner.

Before leaving for the conference, I had had a brief correspondence with the team lead for the Ohio lobbyists: a woman from the Cincinnati, Ohio NBCC group. She had been pleased to see my name on the list because they rarely have a representative from my district at the Conference. That night, I was able to join her and the rest of the Cincinnati group for dinner. The twelve women I met and befriended for the rest of the conference were twelve of the most intelligent, savvy, politically minded firecrackers I have ever met. They were all in their late 30s to 40s and four were African American while the other eight were Caucasian. Most seemed to be fairly affluent white-collar professionals from the Cincinnati area and everyone except for me, and an oncology nurse were breast cancer survivors. I felt immediately welcomed and included by the group and when I told them about my research, they were interested and wanted to know more. As I explained the purposes of my work and that I was interested in the messages that breast cancer organizations create about this disease, they quickly latched on to the topic and began to talk about their experiences with breast cancer. As we ate, they shared their stories with one another and with me.
One, a lawyer, told horror stories about surgery after surgery and had eventually traveled all the way to Houston, Texas to be treated at M.D. Anderson Cancer Clinic where she received amazing care from a team of doctors and a surgeon who specialized exclusively in breast surgery. She felt that health care like this had saved her life and every woman deserved access to such quality services.

An African American woman sitting next to me talked about how African American women needed different messages about breast cancer because women she knew weren’t finding tumors early enough, and if they did, they often refused to tell anyone or seek treatment. She explained that pride and family responsibility were a stronger force than personal health needs. She also talked about how her battle with breast cancer was regarded as a shameful secret by her own family, but she knew that she had to save herself and set a new example for other women.

At one point, all the women laughed and joined in with stories of “chemo brain” when an advertising executive started talking about how forgetful she had been since her treatment. Although I’d read a lot about breast cancer, books fail to really humanize the experience, and as these women shared their frustrations and their laughter, I felt inspired and humbled.

When I asked them about why they were active with the NBCC and what they thought about other organizations like the Komen Foundation, they all talked of wanting to do more, feeling angry and wanting to incite change, and needing to know why women get breast cancer and how we can stop it. Most of them agreed that pink ribbon things
were fine for some but not for them – these women wanted action and answers and they were in D.C. to get them.

*Day two.*

Thinking reflectively about the NBCC Conference, I feel like my first day was spent getting to know the people, but my second was all about getting to know the organization. This was the day I would be introduced to the values and traditions of this organization.

Prior to my discussion of the second day, a brief explanation is in order: because there were a great number of plenary sessions and workshops on the second and third days of the conference, each containing a great deal of often technical information, I’ve decided to focus on one session in great detail rather than attempt to discuss them all. Keeping quality over quantity in mind, I’ve chosen a session that I found to be representative of the conference, most relevant to my research purpose, and well received by conference attendees. In addition, I was able to purchase a recording of this, (and other) sessions on compact disks, and obtain supplementary material presented in the session to accompany and add depth to my field notes.

The second day opened with a continental breakfast and two plenary sessions in which all conference attendees were present. The first was entitled, “New directions: Where are we and where should we be headed” and focused on the current state of breast cancer treatment, prevention, and diagnosis and the role of advocates in fostering change. The second plenary session was, “Not just ribbons: Accountability and ethics in fundraising” this is the session I will describe in detail.
At these large sessions, I was able to get a sense of the attendees that were at the conference. There were around 400 attendees total and looking around the room revealed that about one third of the participants were African American and most of the rest were Caucasian. During these same sessions, when survivors were asked to stand and be recognized, about half of all participants stood up. Many of the women I met and talked to were members of regional groups that belong to the NBCC and had come with other group members in order to learn and lobby. Many of these women were survivors and had become involved as a result of their personal history with breast cancer. Other women who were not survivors told similar stories of family history with breast cancer, or of working in a health care field with breast cancer patients – I was something of an anomaly as an academic. (Interestingly, it was on this trip that I discovered my own family history with breast cancer and began to think less from the mindset of an academic-activist, and more like an activist-academic.)

I was especially eager for the session, “Not just ribbons: Accountability and ethics in fundraising” since the topic of cause related marketing was included in the session description. As cause related marketing is the lifeblood of the Komen foundation, I was interested in hearing how panelists at the NBCC conference would address it. As I sat in the ballroom waiting for the session to begin, I looked over the speaker biographies printed in my conference notebook. Here is what I read about the moderator, Cynthia Pearson, and the speakers who were on the panel:

Cindy Pearson is the Executive Director of the National Women's Health Network. Founded in 1975, the Network was the first feminist health group to
utilize a national membership in support of DC-based health activism. The Network's goal is to bring the voices of women everywhere decisions are being made that affect women's health. The Network testifies before Congress and the FDA, speaks out at scientific meetings, publicizes issues through the media, networks individual activists and other local and national groups working on women’s health, and mobilizes its constituency to influence decisions made by federal regulatory agencies. Cindy has worked at the Network since 1987. In addition to representing the Network in the media and to the government, Cindy has served on the boards of the Reproductive Health Technologies Project, the National Breast Cancer Coalition, the Campaign for Women's Health, the D.C. Women's Council on AIDS, the National Action Plan on Breast Cancer and the Advisory Board of the Boston Women’s Health Book Collective. Cindy has received the Special Service Award from the National Association for Women’s Health, the Commissioner’s Special Citation from the Food and Drug Administration, the Margaret Sanger Award from the Federation of Feminist Women’s Health Centers and the Susan B. Anthony Award from San Diego County N.O.W. Cindy is also the lead author of "The Truth About Hormone Replacement Therapy," the Network's book about the medicalization of menopause and alternative approaches. Prior to working at the Network, Cindy served as the director of Colorado NARAL and WomanCare Clinic in San Diego, California. (Coalition, 2003a, p. 15)

Ronald S. Johnson currently serves as Associate Executive Director at Gay Men's
Health Crisis, Inc. (GMHC) in New York City. In that capacity he manages GMHC’s public policy and public advocacy functions and serves as a member of senior management. Prior to coming to GMHC in November 1997, Mr. Johnson served as the Citywide Coordinator for AIDS Policy in the Office of the Mayor, City of New York under Mayors Dinkins and Giuliani. Mr. Johnson has also served as the Executive Director of the Minority Task Force on AIDS, which is located in New York City (1988-92). Mr. Johnson served as a member of the Presidential Advisory Council on HIV/AIDS (1996-2001). Mr. Johnson is a person living with HIV. His infection was diagnosed in October 1989. He was born in New York City and currently resides in Brooklyn. Mr. Johnson has one son, J. Marshall. (p. 11)

Susan Orenstein began working at Business 2.0 after serving as a frequent contributor to the magazine. Susan has authored in-depth features for the magazine on a variety of topics, focusing on business and society. She wrote about one company’s efforts to get through 9/11, after suffering the tragedy of losing employees and being displaced from its offices. Her recent pieces include “The Marketing of Breast Cancer,” focusing on the trend to tie corporate identity to good causes, as well as an in-depth look at how Atkins Nutritionals turned the diet world’s flavor of the month into a $100-million plus empire. Susan was formerly a feature writer with the Industry Standard. During that time, she received a Newswomen's Club of New York award for a cover story on sexual harassment allegations at Juno Online Services. Her extensive writing background
also includes stints at *American Lawyer*, the *New York Observer*, and the *San Jose Mercury News*, among others. (p. 15)

Janice Rosenhaus is the founder and driving force behind Harris Marketing Group. A true entrepreneur, she has served as president since the firm's inception in 1976. Through her leadership, HMG has evolved over the years into a highly successful and sought after full-service, integrated marketing and advertising company, with a specialization in cause-related marketing. By 1987, HMG was listed among the top 50 women-owned businesses in Michigan. The firm's success can, in part, be attributed to its timely recognition of the importance of tailoring advertising and marketing messages to the female audience. Most recently, Janice's marketing expertise and efforts led to the development of Concept: Cure, a groundbreaking, cause-related program that partnered General Motors with the American fashion industry to raise almost $4 million for organizations dedicated to fighting breast cancer, including the National Breast Cancer Coalition Fund. Harris Marketing Group clients include Dr. Pepper/Seven-Up's Diet Rite cola brand, the Bristol-Myers Squibb Foundation's Individual Cancer Assistance Network, Lear Corporation, Pizza Hut and the Midwest AIDS Prevention Project. Ms. Rosenhaus is a member of the Association for Women in Communications (AWC), the National Association of Women Business Owners (NAWBO), and the National Association of Female Executives. She supports, both personally and professionally, the Women's Sports Foundation and the National Breast Cancer Coalition Fund (NBCCF). She is
active with the Women's Economic Club and the Adcraft Club of Detroit. (p. 17)

The moderator, Cindy Pearson, began the session by introducing herself briefly and then reading each of the speakers’ biographies to the audience. Then, she explained that each speaker would make a brief presentation and then there would be time for questions. A summary of each speaker’s remarks follows. The first speaker was Ronald Johnson.

Ronald Johnson began his remarks by explaining that when it comes to ethics and accountability in fundraising, there is no such thing as clean money. He continued to explain: we approach it as if there were clean and dirty money, but in reality there are aspects to all the funds that we raise that are questionable and as nonprofit organizations, we need to be accountable for those funds. Like beauty, ethical problems in fundraising are often in the eye of the beholder: one organization’s needs and efforts may be seen by another organization as a crass sell-out. When it comes to issues such as taking money from pharmaceutical companies, the main question to ask is whether public policy development and advocacy are tainted by donations from corporations that have a stake in the debate. Nonprofit organizations need to ask: how can we avoid the perception of influence if we receive these donations?

Johnson then explained the grant policy of the Gay Men’s Health Crisis, Inc. (GMHC) as one way to respond to these concerns. He explained that transparency is most important in corporate support: no donation shall limit GMHC’s activities to help people living with AIDS; GMHC policy will not be swayed by any donation; GMHC will not endorse a company based on a donation; and GMHC reserves the right to refuse a donation from a company with conflicting policies. He warned: this policy works for us,
but it has not made us immune to criticism. No money is clean. Ethical purity is not
attainable unless you refuse the money and while abstinence has its place, it is rarely the
complete and total solution to all our problems.

The audience laughed at Johnson’s witty comparison and applauded. His
comments were well received by the audience in general, and certainly by those around
me. I was impressed with the NBCC for including Johnson on this panel and in this
conference as his knowledge and experience brought greater depth and relativity to the
issue. This promotion and interest in global perspectives was characteristic of many of
the sessions and workshops I attended. Rather than being insular and inter-
organizationally focused, much attention was given to concerns that included but were
not exclusive to breast cancer, like this one.

The second speaker, Susan Orenstein opened her remarks with a story to explain
how, as a journalist writing for a business magazine, she had come to be involved in this
issue. She explained that she had been thinking about training for an AIDS charity ride
and discovered that there was a great deal of controversy surrounding the ride and others
like it, especially the Avon 3-day walk. After a little research, she found that when it
comes to cause related marketing and fund raising, the breast cancer community is deeply
divided.

Orenstein went on to explain: this is booming business. This disease has spawned
a very lucrative market that companies are eager to exploit. This is especially obvious in
October, “pink month” – you can’t avoid it. There is a sense among activists that this has
gotten a little bit carried away. With this remark, Orenstien was cut off by loud applause from the audience.

She continued: this is big business. Companies are motivated by the bottom line, sure altruism is involved, but this is very much a competitive market. Clearly Avon developed their 3-day walk to be in direct competition with Komen events.

Second, this is a very gray topic; it’s not black and white. There are strong feelings on both sides. It’s not an easy question to answer whether this corporate embrace of the disease is doing more good or not. There is much concern over who really benefits in the end.

This is a very emotionally charged issue and much of the debate is really a tug-of-war for ownership over a disease and the message that the public consumes. If I learned one thing, it is that nothing in breast cancer is uncomplicated and corporate America has pretty much no interest in confronting us with anything difficult to digest. They are selling products and they want the image of this disease to be upbeat, pink, pretty, and happy. The overwhelming message at a Race for the Cure event is that we are going to win this and its pretty straight forward. There’s a sense among other activists that counters this – a sense of anger: there are things to be angry about, things that are not being done well, and that no, it’s not easy: just because you do your breast self-exam every month doesn’t mean you won’t get breast cancer. Orenstein was again interrupted by loud applause before continuing: I think there is a real danger that through the corporate packaging of this disease, that it has become sanitized and packaged to sell more product than to inform, and the public is not hearing all that they need to know.
That said, AIDS and prostate cancer supporters that Orenstein interviewed were very wistful and envious of breast cancer’s mainstream image, especially the message of importance and the money. It really puts credibility behind your cause to have large auto manufacturers paying huge sums of money to have award-winning directors create television advertisements. The pros and cons are not easy to tally up. When one disease gets popular, others get neglected.

Orenstein closed by saying: there’s a sense among a number of activists that women are encouraged to shop and this is an offending message. The audience agreed with their applause and Orenstein continued: The message is that the way to reach women is to tap into their shopping influence and women are being led to believe that if they do buy pink ribbon merchandise that they are taking care of a complex problem that defies easy sound-bites.

With this, the audience gave Orenstein lengthy and enthusiastic applause. The women seated around me nodded and briefly commented on the truth of her argument. I was pleased to see that an argument so close to my own was so well-received by the NBCC attendees and I thought it was interesting that Komen was explicitly singled out and criticized. Later, when I asked one of the women from the Cincinnati group about her thoughts on Komen, she told me that she had done the 5Ks in the past and really didn’t see why Komen and NBCC couldn’t work together more.

I also found the open criticism of Avon interesting, as Avon funds one of the NBCC’s most exclusive and prized training programs: Project LEAD (Leadership
Education and Advocacy Development) which is an intense science training course for dedicated activists. This relationship would come up later in the session.

The third speaker, Janice Rosenhaus, opened her presentation by explaining that as a member of a marketing agency that focuses on women, she had worked on a lot of cause related marketing and she believed that if well done, corporate partnerships with charities can really benefit the consumer and the cause. Rosenhaus brought a video of selected advertisements to demonstrate the investment that corporate America is making in their breast cancer programs. After the session, I asked Rosenhaus if I could get a copy of this video and she offered to mail a copy to me, so I’ve been able to review it in coordination to the audio recording of this session.

The lights were dimmed and the video was played on the large screen at the front of the room. It opened with the title: Cause Related Marketing, the Harris Marketing Group name and some upbeat generic music featuring an electric guitar. The images included still shots of print ads and television commercials produced by Harris: first a series of print ads for Ford Motor Company featuring celebrities wearing a scarf by designer, Kate Spade. Then, a Ford commercial featuring a Race for the Cure event and a survivor cheering over her last treatment. This was followed by print ads for Mercedes, and BMW in which cars were featured most prominently, but the surrounding text seemed to address breast cancer. Then, a Yoplait ad depicting pink yogurt lids floating through the sky to form a giant pink ribbon reminding us to “save lids to save lives.” Next, a series of commercials for General Motors Concept Cure featuring designers, Vivienne Tam, Joe Boxer, and Max Azria and cars that they had designed as prizes for a
“fashion targets breast cancer” sweepstakes. The designers narrated and their scripts included phrases like: “so breast cancer goes out of style forever,” let’s stop breast cancer in it’s tracks,” and, “because there is nothing stylish about breast cancer.” I found it interesting that Max Azria was escorted by three very tall, skinny, young models though part of his ad. His “arm candy” struck me as oddly contradictory: promoting a beauty ideal while plugging for a disease that leaves women deformed, depicting women as ornamentation while trying to target a female audience, and pairing very young women with a disease that typically strikes a more mature segment of the population. I was surprised at how credible the other designers seemed, in spite of the inanity of their actual words, when they delivered their message alone with the car.

The next ad seemed like an odd fit, it featured Tiger Woods talking about his program with Target stores to help kids. The following print ads returned to breast cancer: a special edition KitchenAid mixer, and MAC cosmetics. Then, an Avon commercial with a very serious and respectful tone filmed in black and white. Images of glass balls being carefully balanced and rolled in a pair of hands were paired with images of an average looking woman who says, “If one thing falls out of balance, your whole life can crash. I thought was pretty healthy, I thought I did everything right. I have a son who’s nine. Women, please take care of your selves.” This somber message was followed by what seemed like it’s absolute opposite: a Eureka vacuum ad with sing-songy music and a very perky Asian woman saying, “you’ll feel good about helping a great cause: Clean for the Cure!” Followed by a man’s voice that says only: “the Susan G. Komen
Breast Cancer Foundation.” The final ad in the segment was another ill fit: a pairing
between Crest toothpaste and the Boys and Girls Clubs.

When the video started, I could feel the skepticism surrounding me – there was
some eye-rolling and head-shaking as the images began and we all saw the very familiar
Komen-linked, pink ribbon based ads that most of us had seen before. Some of the
women sitting around me muttered comments that reflected Orenstein’s earlier
presentation and the corporate push to encourage women to shop for a cause. A few
sarcastically noted that the cost of mailing in a pink Yoplait lid exceeded the ten-cent
donation that Yoplait would make in return. The audience actually grew quiet during the
Avon ad and seemed to appreciate it, but exploded with laughter at the phrase, “Clean for
the Cure.”

When Rosenhaus resumed her comments, she seemed to sense that there was a bit
of confusion lingering regarding the ads for Tiger Woods and Crest that appeared to have
nothing to do with breast cancer. She explained that she had included these to show that
cause related marketing is a major highway and some do it better than others.

She continued with an estimation that up to one million dollars are being spent
each October in paid advertising and it’s continuing to grow. We talk to major
corporations all the time who want us to help them take a look at charities and causes that
they can use to help them reach their consumers. Their interest is in doing the right thing
and in building a relationship with a customer base. It can be a win-win. A large amount
of money has been spent in the “branding” of breast cancer.
In the end, how do we make sure that cause related marketing works for the good of the people who are suffering from this disease? How do you remain true to the cause and not cross the line where corporations benefit more than causes? Partnerships between marketers and charitable organizations really can bring better options to the consumer. There is a need for corporate sponsorship money – it helps organizations do the work that they need to do.

Applause for Rosenhaus was a bit lighter than for Orenstein, but not unkind. It was clear that she was in a difficult position trying to explain her professional responsibilities without alienating or apologizing for them while also keeping in mind the interests of the NBCC. By the end of her comments, I realized just how difficult her job must be and how skillfully she must negotiate between all her clients, both for-profit, and not-for-profit, in order to achieve such success and notoriety.

Now that all the panelists had spoken, attention turned back to moderator, Cindy Pearson, who asked a variety of questions of her own, as well as many questions submitted by audience members. (During these large sessions, questions from the audience were written down and then relayed to the moderator, who would then select and read questions for the panelists.)

Cindy Pearson opened the discussion by asking more about cause related marketing and by specifically referencing the Komen Foundation. While she noted that the point was not to grapple with what Komen does, she asked, if only one large organization, like Komen, is benefiting, how can cause related marketing benefit groups that are growing as well as groups that are established?
Janice Rosenhaus responded by explaining that in the campaigns she had worked with for General Motors, a great deal of thought and research went into distributing the proceeds including the creation of programs and partnerships specifically for allocating charitable giving. She noted that when companies choose one organization without looking around to see who is doing what sort of work, they are making a big mistake. This comment was met with much applause from the audience.

Susan Orenstein also contributed to this conversation with the explanation that one of the reasons so many companies ally themselves with Komen is that they get instant credibility and access to the Race for the Cure, which she described as a marketing dream.

Pearson then turned to Ronald Johnson and asked about the acceptability of the images used to market a cause. She asked why there are no black women in breast cancer advertisements, and who is it acceptable to show?

Johnson noted that this frustration is well known within the AIDS community and noted the controversy over Galaxo Smith Klein featuring Magic Johnson in pharmaceutical ads. The image of the basketball legend does not match the reality of many people living with AIDS around the world. Simply: often the true reality is not presented because it is not pretty.

Pearson agreed and noted the additional problem that marketing campaigns are somewhat educational in bringing the reality of the disease to people’s minds and that the depiction of certain people creates the misleading, troublesome view that it doesn’t
happen to women of color, that it doesn’t happen to women who are outside the age range, and why are all the women in the ads so thin!?

Following a bit of laughter at Pearson’s brief rant, she shifted subjects a bit to ask this question from the audience: what is the generally accepted margin of profit versus the expenses to produce a fundraising event?

Orenstein explained: the Better Business Bureau Wise Giving Alliance recommends that no more than 35% should go to overhead. The controversy over Avon’s Three-Day Walk, mentioned earlier, was that this amount had gone higher and reached about 40%. Breast cancer activists were upset over this percentage and felt that Avon should pick up the cost of these events. Avon responded that they spend 20 million a year on their breast cancer efforts and made the point that if they don’t make money, they can’t give money to charities.

Johnson noted that the GMHC kept event overhead between 25 and 30% and noted that similar to the Avon Three-Day Walk, some AIDS rides were also growing controversial for having 70 to 75% overhead, which he called unconscionable.

Pearson’s next question brought the focus back to the corporations. She summarized from several audience questions to ask: what qualifications do corporations have to decide where money goes?

Rosenhaus repeated that GM and Bristol-Meyers, companies she works with, have their own foundations, some of which have NBCC members involved, to make these decisions, and that in her opinion Avon had always done a good job. She also explained that: cause related marketing grew so quickly and it’s such a big business that
people weren’t really prepared for the kind of responsibility they were taking on and what a complicated thing it is, and what the right thing is. Organizations are learning as they go.

Orenstein agreed that Avon does do a very good job of allocating money and praised Avon for taking the issue seriously and for starting their foundation for breast cancer research. She added that it’s important for consumers to know where their money is going when they support a campaign because often times it’s not groundbreaking or foundational work. The most popular place that companies want to spend is awareness because it’s not ugly and it doesn’t challenge the status quo.

Following some additional and largely redundant discussion on sources of funding for non-profit organizations, Pearson returned to the consequences of marketing and asked: will there be a negative backlash if and when breast cancer becomes stagnant due to over-saturation or the boredom of the public?

Rosenhaus said: many corporations want to find a new charity, something that is less busy, but still support things that are important for women. No, it won’t go out of style, but there are playing fields where it is just too full.

Orienstein noted: 10 to 15 years ago people thought that breast cancer was a troubled field.

Pearson countered with: 20 years ago we couldn’t talk about breast cancer in public…. And was cut off by applause. She continued: that’s a big change in 20 years. Where do we go from that?
Rosenhaus replied by explaining that breast cancer had become “branded,” it has become a brand in its own that corporations who never used to talk to women now want and want badly in order to reach that female market.

Orenstein added this historical reflection: the emergence of breast cancer in the public mind owes a lot to the AIDS movement. The AIDS movement set a good example of how to rally a lot of public support...she paused for applause…. And that in many ways has spurred women to start going public and start talking to Congress. A key support was that of celebrities, you had some really well known philanthropists like Ralph Lauren. Celebrities like this also start mass trends and then corporations get interested and you have things like pink ribbons everywhere and the rest is history. Happily, the corporate campaigns should get credit because we are talking about this disease and that’s one of those gray areas where good is done and this issue isn’t just black and white.

The next question, Pearson both asked and responded to – she said: the audience keeps asking, what’s the deal with the Coalition? I’ll take this one, since I’m a member of the board. We’ve talked a lot about this at the board level because the Coalition’s effectiveness is such a treasure to us, we don’t want to do anything to jeopardize that, and we want as much money as possible to put into our great programs. Right now, our policy is to limit to 15% of our budget, funding from pharmaceutical as a whole, and we limit to no more than 5% from any one drug company. We limit similarly in spirit in terms of keeping a firewall between budget and policy people. There are projects that we won’t take drug company money for: quality care and clinical trials for example, because we
believe that the appearance of pharmaceutical money in those programs might provide reason to question the results. The Avon Project goes to support Project LEAD, international scholarships, and the Quality Care Guide. This is an issue that the Coalition faces as much as any non-profit: we are not immune to any of the issues that have been raised here.

With this explanation, Pearson offered the panelists the opportunity to make closing remarks in the last few minutes of the session. Each panelist took a moment to repeat their original point and then remark on how much they had learned from one another and enjoyed the discussion. Pearson made a closing statement regarding the difficulty that every nonprofit faces when sorting through the competing tensions of taking advantage of resources, doing good work, and relationships with corporate sponsors. Finally, she thanked the speakers and activists, and the audience applauded for a final time.

The rest of the day was filled with more plenary sessions and panels and most attendees made early dinner plans before retiring for the night. The full daily schedule and invigorating learning environment left most of us exhausted and ready for a night of sleep. I spent the evening reviewing what I’d learned and witnessed up until this point and prepared myself for the next day.

Day three.

The third day of the conference was scheduled much like the previous one with plenary sessions, workshops, and plenty of discussion. Most of the workshops were repeated this day so attendees were able to catch a session that they may have missed
earlier. As the final day of regular conference activities, this day was largely about celebration and organization for the following day of lobbying.

Over lunch, we celebrated the culmination of the NBCC’s National Petition Campaign requesting increased funding for breast cancer research and health care access for all. The Avon Foundation was formally thanked by the NBCC for their continued funding of advocacy training programs, and EPA Administrator, Christine Todd Whitman spoke and praised the NBCC for its efforts to highlight cause related research.

Later in the day, we met in state delegation meetings to coordinate our lobbying strategies. Each state had a Field Coordinator who took care of the overall organization of people and resources, and several Team Leaders, who were responsible for presenting the NBCC legislative priorities and guiding a team of NBCC members through the process. We were all briefed on the priorities and given time to ask questions. The priorities were:

Priority #1: Guaranteed access to quality healthcare for all. We will not end breast cancer until all women have guaranteed access to quality health care regardless of their ability to pay.

Priority #2: $175 million dollar appropriation for the Department of Defense (DoD) peer-reviewed Breast Cancer Research Program (BCRP) for fiscal year (FY) 2004.

Priority #3: Enactment of the Breast Cancer and Environmental Research Act. It is generally believed that the environment plays a role in the development of breast cancer, but the extent of that role is not understood. The National Breast Cancer Coalition believes that this critical issue must be approached thoughtfully
and methodically and that a national strategy for increasing knowledge in this area must be developed. This legislation would make grants for multi-institutional, multi-disciplinary research centers to study the potential links between the environment and breast cancer. These centers would award grants based on a competitive, peer-reviewed process that involves consumer advocates.

Priority #4: Enactment of H.R. 1288, the Access to Cancer Therapies Act. The National Breast Cancer Coalition believes that Congress should enact comprehensive prescription drug coverage for Medicare beneficiaries. While NBCC supports a broad approach to prescription drug coverage, it believes that a special provision might be necessary for coverage of oral anti-cancer drugs in light of certain historical and cost considerations that argue for continued access to cancer therapy under Medicare Part B. H.R. 1288 would build on current Medicare policy by extending coverage to all cancer drugs, whether oral or injectable, for Medicare beneficiaries under Part B.

Priority #5: Enactment of the Genetic Nondiscrimination in Health Insurance and Employment Act. The Kassebaum-Kennedy Health Insurance Reform Act (1996) took an important first step by including genetic information among the factors that may not be used to deny or limit insurance coverage for members in a group plan. Congress must now close the loopholes and provide comprehensive protection against genetic discrimination for all Americans. This legislation, which has strong enforcement mechanisms that include a right to sue, would
prohibit health insurers and employers from discriminating based on genetic information. (NBCC, 2003a)

My Team Leader turned out to be one of the women who had initially contacted me from the Cincinnati, Ohio group and over the past two days I’d found that she was a natural leader and well respected by group. I was pleased to hear that we’d be working together. Overall, the state delegation meeting had a feeling of anticipatory excitement – as if we were all finally going to do what we had come here for. That feeling carried us into the evening activity – the Annual Conference Reception.

The Reception was a casual party with cocktails, hors d’oeuvres, music, dancing, and door prizes. After having spent the past three days wearing fairly standard business attire, everyone looked happy to be wearing jeans and party-wear (especially the few women in sequined dresses I spotted on the dance floor). True to form, this was a party like none other – I’ve never seen so many women dance with such joy and abandonment before. I danced a few songs and then found that my friends from Ohio were sitting just outside the action-packed ballroom enjoying some wine and talking. Unlike the first night when we talked about their cancers, this night, we talked about other aspects of their lives. Their stories were like before and after snapshots of how each had lived before her diagnosis and how life, priorities, relationships, values, and goals changed afterwards. Interestingly, all of them were happier now with their friends, family, relationships, and decisions than they were before breast cancer. As one of them said, “its the best club you never want to join.”
Day four.

Lobby day had arrived and it was raining – a quite literal dampener to our morning as we had to do a lot of walking around outside to get from building to building. We all got up a little earlier than normal (or maybe that’s just what it felt like post-reception) and met in the hotel lobby to wait for the busses that would take us to Capitol Hill. I found my Ohio group and we piled into the bus together. As I watched the attendees boarding the busses it was interesting to note that on this morning there was a great deal more pink ribbon paraphernalia than I’d seen at this conference. Many women were sporting designer scarves and pins – a few state groups had even coordinated to all wear the same scarves. As much as I’d seen women rally against these symbols the past three days, I was surprised and a little impressed to see them. Whatever intention the wearers had, their use of powerful pink symbols was bold among this group, and clever – it made their purpose on Capitol Hill immediately discernable and made them appear as a force to be reckoned with.

We arrived at our designated meeting place and were given a quick pep talk from NBCC organizers. We were also given bright orange badges to wear to identify us as NBCC members to help the security guards to know the purpose of our visit. Post September 11th security was still very serious around the Capitol buildings. Before I knew it, I was off with my Team Leader and on my way to meet with Ohio Senator, George Voinovich. The Senator’s staff ushered us into a conference room with walls covered in plaques, awards, pictures, and framed letters. It was an impressive display while we waited and chatted with one of his staff members. She told us that Senator Voinovich was
on his way and was pleased to be speaking with us – breast cancer had become a great concern of his, as his wife was a survivor. Our Team Leader had clearly worked with Voinovich and his staff in the past and asked about his wife’s health, their family, and other projects that they had been working on. When Voinovich arrived, we all shook hands enthusiastically, but a noticeable nervous hush fell over the NBCC members. Our Team Leader was prepared: she caught up with the Senator for a few minutes talking more about his wife and their prior collaborations, then she turned to our legislative priorities and spoke knowledgeably and briefly about each one. As she spoke, she would occasionally turn to one of the NBCC members and include her in the explanation of why a priority was so important to support. At priority #4, she turned to me and I spoke for a few minutes about Ohio University’s partnership with the American Cancer Society, and how I had volunteered with our College of Osteopathic Medicine’s Community Service Program and their Breast and Cervical Cancer Screening Program. Voinovich seemed impressed that I had made this trip as a student and asked me more about what I had learned in my work and research.

At priority #5, she turned to a woman in her late 20s, who explained that the Genetic Nondiscrimination Act was particularly important to her, because she had tested positive for both BRCA1 and BRCA2. This information paired with a family history of breast cancer and noticeable tissue change in both her breasts, she was planning a prophylactic double mastectomy. Because she had been concerned about insurance discrimination, she had opted to receive genetic testing under an alias and pay out of pocket. Her story was compelling as it was, but additionally so because she was a nurse
and had a firm grasp on the technical medical language that helped her explain the situation with beautiful clarity. I heard her tell this story three times on Lobby Day and it sent shivers up my spine each time.

After shaking hands with Senator Voinovich one last time and thanking him profusely for his time with us, we moved on. Our meetings with State Representatives were not nearly as official feeling as our meeting with the Senator: for one thing, the offices were less impressive, and about half the time we met with a Legislative Assistant and not the Representative him or her self, so it was difficult to tell if we had made any actual impact with our requests and stories. We were politely received and heard by someone at each meeting, but were still left with some uncertainty when we weren’t able to speak to a Representative directly.

By lunchtime, most of us had finished our scheduled meetings and were headed back to the conference hotel to pack up and head for home. It felt anticlimactic to leave without being able to say goodbye to all the friends I’d made one last time, but it also felt really good to have seen this side of breast cancer awareness and to have been a part of such a powerful weekend. As I started my long drive back to Ohio, my mind was filled with amazing memories.
CHAPTER FIVE
RESULTS AND CONCLUSIONS

Introduction

Now that we have traced U.S. breast cancer campaigns through history and arrived at the resultant thick descriptions, what can we learn from these narrative accounts? What can we derive from this ethnography about the ways that we communicate about breast cancer? How do these performed narratives shape our experiences with this illness? To answer these questions, I will first use Goffman’s principles of frame analysis to systematically categorize and compare the data presented in the thick descriptions. This analysis will then be used to address each of the three research questions. The final section will discuss the theoretical and practical implications and the limitations of this research.

Frame Analysis of the Race for the Cure

Primary Frames

The Race for the Cure at its most basic level, exists as a social framework. The Race is a very human, organized, purposeful response to breast cancer that makes it an obvious fit for this frame as opposed to Goffman’s natural frame, which accounts for purely physical, unmitigated occurrences. Essentially a fundraising event, the Race provides a context for making sense of breast cancer, a context that says: if we work hard together to raise money and awareness, we can find a cure. The idealism inherent in Komens social frame is apparent in the title alone: the word “race” implies a start and a finish, which participants create literally through the secondary frame of a contest, but also create figuratively regarding breast cancer. Brest cancer is the race, there is a finish
and as Koman reminds, “each step is a step closer to the cure.” The “cure” is of course, the ultimate finish line: year after year, race after race, dollar after dollar, we all get a little bit closer to crossing it. As a social frame, the Race for the Cure presents hope and optimism in response to what is ultimately a frustrating and difficult disease.

Secondary Frames

More than merely a fundraiser of course, Komen keys the Race for the Cure in a variety of secondary frames which mask the central purpose in some interesting ways.

Make-believe. At the Race, make-believe provides a secondary frame for understanding breast cancer fundraising in two ways. First, I think that participants are asked to make-believe that they are making a purchase rather than a donation. When a runner/walker hands over a registration fee and in return receives a t-shirt, access to the event, and sponsor handouts, it feels more like an admission fee than a donation. The source of all the Race “perks” is actually the sponsors: knowledge that seems to get lost in the overall excitement of the event.

The second way that the Race is keyed as make-believe has to do with the way that breast cancer is defined. Participants are asked to believe that life returns to normal for the legions of pink-shirted breast cancer survivors. Interestingly, were it not for the very “pinkness” of the survivors, one would be hard pressed to pick them out of the rest of the crowd. At the Race for the Cure, breast cancer survivors look just like all of the other women – they appear to have two breasts, they have hair, they have the energy to walk or run, and they give the appearance of being perfectly healthy. Breast cancer has been simultaneously and paradoxically marked and unmarked, almost made present and
“disappeared” from their persons by prostheses, wigs, and time. In one respect, this make-believe of happy endings is a courageous one. It allows women to be more than a disease and provides permission for others to see life after illness, a return to health, and an image of recovery. For a woman who has experienced breast cancer, this assertion of identity may be a symbolic landmark in her recovery. For her friends and family, it may signify the turning point that will allow them to focus on a future after breast cancer. For women who are currently fighting breast cancer, the ideals of recovery might provide comfort and hope. For other participants, the image of survivorship might make cancer less frightening and alleviate some of the anxiety associated with detection methods.

Cancer is frightening though, and happy endings aren’t always realized. The dark side of this framing is that for every current survivor, countless women have died from breast cancer. Participants and women who have faced breast cancer use their corporeal presence to bear witness to these deceased in interesting ways at the Race for the Cure. These women are memorialized on the “in memory of” signs that walkers and runners wear, but beyond this action, they often are not identified within the context of the Race. Almost eerily, participants pin loved one’s names to their backs and run as if they might escape the pain of their passing. It seems as though they only find themselves confronting the reality of other losses though as they run into a sea of backs and waves of pink signs saturate the visual field. In a sense, there is an unspoken communality among Race participants that respects these losses, but also seems to be moving beyond them.

Contests. The frame of a contest is perhaps the most significant secondary framing that occurs at a Race for the Cure. By pairing a serious social concern with a
light-hearted family event, Komen is able to successfully accomplish the dual purposes of generating awareness while providing entertainment. The 5K run/walk is a brilliant format in a number of ways: it is simple, requires little to no specialized equipment, and it provides enough challenge for athletes, but not so much as to discourage aspiring or non-athletes. Further, it fosters friendly competition: walking and running are individual, not team sports. While there are some participants who compete for the best time, I would argue that more people strive for a personal best rather than an outright win at the Race for the Cure.

_Ceremonial._ Goffman’s definition of a ceremonial frame, “something unlike ordinary activity goes on in them, but what goes on in them is difficult to be sure of” fits the Race for the Cure to a tee. While we can see the elements of make-believe and contests clearly, the ceremonial aspects are a little harder to distinguish. Certainly there are moments that are without a doubt ceremonial: the survivor’s ceremony, and the announcement of race winners, for instance. But it is difficult to explain why the entire event feels ceremonial from start to finish. In part, it seems that participants have developed expectations for these events. Charity runs have become popular fundraisers since Nancy Brinker first launched hers in 1983. The Race for the Cure has become an annual event in many cities and people return to it, tell others about it, and look forward to it year after year. Further, it feels ceremonial because, it is. There’s something quite amazing about being surrounded by Race participants on an early weekend morning and knowing that you share a common interest. Being part of a great parade through the city, everyone uniformed and moving together feels important.
Technical Redoing. Nothing at a Race for the Cure seems to fit Goffman’s definition of technical redoing frame. This frame accounts for strips of activity performed out of their typical context, as in trainings or rehearsals. It is conceivable that prior to the actual Race organizers and participants may engage in this secondary frame in order to prepare. Announcers may rehearse speeches, participants may train for running or walking the 5K. The race itself though is the real deal and while participants may still have individual motives that frame it as something else, collectively it does not qualify as a redoing.

Regrounding. The final key of regrounding is also rarely part of the Race for the Cure. This frame accounts for actors who perform an activity for radically different reasons than the other actors. As such, unless Komen protestors or radical activists caused a significant disruption to the Race, it is generally difficult to determine individual intentions. At the Cleveland Race, there was a high school track team that seemed to be using the Race as a site of regrounding. They were clearly there to train and run a timed race against one another. This was apparent in their apparel, which did not consist of the standard Race t-shirt, instead they wore their team shirts, and in their general attitudes: they had clearly finished the Race well ahead of the majority of participants and afterwards could be seen clustered together talking, comparing times, and making plans for later in the day. This group of teenagers at a breast cancer fundraiser looked generally out of place and I got the impression that they entered whatever races were available in Cleveland, regardless of cause, just to get out and run.
My participation in the Race may also be considered a regrounding. As a researcher, I looked for different things than I would have as a participant. I’m sure there were other participants who attended the Race with more than the sole purpose of supporting the Komen Foundation in mind. Our motives were masked by our ability to blend into the crowd and do what we had come to do without anyone noticing. Other than the high school group then, whatever other instances of regrounding were occurring will remain a mystery.

Performances

Personal fronts. Goffman describes personal fronts as the accomplishment of character that transforms individuals into persons. As each of us works on our own personality, we take on roles in the various frameworks that we encounter. At the Race for the Cure, there are four distinct roles available for adoption to ones personal front. These are: survivor, supporter, volunteer, or underserved.

The personal front of survivor is in many ways assigned by Komen. Survivors are asked to self-identify when they register so that they can be given the pink apparel and number and appropriately honored throughout the event. Their role is to accept the honor, allow themselves to be recognized, serve as a role model, and provide purpose to the event. Time and time again throughout the Race we are reminded that the day is about supporting survivors and ending this disease. In addition, survivors represent medical success. Each woman is living proof that cancer can be beat and reminds us to support the science that will find a cure.
Supporters then, serve an equally important function at the Race. The supporters’ role is to outnumber the survivors and demonstrate how important breast cancer is to everyone, not just those who have been diagnosed. Supporters cheer on survivors, and dedicate their efforts to them with the “in memory of” and “in support of” signs. They are, in a sense, carrying the hopes and dreams of others as they walk or run and willing their effort toward a better future.

The personal front of volunteer includes all of the Komen workers who make the event possible. Because Komen is a non-profit organization, just about every worker you encounter is a volunteer, whether they are taking money behind a registration table, making announcements, or handing out water on the race route, this event would not be possible were it not for the volunteers. The role of volunteers is to help make the event a success. Volunteers don’t run or walk, but they seem to serve a greater good by helping everyone else have a positive experience.

The final presence at a Race for the Cure event can be felt more as a void than as a physical manifestation. This is the ambiguous personal front of the “medically underserved” who are the benefactors of seventy-five percent of a Race’s proceeds. Of course, visually, it is impossible to know who might benefit from educational efforts or screening services paid for through these funds. At the Races in Cleveland and Houston, these efforts are largely absent from recognition. There is no mention of the specific local projects or agencies that have received funds and how they have helped the community. This creates an absent role and it seems that the other participants are encouraged to forget about the final destination of their donation. One would think that at a Race
function, some of the local organizations receiving Komen funds might seek out new volunteers, advertise their services, or create a display of gratitude, but this does not seem to be the case. Unless these organizations come together to re-invest in the Race as survivors, supporters, or volunteers, or unify by wearing “team” shirts, their presence remains an absence. The larger narrative is continually reinforced in this respect. By not facing the ways in which the medical establishment fails certain groups of people, participants are free to continue focusing on the great potential of medicine and place faith in the system.

Performance teams

According to Goffman, a performance team is formed when individuals collaborate to define and sustain the performance of a framework. The Komen Foundation serves as a performance team for much of the breast cancer awareness activity that currently occurs in the U.S., including the Race for the Cure. This organization defines breast cancer awareness through its use of language and symbols and perpetuates the current performance of cure-based, pink-ribboned, shop-for-a-cause type of breast cancer advocacy that is the norm. Clearly, this norm is extremely popular with the breast cancer community, and for good reason. As shown, Komen has been instrumental in making breast cancer an important issue and generating funds. The Foundation leads a performance that is hopeful, active, and optimistic and invites people to participate at any level – be it small or large, time or money. Komen’s message is consistent – on their site, at their races, in their literature, and as carried out by their
sponsors. As a performance team, Komen and its supporters are hugely successful in their accomplishments.

*Information control*

As with any large organization, information management must occur. In this section, I will analyze the way that information is managed at the level of the participant.

*Dark secrets.* Goffman describes dark secrets as information that a team knows and hides because it is in some way contradictory with the public performance. As a participant, nothing at a Race for the Cure event qualifies as a dark secret. Participants are not asked to withhold any information or maintain any sort of secrecy about the event, the organization, or their involvement.

*Strategic secrets.* Strategic secrets are also almost nonexistent at a Race for the Cure. The only way these might be present would be if the Komen Foundation made an announcement about an upcoming campaign or offered a preview of a new event or product. It would also be conceivable that a sponsor would use the event to promote a new product and offer demonstrations or samples to participants. Granted, any information provided in these forms would barely qualify as strategic, as Komen or a sponsor would be counting on participants to disseminate the information rather than conceal it. In this case, it would be best described as privileged information strategically provided to a specific consumer group. Because such information would still be withheld from the general public, it still qualifies as a strategic secret.

*Inside secrets.* This is the information that makes you a group insider and Komen works hard to make Race participants feel included and important. Before the Race in
Houston and the one in Cleveland, I was provided with a great deal of inside secrets: I was given a copy of the schedule of events for the day, a map of the race route, a list of sponsors, a newsletter from the local Komen affiliate, and of course my official Race t-shirt, number, and signs to memorialize or dedicate my efforts. In many ways, all one needs to become a member of the group is knowledge of the Race for the Cure and registration, aside from showing up at the correct time and place, Komen will take care of the rest. Granted, it was clear at both Races that some participants had more inside information than others. This could be seen in the way that people had modified their t-shirts to include additional embellishments such as fringe, painted-on names, or computer-generated dedication or memorial signs – efforts only someone who had attended a Race before might think to make or tell others about. Participants who were familiar with the format of a fitness run/walk were also subject to more inside secrets – especially if they were there to run - as they knew where and when to line up and just how to tie the timing chip to a shoe. Levels of inside secrets may have varied, but by virtue of attendance and affiliation, everyone who was present qualified as an insider.

Entrusted secrets. These are secrets that we learn about other teams, but are obligated to keep hidden based on ones relationship to the other team. As a participant at a Race for the Cure event, there is almost no information available that has not been provided or in some way sanctioned by Komen. Even when outside information is present, for instance if a participant were to bring information from another organization, it would not be considered entrusted as it still counts as public knowledge. Since
participants are never asked to conceal information gained at a Race, it is difficult to find anything that fits into this category.

*Free secrets.* Free secrets are information about another team that does constitute public knowledge, so one is not obligated to withhold it or conceal it. Information about sponsors and Race partners may be considered free secrets. Many organizations also offer a free secret when they print their own event-specific t-shirts for a team of employees who attend the Race. These organizations very purposefully pair their name and logo with Komen’s to benefit from the association that comes from being paired with a popular good cause: it’s a free secret that they very much want to share. Spectators of the Race for the Cure are also subject to a free secret – the knowledge of what occurs during a Race event, and the knowledge of just how many people it draws. Its awareness that Komen counts on: a free secret this large will hopefully entice spectators to become insiders in the following years and learn what the Race is really all about.

Frame Analysis of the National Breast Cancer Coalition Conference

*Primary Frames*

The National Breast Cancer Coalition Conference is best categorized as a social frame guided by human motive and intent, rather than a natural frame which describes events that are entirely unguided. The intent of this event is twofold: to educate its membership, and to lobby for increased funding and resources on behalf of the breast cancer community. The Coalition stays true to these intentions almost without fail. As an umbrella organization formed when groups with common interests and goals decided to join efforts, the NBCC was formed with a clear purpose and with an immediately existing
base of support. Perhaps because the NBCC did not have to initially concern itself with attracting membership, the Coalition was able to focus more attention on the agreed upon goals of education and lobbying rather than marketing and publicity. With membership in place and a determined focus, the NBCC has had to rely on very few secondary frames to vary the meaning of its original and enduring purpose. That being said, there are always variations of meaning and understanding among the membership of any organization, including the NBCC and this provides some interesting secondary frames at the participant level.

Secondary Frames

*Make-believe.* Goffman defines make-believe as a secondary frame based on an imitation or dramatic staging of an actual event. From my experience at the Conference, the NBCC and its membership work hard to avoid any sort of imitation of reality. The conference is a very serious event and anything that would fall into this category would have been seen as a waste of time and energy. Since most of the attendees had experienced breast cancer first hand and had intimate knowledge of the reality, they had little patience for make-believe of any sort.

*Contests.* This frame accounts for controlled aggression based on a framework of fighting. At the Conference, there were two topics that seemed to always be framed as a contest: the NBCC’s relationship with Komen, and the public’s relationship with the medical industry.

Discussion regarding NBCC’s relationship with Komen manifested itself in some interesting ways. Among the attendees, there seemed to be a general attitude of
acceptance for Komen. One attendee even commented that she didn’t know why we couldn’t work together with them more. If provoked however, attendees would not hesitate to adopt an “us versus them” attitude and quickly find fault with Komen’s practices. Panelists would only need to drop a hint of disdain for a Race for the Cure, a pink ribbon, or a Yoplait yogurt lid to generate a collective scoff and much head shaking from the audience. I saw this happen more than once, but only develop into an actual discussion a few times. Once, during a panel entitled, “How Activists Can Shape the Story” which focused on how to handle interviews with reporters, an attendee noted that the media most often seeks out a Komen representative for a breast cancer related interview and wondered how members of alternative organizations like the NBCC could ever be recognized. This generated a brief conversation on how often attendees have seen a Komen bias in the media’s breast cancer coverage and how often it didn’t present an entirely accurate truth. The best advice the panelist could provide was to build relationships with local reporters and let them know that you are always ready to talk.

The second time Komen was mentioned and then developed into an actual topic of discussion was during the “Not Just Ribbons: Accountability and Ethics in Fundraising” plenary session that I highlighted in my ethnographic data. During this session, the contest framework was used again and again to describe the relationship between the NBCC and Komen, and the favoritism given to Komen because of their marketing and popularity with sponsors. When it was all said and done, the underlying message was one of pride and determined entitlement.
The second topic that was frequently keyed as a contest was the public’s relationship with the medical industry. The key players would vary depending on the context being discussed. During my first dinner with the Ohio attendees, the focus was on one woman’s struggle with her doctors – and each woman had a story of struggle. During the panel sessions like, “The Long Island Breast Cancer Study Project: Where Do We Go from Here?” the focus was initially victims versus industrial pollution, but quickly moved to victims versus insurance companies and medical establishments that failed to help when necessary. During a very charged plenary session, “The Politics of Healthcare for All,” the primary focus of the discussion was about the public’s access to quality healthcare and pitted un- and under-insured citizens against government sponsored healthcare programs, insurance companies, medical research, and access to treatment. This same issue is reflected in NBCC’s first legislative priority: “Guaranteed access to quality healthcare for all.” Every time this contest frame emerged, it was also framed as an uphill battle in which the ill always find themselves slipping back down. In the stories told by the women from Ohio, they had persevered due to persistence and intellect and had become NBCC members to fight for a better future. In the panel sessions, the victims were afraid of their fate befalling somebody else and wanted to make sure that harmful practices were halted and past and future victims would be ensured compensation. In the plenary session, the battle was one that NBCC members could win with their votes, as the focus was on the upcoming 2004 presidential election. The attendees clearly had a sense of the power behind numbers and that their strength in any contest was greater when working together rather than individually.
Ceremonial. The frame of a ceremony is often used to mark important life events, and at the NBCC Conference, each morning began with one such marking. Each day began with a continental breakfast and a large plenary session. As we all quietly finished our morning coffee and prepared for the speakers to begin, before any other announcements were made, members of the NBCC Board of Directors would ask for a moment of silence for one or two specific members who had died of breast cancer during the previous year. One morning, the woman being remembered, Edith Dudley, had been a part of the Cincinnati group that I was sitting with. Edith had reluctantly told her story of being under-insured and diagnosed with breast cancer to both a local newspaper and at a later press conference and had been instrumental in getting the Breast and Cervical Cancer Treatment Act Bill passed in Ohio. Several of the women from the Cincinnati group smiled and grew teary as Edith’s story was told again and as photographs of her were displayed on the screen at the front of the room. They later told me that she had been quite nervous about speaking in public and as an African American woman, she felt pressure from her community to keep her cancer hidden, sharing her story publicly was a difficult decision for her. Sadly, they also told me that she had died just days before the Bill had passed. The woman who told me this grew teary just recalling the heartbreak of not being able to tell Edith how important her contribution was for other women in Ohio.

The ceremony then, offers a way for the conference to memorialize specific women who have passed away and account for the absences that will naturally befall a group so intimately connected to their cause. In this way, the ceremony serves as a sobering reminder of the collective purpose, as well as an inspiration to carry on the work
that these women had participated in and hopefully ensure a future of fewer goodbyes like these.

Technical Redoing. A technical redoing is keyed when an actual strip of activity is performed outside of its normal context. At the Conference, several events constituted this frame. Preparing for the lobby day qualifies as one instance. To prepare, attendees who served as Team Leaders were required to attend extra meetings to rehearse their presentations and receive feedback from one another. A few sessions also offered opportunities to practice a skill, for instance the session entitled, “How Activists Can Shape the Story” provided information on giving media interviews and attendees were invited to stay after to ask questions, and set up times to work together later or talk more about how to hone their individual skills. The large plenary session, “The Politics of Health Care for All” provided an opportunity to begin evaluating political messages well in advance of the election in which they would be pertinent which provided attendees with some practice weighing the issues and the campaigns of future candidates. Finally, the entire conference serves as a technical redoing in that it is the gathering point for representatives from all 50 states and several countries other than the United States. The attendees are expected to act as delegates and not only represent their home constituent at the conference and lobby day, but to report back to them on the experience as well. Many times, we were offered extra copies of handouts to take back with us, or the opportunity to purchase recorded sessions to share with a group back home. Judging by the number of participants who did collect resources for others, the representative role was taken quite seriously. Attendance at the Conference for some then, equaled an opportunity to gain
and practice understanding the knowledge available at the conference before returning home and reporting to the rest of the group.

Regrounding. In this frame, an individual performs an activity for motives far different than other participants. As a researcher, I again found myself to be of dual mind as an activist/academic and wanting to serve both the community I was engaged in, as well as my own work. Interestingly, I found that I was not the only person in this position at the conference. As people heard about my work and began making connections, it did not take long before I was told that there were other academics at the conference. Eventually I was able to track down and meet Karen Kedrowski and Marilyn Stine Sarow, professors of political science and mass communication, respectively. Both were from Winthrop University in South Carolina. We talked some about their book project and I told them about my research. Perhaps it was the unexpectedness of running into a colleague (however distant) while in the field that made conversation awkward. After our initial conversation, we didn’t seek out one another again.

Personal fronts

Goffman describes us as having a frontstage and backstage persona. At the NBCC Conference, I felt that I was always backstage. Attendees were bonded by the common knowledge or experience of breast cancer and readily assumed that everyone present was a part of this connection. It wasn’t until one windy afternoon walk to lunch when I fully understood this. As my hair blew into my eyes I made a comment about how since I’d started growing it out, my hair was starting to become a nuisance. The woman I was walking with asked how long ago I’d finished my chemo. As I quickly corrected her
assumption I realized that the Conference feels like a backstage environment because for
the women who attend, it is: they can talk about their cancer experience openly and
assume that others will understand because most of the time, they will. The personal front
of survivor is certainly the most prevalent and significant one present at the NBCC
Conference. The role of survivors is to educate themselves, ensure that they are heard at
decision-making events, and fight for change. These are women who told me that they
want to take an active role in changing the system that they faced during their experience
with breast cancer.

The second most prominent role performed at the Conference is that of activist.
As I noted in my ethnographic account, when survivors were asked to stand during a
plenary session, only about half the women in the room stood up. Of those that remained
seated, some may have been survivors unwilling or unable to stand, but most fell into the
category of activist. These women, like the oncology nurse, and the young woman who
had tested positive for BRCA1 and 2, were at the Conference because of their connection
to the breast cancer community and their interest in creating change for the good of
themselves as well as others. As opposed to survivors, who had often felt medical
injustice in the past, these women foresaw a future of medical injustice and were equally
invested in lobbying for better resources in the future. When lobbying, the urgency and
passion of activists provided the perfect compliment to the survivor’s stories and
experiences and often created an incredibly moving presentation.

Experts create the third presence at the Conference. As guest speakers, experts
may be scientists, doctors, journalists, politicians, administrators, researchers, or activists.
These individuals were often the center of attention for their session and a source of much interest afterward. Many chose to stay beyond their professional obligation and attend other events at the conference, and engage in conversation with attendees. The role of the experts was to provide high-level information about their study or profession for attendees. They often spoke quickly, technically, and passionately – in fact, there were a few scientists that presented information that I had a hard time following due to the specialized language and specificity of the material. Looking around at other attendees revealed that I was often alone in my lack of comprehension as others nodded, took notes, and asked questions. Attendees were thrilled to partake of such cutting edge information and eager to report back to home delegations with this new knowledge.

The final role at the Conference was that of researcher. At an event like this, it would be unethical and near impossible to pose as anything else, and so I willingly made my reasons for attending clear. Finding two other researchers at the Conference was surprising, but also legitimating for all of us. Instead of banding together as our own subgroup, we remained separate, which allowed me to spend time with the group from Cincinnati and to witness the Conference from as much of a participant perspective as I could.

Performance teams

Together, all of the different categories of personal fronts collaborate to create the performance team that is the NBCC. As a performance team, the NBCC helps to create and sustain a definition of breast cancer for its constituency and for the rest of the United States. This performance defines breast cancer as a disease that has preventable causes.
By examining why cancer forms, we can take measure to stop it before it starts. While the NBCC would agree that we still need to pursue a cure for cancer, they also insist that we can minimize our need for it through the science of prevention. This definition is performed for NBCC constituents and the legislative and scientific communities. Rather than attempting to reach the entire U.S. public, the NBCC has focused its efforts on gaining the attention of a small audience with enormous resources rather than an enormous audience with minimal resources. This strategy has served them well, as they are a highly respected lobbyist organization and have seen great successes.

Information control

All organizations require information to be managed throughout its levels of membership. The NBCC manages information across a network of smaller regional groups all connected to a central office in Washington D.C. At the Conference, participants are typically well aware of current NBCC announcements and projects and attend to continue to learn about and participate in organizational goals.

Dark secrets. Dark secrets are those that a performance team hides because they conflict with the self-image of the group. As a participant, I did not come across any such information. Given the NBCC’s commitment to ethics and their overall cause, I would be quite surprised to learn of anything that would constitute a dark secret.

Strategic secrets. Strategic secrets are intended to be contained within the team to prevent early adoption by the general public. We were entrusted with two strategic secrets while at the Conference. First, the “Not Just Ribbons” campaign was officially
launched at the Conference – the NBCC’s first national publicity campaign. We received
a glossy press-release type of announcement that explained:

The campaign includes three print ads, which will appear in national publications,
and two on-air PSAs featuring well-known celebrities, which will air on cable.
The print campaign uses various symbols of power and strength, including a
bulldozer, tool belt and hardhat to communicate NBCC’s message that “pushing
in the right direction,” “using all the tools at our disposal” and “working
relentlessly” are the most effective means to stopping breast cancer. (2003b)

Although we were told at approximately the same time as the general public, the
information felt like a privilege since we received the official press release and were able
to see all the ads at once instead of waiting to discover them in a magazine.

The second strategic secret we were entrusted with was research findings. Many
of the researchers who served as panelists were engaged in long-term research and some
had not yet published the final findings. We were entrusted with preliminary findings and
knowledge not yet available to the general public or research community. Often,
researchers would give us a timeline as to when findings might become public, and in
some cases when we would be able to expect to see something like a new medication or
treatment become available. This type of secret was always exciting because it
demonstrated the respect that the scientific community has for the NBCC and it’s
members.

*Inside secrets.* To be an insider at the NBCC Conference, there was a minimum
level of information, or secrets, that an attendee was required to be familiar with. Among
the general membership, there was an expectation that everyone would have a fairly thorough understanding of the science and experience of breast cancer. This was especially true for me – as a young academic, I felt tested on several occasions during the first few days as to how much I knew and how serious I was about my subject matter. For example, the other attendees I talked to would casually abbreviate the names of drugs used for chemotherapy, or refer to a specific piece of legislation like the Breast and Cervical Cancer Treatment Act to see if I knew what they were talking about or not. On most occasions I was very familiar and was able to engage in a good conversation on the topics that were thrown at me. On the occasions when I wasn’t entirely knowledgeable, I knew enough to admit my ignorance and ask for more information. Sincerity is almost always a better strategy than arrogance, and is especially so at the NBCC Conference.

Other than possessing a working vocabulary and understanding of breast cancer, the information that made an individual an insider consisted of general Conference knowledge. Being aware of the days events, or having opinions on speakers or the legislative priorities provided a social bond.

Entrusted secrets. Entrusted secrets include the stories that we tell to others based on trust and a mutual understanding that what we share will not be repeated to others. While Goffman discusses this type of secret as being between teams, it may also be used to describe information between individuals, as is the case at the Conference. Of course, some of the information that was shared with us strategically – like when scientists told us about research in progress – qualifies as entrusted information, more often attendees entrusted one another with secrets of their own. The twelve women who welcomed me
into their group for dinner on the first night entrusted me with their stories, as did others throughout the Conference. Everyone had a story and attendees were amazingly respectful about keeping each other’s secrets and refraining from gossip. Perhaps because there existed a commonality of understanding regarding the breast cancer experience, or the fact that these women were far more interested in getting their political work accomplished, that trust was maintained and stories were not re-told outside the group.

_Free secrets._ Finally, free secrets are those that we learn about others whether we know that person or team or not. Free secrets at the Conference were readily available: Organizational alliances for example were apparent merely by virtue of observation: groups like Avon Corporation, National Cancer Institute, Gay Men’s Health Crisis, Inc., and Silent Spring Institute sent representatives to the Conference to serve on panels and attend the sessions. Their presence indicates an alliance and belies an interesting network of like-minded organizations building relationships with NBCC. Conference presence was as telling as conference absence. The absence of pink and casual disdain for all things Komen made it apparent that their presence would not be welcome in this environment, a secret that the NBCC was freely sharing.

Interpreting Results

_Dramaturgical analysis_, as described by Goffman, aids a researcher with the sorting out and determination of, “the techniques of impression management employed in a given establishment, the principle problems of impression management in the establishment, and the identity and interrelationships of the several performance teams which operate in the establishment” (p. 240). In other words, Goffman’s narrative
paradigm offers a lens that allows us to see how a narrative is performed. Having applied this lens and identified the different features of the narratives performed by Komen Foundation and the NBCC, it is time to return to the initial questions that launched this study and address how each may now be answered.

Q1: How do the Susan G. Komen Breast Cancer Foundation and the National Breast Cancer Coalition perform a narrative of breast cancer at their respective events? The dramaturgical analysis demonstrates quite clearly that both organizations accomplish their performances by presenting specifically defined frames to their members and by carefully managing information at and about their events. The analysis also highlights the different strategies that Komen and the NBCC employ in their performances, which I will discuss further:

The Komen Foundation uses the Race for the Cure to reframe both its organizational purpose and breast cancer as make-believe contests – a blending of the two most prevalent frames at a Race event. Through this secondary framing, a fundraiser becomes a race and a disease becomes an enemy to fight. Komen casts its narrative with survivors and supporters and provides them with the costumes to create a strikingly pink presence. Presence, in this case, is all that is required of cast members. To Komen, it seems physical presence is valued above mental presence. Essentially, it doesn’t matter what a participant does with the rest of the day, week, month, or year for that matter: contributing economically and physically at an annual Race event yields the appropriate public impression of enormous concern, awareness, and effort and maintains Komen’s position as the most widely recognized non-profit breast cancer organization in the U.S.
Komen performs a narrative of breast cancer that if told by an individual, would fit Arthur Frank’s definition of a restitution narrative. Since Komen as an organization presents a unified front to the public and maintains a single narrative of itself, it is appropriate to examine it with Frank’s categories even though scholars normally reserve these labels for individual narratives. The restitution narrative envisions the self as temporarily interrupted by disease and anticipates a full recovery and complete return to the pre-illness self in the future (p. 77). Komen reinforces this narrative both linguistically and symbolically at a Race for the Cure.

Linguistically, Komen performs a restitution narrative by framing breast cancer with words like, “survivor” and “cure.” These are not arbitrary word choices – they are deeply reflective of Komen’s mission and goals: to eradicate breast cancer as a life threatening illness. Komen envisions itself as the hero in this narrative: given enough money, time, and social support, a cure for cancer will be found, and Komen will back the science that says it’s possible. This is a lofty and ambitious role for Komen to take on, it is also the only role that Komen is willing to take on. Searching for a cure is noble, honorable, and politically neutral which makes it an easy choice for corporate America to ally with. It is simple, optimistic, and at times make-believe, which generates enormous popular support from a public that will happily support an apparent good cause and may need a positive outlet for the heartbreaking realities of cancer.

Komen also performs restitution in a symbolic manner. The Race for the Cure alone is highly symbolic of a return to a normal pre-illness self. It tells survivors that they are healthy and should be out walking or running. On one hand, this is a fantastic
message to provide for cancer survivors: exercise is healthy, walking is a moderate activity that will not over-tax a healing body, and spending time in fresh air celebrating with friends and family is certainly time well spent. The Race and its combination of physical activity, positive energy, and simple accomplishments make you feel good in the end. On the other hand, not all cancer survivors are physically or mentally capable of participating in a race. This symbol may also serve to alienate segments of the cancer community that it seeks to support. Surgery, chemotherapy, and radiation are enormously taxing on a body and often contribute to a weakened immune system, physical weakness, and fatigue – and in no state to attend a very public 5K run/walk. A few women at the NBCC Conference scoffed at the idea of walking in a 5K when I asked if they also supported Komen. When I asked for an explanation, one woman said that she had attended a Race for the Cure after finishing her treatment and she felt so uncomfortable and conspicuous that she never wanted to go again. As I noted in my ethnographic data, most women wearing pink at a Race appeared to have two breasts, indicating that their treatments have been breast conserving, or they have opted for reconstruction, or have chosen to wear a prosthesis. Just as it alienates women physically, the Race can also serve as a symbol of restitution that alienates women who are uncomfortable with their post-treatment bodies. The Race tells survivors to look “normal,” act “normal” and before you know it you’ll be back to “normal” when that simply isn’t the case for everyone.

Perhaps more powerful than the Race itself, is Komens famed pink ribbon. Pezzullo coined the term “pinkwashing” to describe the effect that the pink ribbon has had on breast cancer. She likens it to the greenwashing that occurs when people,
organizations, or groups purport to have an environmental agenda when in reality continues to participate in harmful practices or activities and do little to actually create the change that they market (2003). The pinkwashing of breast cancer has had the same effect: Komen as an organization talks a great deal about women but fails to actually empower them. Instead of knowledge or an opportunity to participate in political or policy-changing action, women are given t-shirts and a free breakfast at a Race for the Cure. Komen is also happy to share the pink ribbon with corporations like Ford Motor Company, regardless of the carcinogenic toxins created by automotive exhaust; AstraZeneca, a pharmaceutical company who produces some of the most popularly prescribed chemotherapy drugs; as well as a host of other corporations who benefit either from this disease or from the positive association. These relationships fuel the monetary fire, but do little to change the current status of breast cancer. Fitting with the restitution narrative, Komen tells women that change is not for you to worry about, give money to medical researchers because that is their job, your job is to wear this pink shirt and feel good about yourself.

Komen’s pinkwashing of breast cancer linguistically and symbolically frames cancer in a manner that perpetuates the “it will all be okay” attitude of the restitution narrative. For better or worse, this has been an enormously popular strategy that has paid off well for Komen.

The National Breast Cancer Coalition on the other hand, uses an entirely opposite strategy to find success for their cause. The NBCC does little to mask its primary social frame as an educational lobbyist group. Even at its annual conference, or perhaps
especially at its annual conference, education and lobbying are the primary focus. To achieve this, the NBCC casts its performance with survivors, activists, and expert speakers and manages information in such a way that attendees work hard to learn as much as possible and make as big of an impact as they can when lobby day comes.

The organizational narrative performed by the NBCC would be categorized as a quest narrative according to Frank’s categories of illness narratives. Those who frame illness as a quest use their experience towards a higher purpose, they seek to invoke change and to influence others (p. 115). Unlike the restitution narrative told by Komen, the NBCC’s quest narrative accepts that life is different after breast cancer and uses that personal change as a source of strength and ambition to learn more and fight harder.

The metaphor of a quest can be observed in several aspects of the NBCCs narrative performance. To begin with, the Conference itself is a quest for most attendees. Representatives from NBCC affiliates across the country and around the globe engage in a pilgrimage-like quest towards Washington DC once a year for this event. Some of the women I talked to told me that women will come even if their health is not at its best: they simply wouldn’t dream of missing out on the Conference and the Lobby Day. These women recognize that their intellectual presence matters just as much as their physical presence and choose to use both to make an impact.

The Conference is also a quest for knowledge. As I described in my ethnographic data, many attendees are charged with the responsibility of reporting back to a home group. The NBCC helps attendees perform this duty of their quest by providing expert speakers, plenty of accompanying materials packaged in three-ring binders or CD-ROM,
and recordings of sessions. Breast cancer at the NBCC Conference is not as much an enemy as it is a mystery or a puzzle to be solved by learning more, studying harder, and investigating further. Attendees quickly discover that their role in ending breast cancer is to understand as much about it as possible and to put this knowledge to use. Unlike Komen, the NBCC does not hand decision-making authority back to the medical community, instead, NBCC advocates fight for the knowledge that will result in respect and the right to be at the table when decisions get made and money gets handed out.

The NBCC also frames Lobby Day as a quest. It is prepared and planned for, it becomes legend as lobby days of years past are seen in photographs and discussed by members who were there. It serves as the high point of the entire weekend – the journey to Capitol Hill to tell our elected officials what we need from them this term.

The NBCC does not pinkwash breast cancer, in fact, it vehemently opposes such practices and works to empower women rather than please corporate friends. Empowerment is a big responsibility and the women at the NBCC Conference do not take it lightly. They seem to recognize that their interest to do more, their need to fulfill a personal quest, is not the norm. They know that not everyone is capable of activist level effort and so they work even harder to make their contribution meaningful and impactful.

When asked to compare the narrative performances of Komen and the NBCC, I find that I always return to the same metaphor that helped me to initially make sense of the similarities and differences between these two organizations. Komen and the NBCC exist as two sides of the same coin: bound by a common interest in ending breast cancer, yet separated by nearly opposite strategies. As a coin cannot be one-sided, neither can
breast cancer awareness or activism: each organization needs the other as a counterbalance. Not everyone can be an activist, some people need to participate at the level of awareness and feel good about that effort. Correspondingly, not everyone is satisfied with mere awareness. Some feel a need to do more than donate, shop, or show up. For these people, there is the NBCC and a chance to learn and actively participate as an agent of change. Having participated in both events and read a great deal about breast cancer politics, its occasionally difficult for me to appreciate the Komen Foundation, as their popularity overshadows the work of the NBCC. Its easy to forget that Komen was the first nonprofit breast cancer organization to successfully emerge and their work to make breast cancer a popular cause may make the NBCCs work easier: they don’t have to explain to the public why breast cancer is important, we already know. By that same token, Komen may also make it more difficult, as it may appear that plenty is already being done for breast cancer – why do more?

So, given their differences, could these two organizations ever collaborate their performances for mutual benefit? Initially, I thought maybe they could, but the more I examined their position within cultural and historical context of breast cancer – the topic of my second research question, the more I realized that the answer is no.

Q2: How are these performed narratives shaped by the cultural and historical context of breast cancer awareness in the United States?

Breast cancer politics were divided long before Komen and the NBCC arrived on the scene to help us delineate different sides. Throughout the history of breast cancer in America, there exists a continual struggle between physicians and laypeople when it
comes to owning the knowledge surrounding this disease. Komen and the NBCC reflect and in many ways, emerged from these competing traditions: Komen reflecting the physicians and a biomedical approach to health; NBCC reflecting laypeople and alternative practitioners of health and wellbeing. To further explain, I’ll discuss each tradition in detail and describe how Komen and the NBCC fit into the historical landscape.

The biomedical tradition has historically been dominated by physicians: we can trace the emergence of this back to 1847 when physicians rallied against the Popular Health Movement and formed the American Medical Association (Weisman, 1998). The AMA excluded women and alternative practitioners and provided an organization in which knowledge could be contained and dominated by its members. Granted, many organizations form to share specialized knowledge and advance their field and this process undoubtedly served the medical community well in providing continually improved care for their patients. My purpose here is not to vilify the AMA, it is merely to point out that actions have consequences and in this case, the act of forming and excluding certain categories of practitioners led to them also excluding the knowledge that these groups possessed: knowledge that may have contributed to different advancements in women’s health and cancer care.

By claiming control of medical knowledge and practice, the AMA also claimed responsibility for the treatment of difficult diseases like breast cancer. As the reality of treating a disease with no cure became realized, specialists that normally focus on women’s health, like gynecology, passed on concerns of breast health. Consequently,
surgeons emerged as the only ones willing to take on breast cancer – and their solution was to cut it out. Thus, Halsted’s radical mastectomy remained the treatment of choice until the 1970s.

The biomedical tradition is also responsible for forming the American Society for the Control of Cancer, later to be known as the American Cancer Society (ACS). When this organization was formed in 1913 by a group of surgeons, physicians, gynecologists and laypeople, it began disseminating messages that supported the recommendations of the AMA and urged women to trust their physicians. Early ACS campaigns relied heavily on fear appeals and even convinced women to deliver these messages to other women by means of the Women’s Field Army - initially a powerful tool of the biomedical tradition, but I will argue eventually shifted to be an early example of the movement formed by laypersons.

The AMA and ACS have continued to maintain their hold on knowledge and use of fear appeals to assert their control over breast cancer care. One powerful example of this is the endorsement of both organizations of breast self examinations – a practice that even when new had admitted shortcomings. That these organizations would so readily and heartily accept and promote a health practice with absolutely no scientific backing is truly amazing.

It is this biomedical tradition that I believe gave birth to the Komen Foundation. Like the AMA and ACS, Komen also places great faith in physicians and science. Komen does not question that medical knowledge should be the domain of physicians and therefore does little to encourage its followers to question or challenge the medical status
Yes, Komen actively funnels money into advancing the status quo, but does so in a way that stays the course we are already on rather than suggesting new paths might be forged. In some ways, this strategy is a smart one – Komen recognizes that not everyone possesses the specialized knowledge that medical researchers do and as a result chooses to hand over the resources and stay out of the way. There’s certainly nothing wrong with this strategy and to Komen’s credit, resources and money are only handed over after extensive review processes that include the advice of medical experts.

In keeping with this tradition, Komen also uses veiled fear appeals in its self-marketing. The story of Susan G. Komen and her sister, Nancy Brinker is a prime example. This story tells us Susan didn’t know about early detection methods like breast self examination and she died. Nancy did know about early detection and she lived. If you don’t do breast self examinations, you are risking your own life. Komen’s use of the word, “cure” also constitutes a fear appeal: to not support Komen in an objective so pure and desirable would be shameful, so of course we are willing to purchase nearly anything with a pink ribbon on it. Komen has quite effectively carried on the domination started by physicians long ago and has become a voice and advocate for this breast cancer tradition.

On the other hand, there is the tradition of the laypeople and alternative practitioners. This tradition was formed by the people who were excluded from membership in the AMA: the herbalists, bonesetters, Hydropathologists, homeopaths, botanists, and midwives – and all women. These alternative practitioners sought to popularize medical knowledge and prevent it from becoming the sole domain of physicians they considered to be elitist (Weisman, 1998). I do not consider it coincidence
that as women’s health was taken from the hands of women and claimed by the men of
the AMA, many of the organizations who opposed this were formed almost exclusively
of women. For example, the Women’s Field Army, initially the pride of the ACS, quickly
became a concern to all-male AMA. As women began talking to women, questions
formed, challenges were raised, and with these women’s support the National Cancer
Institute Act was passed in 1937 (Altman, 1996). With the government now involved in
medical research, the women of the Women’s Field Army had effectively pulled a little
bit of knowledge back from the control of the AMA.

In 1952, another group of powerful women began talking to one another with the
formation of Reach to Recovery (Olson, 2002). Women who had experienced recovery
from a mastectomy went to hospital rooms to talk to other women who were just
beginning their recovery. Physicians claimed Reach to Recovery volunteers interfered
with the doctor-patient relationship, but women persisted and continued to reach out to
one another, popularize the knowledge of healing, and become activists for one another.

In the 1970s, the Women’s Health Movements took on breast cancer as part of
their overall effort to reclaim a woman’s control over her own body and reproductive
health (Leopold, 1999). Reclaiming control means reclaiming knowledge and actively
investigating and restructuring information so that it may become popularized. The
Boston Women’s Health Book Collective took on this task in publishing Our Bodies,
Ourselves, and activists like Rose Kushner worked to both translate the technical
language of the medical industry for others, as well as learn it well enough to infiltrate
and effectively influence the medical community (Leopold, 1999; Lerner, 2001). Her
wok was so influential that it inspired the formation of the NBCC, an organization that has carried on her powerful example that education is the way to build a bridge between medicine and laypersons.

The NBCC emerged as a direct result of these earlier layperson/alternative movements and has maintained the values that characterized this tradition. The NBCC fights to popularize medical knowledge not just so that it is widely accessible, but also so that there is a transparency in place for medical research. Transparency is important not because the NBCC lacks trust in researchers, but because they believe that we can accomplish more by pooling our intellect rather than partitioning it. The NBCC might argue that diversity of experience and perspective make for good decision making, and rather than asking researchers to translate their work to laypeople, the NBCC will help laypeople to learn the language they need to understand and make meaningful contributions to researchers.

In addition to popularizing knowledge, the NBCC also reflects this tradition’s interest in challenging our thinking. This is evident in this organization’s interest in cause related research rather than only cure based research. In this respect the NBCC chooses to promote messages of empowerment rather than fear. A focus on the causes of breast cancer reassures women that breast cancer is not always preventable or detectable at the individual level. NBCC’s official position against breast self examination is reflective of this: until better tools are available, this organization will not accept an unreliable or unproven method.
Finally, to return to my claim that Komen and the NBCC face an unlikely relationship in the future. My assertion is based on the historical and cultural traditions that gave birth to these organizations. Between physicians and laypeople there has been a system that required checks and balances. Occasionally the sides butt heads, on other occasions they work together – either way, these traditions look after each other: the medical community continues to strive to provide better care and has a great deal of support in that mission. Laypeople continue to demand the best care and find ways to challenge and assist the medical community in the provision of that care. Komen and the NBCC work in the same fashion – working towards the same goal from different sides. Separately, these organizations may do more work to spur one another on and assist in the checking and balancing of these sides. Working together, I fear that one voice may be subsumed by the other and we will lose half of the system that has accomplished and provided as much as it has.

Q3: How do these performed narratives shape current breast cancer awareness in the United States?

Komen and the NBCC shape our awareness of breast cancer by providing the primary frameworks through which we understand this disease. The narratives that these organizations perform at their events shape our knowledge and understanding of breast cancer and consequently influence our experiences with breast cancer. As reflections of their historical and cultural roots, Komen and the NBCC offer the public two frameworks from which to choose: awareness or activism.
Komen’s performed narrative offers the public breast cancer awareness. Through events like the Race for the Cure, Komen helps supporters meet their personal needs and feel good about being aware and making a small investment of time and money toward this illness. At a Race event, I felt like I was seeing the frontstage, as Goffman might say, of the breast cancer performance: it is pretty, happy, and all tied up in a big pink ribbon.

The NBCC’s performed narrative offers the public breast cancer activism. Their events and conferences promote societal rather than personal needs. Instead of making you feel happy, often the information you receive makes you feel angry and inspires effort and energy to enact change. At the NBCC conference, I felt like I was seeing breast cancer from backstage: the political side of things where we forget about campaigns and marketing and get down to the business of making real decisions that have real consequences.

Goffman’s frontstage/backstage metaphor works well for understanding the impact of these two organizations because I believe that they have had an equal impact in shaping the current state of breast cancer awareness in the US. While the spotlight seems to shine most often on Komen and all of their media campaigns and activities, the NBCC has been a powerful force behind the scenes influencing and shaping public policy. A return to the original frame analysis that was used to differentiate these organizations now seems necessary to continue exploring and comparing the strategies that continue to divide the narrative efforts of Komen and the NBCC.
Primary frames

Both Komen and the NBCC frame their events as social, intentional occasions. Both organizations rely on the social nature of its membership, and a predominantly female membership at that, to spread their messages and amass support. Like the Women’s Field Army, Komen and the NBCC encourage women to talk to other women to popularize their cause. While the messages they deliver may differ, their strategies are similar.

Secondary frames

Make-believe. For the NBCC, make believe is a frame that is very intentionally and carefully guarded against. Any imitation of reality would be frowned upon, whereas at Komen’s Race for the Cure, make-believe is used for a number of purposes: to promote a happy event, to gloss over the realities and the ugliness of breast cancer, and to maintain a sort of status quo with regard to cancer politics. While the NBCC presents a harsh and unfettered reality, Komen presents just the opposite. Consider for a moment the founder of this organization, Nancy Brinker, a woman who used her Neiman Marcus marketing skills to start the Komen Foundation. The way that Brinker sells breast cancer to the public and to corporate sponsors very intentionally capitalizes on the frame of make-believe by offering donors a vision of a better future because of their support. Reality won’t sell, but dreams will.

Contests. When the frame of a contest is employed by an organization, it’s important to ask what we are competing for, against whom, and for what purpose? In the cases of Komen and the NBCC, the answers to these questions are very telling. Both
organizations employ the contest frame to a greater or lesser degree. At the Race for the Cure, there is a clear sense of competition. Participants are not framed as competing against one another, rather they are competing against time. Komen is careful to neutralize the enemy in this case as the inevitable ticking of the clock, a reality against which only perseverance will prevail. This, in contrast to the NBCC who is happy to identify, point fingers at, and name enemies for their members to compete against: environmental pollutants, toxins, government, health care, Komen – the NBCC frames its competition as a power struggle and tells members exactly who to do battle with and how to go about it. They even get them started at the Lobby Day. Much like their rejection of make-believe, their insistence that realities be realized and confronted comes through in the contest that they frame.

These differences between the framed contests of Komen and NBCC are vitally important because they inform participants as to what their role is following the event. After a Race for the Cure, according to Komen, there is no more contest – it’s over until the next year. Unfortunately, given the lack of educational material at a Race, one cannot even make the argument that the competition shifts to a personal one: woman against time and disease. Komen effectively suspends reality and trades knowledge, action, and consequences for donations, t-shirts, and pink ribbons. This is pinkwashing at its finest. The NBCC, on the other hand, sends participants back home feeling like the battle has only just begun. After an Advocacy Conference, attendees have the tools, experience, resources, and practice to go out and keep seeking change and answers. These women are empowered by this event.
Ceremonial. Both Komen and the NBCC use ceremonial framing at their respective events, but to varying degrees. At the NBCC Conference, ceremony was reserved for daily memorials and presented as one part of the day’s events. In contrast, Komen uses the frame of ceremony to the point at which it becomes ritual. As defined by Rothenbuhler (1998), social rituals are characterized by their public, performative, and voluntary nature, as well as an embodied, symbolic, social function. He argues that rituals, like the Race for the Cure, “are often not about what is, but what could be, might be, or ought to be” (p. 15). When perceived as ritualized ceremony, explaining the feelings of being at a Race for the Cure event becomes much easier. Ritualized ceremonies like this are performed based on tradition and expectation, there are norms and rules to be followed and patterns that have been established that warrant respect and reverence. Rothenbuhler explains that rituals are performed by actors, but not authored by them, which leads to a feeling of acceptance rather than a need for change. In this sense, it is the familiarity, and perhaps the comfort that comes with fulfilled expectations, that makes the Race for the Cure feel ceremonial and special. This is one of the most important functions of the Race for the Cure, in its simplicity it provides sanctuary. Ironically, an event that is initially keyed as a contest functions more as ceremony in that participants know there is a predictability built into the Race that ensures a sense of personal safety – you may be asked to walk or run, but you will not be asked to fight today – the ceremony is respite from the normal daily concerns.

Technical Redoing. The frame of technical redoing is less important at the Race for the Cure than it is at the Advocacy Conference, where rehearsal and preparation are
key themes. Conference attendees, in their preparation for the Lobby Day, and their several days of learning are encouraged to practice skills for use beyond the Conference. Attendees leave with skills, but also the materials necessary to use their skills. The giant notebook that I took home had not only a wealth of breast health information, but legislative guides, information on other similar programs, and contact information for every speaker and expert present at the Conference. The Race for the Cure, as ritualized suspension of reality fails to send more than a participatory message home with its runners and walkers. Without the incorporation of educational material, all a participant has after the Race is a t-shirt that serves as participatory evidence and one more way for Komen to advertise their event.

*Regrounding.* This frame is difficult to assess from a strictly observational perspective, and equally so at either event. In terms of my experience at the Race for the Cure and the Advocacy Conference, I was far more anonymous as a researcher at the Race than I was at the Conference, which speaks to the different ways that community is enacted at each event. At a Race for the Cure, community equals presence and little else. Participants are not asked or encouraged to interact beyond the friends that they came with. At the Conference, community equals active engagement. Attendees expect other attendees to interact and socialize and because of this, my regrounding as an activist-academic was something that I felt compelled to immediately disclose.
Performances.

Given the differing frames that make the Race for the Cure and the Advocacy Conference function as they do, it is compelling to examine how participants function within these settings to perform the differing narratives.

Personal fronts. The analysis of personal fronts at Komen and NBCC’s events yielded some interesting variation. To begin with, the Race for the Cure felt like a very frontstage performance – a very costumed, structured, deliberate event. In contrast, the Advocacy Conference felt decidedly backstage – behind-the-scenes, raw, honest, and unscripted. Much of this has to do with the purpose of each event and one can see that purpose and front versus back stage performances are well matched. This is equally apparent in the participant categories that emerged from my thick description. At the Race I saw survivors, supporters, volunteers, and the invisible underserved. At the Advocacy Conference I saw survivors, activists, and experts. While the role of survivor appears at both events, the performance of this role is distinctly different: at the Race, the personal experiences of survivors are publicized, at the Conference these experiences are politicized. Again, the purpose of each event makes this possible, as well as the cast of supporting characters and the roles that they perform in these narratives.

Performance teams

Just as the purpose of each event allows for certain personal fronts to emerge, these fronts also make possible the performance teams that give rise to such purpose. Performance teams sustain a narrative purpose and both Komen and the NBCC have strong and capable teams continuing their success. Based on my experiences, I attribute
much of this to knowing their audiences well: while Komen markets a brief, affordable event for a good cause to the mass public, the NBCC niche markets to the smaller organizations already aligned with NBCC causes. Each organization continues to replicate its membership and sustain, rather than challenge, the narrative that their success has been built on.

Information control

Dark secrets. Almost surprisingly, I didn’t come across any dark secrets for either organization. Given that these sorts of secrets should be closely guarded, this isn’t really that surprising, but at the outset of my research I expected to uncover more sordid or suspicious details about the histories of Komen and the NBCC. Given the divided politics surrounding breast cancer, it seemed like these organizations might not only be in the business of awareness and activism, but also in achieving a monopoly over defining this disease; an interest that would lead to unearthing and airing one another’s dark secrets. Happily, this is not the case. Certainly, there are likely to be things that Komen and the NBCC keep to themselves, but I’d like to hope that the lack of mudslinging means that these organizations, though different, are both respectable and respected in their purposes and practices. I think this is why I have such a hard time siding with one organization over the other: part of the reality of breast cancer awareness in the US is that we have options – and good options – about whom and what we support.

Strategic secrets. There were more opportunities for strategic secrets at the Advocacy Conference than there were at the Race for the Cure. The NBCC shared campaign strategies and researchers shared cutting-edge knowledge with us at the
Conference. At the Race, there was nothing that qualified as privileged information. This is a difference that emerges out of different event functions and makes sense in context.

*Inside secrets.* This category of information manifests itself in compellingly different ways at each event. At the Race, you are given the information that entitles you to insider status. At the Conference, you must already possess a certain level of knowledge to be accepted as an insider. Realizing these expectations, or lack thereof, made for an interesting participatory experience. At the Race, I was able to assume that regarding the event at hand anyway, there was a certain level of equality with regard to how much anyone knew. Because we had all received the same maps and t-shirts, we were all at equal footing. This was not the case at the Advocacy Conference, where it felt reasonable to assume that anyone might know more than you did about breast cancer. Given this uncertainty, there was an intimidation factor working for a new attendee like me. It did not take long to realize that in order to be privy to insider information, I had to speak the language of the insiders. Although initially intimidating, being accepted made for a quick and powerful bond to form with other attendees. If Komen could find a way to foster a similar bond among their Racers, I think they could prolong the powerful effects of their event in some very impacting ways.

*Entrusted secrets.* Entrusted secrets function similarly to insider secrets at the Race and the Conference. While I didn’t feel like I was entrusted with any new information at the Race, I did feel entrusted at the Advocacy Conference. I think this is an additional consequence of the differing event purposes. I made friends at the Conference,
I didn’t have to at the Race. Those friends opened up and trusted me with their stories at the Conference – there was nobody to open up to at the Race.

_Free secrets._ Free secrets are described as the information that is shared about and between groups. At the Race, the only other groups present were corporate sponsors who upheld Komen ideals and ideas. At the Conference, a variety of other organizations, sometimes with different goals and ideals were present and were included in panel discussions and nearly all events. It’s telling that the NBCC would welcome divergent thinking into their event. As a participant, I felt that if the NBCC was willing to open its doors and minds to alternative perspectives, then their confidence must be strong and their ideas well thought out. Komen on the other hand, maintains control over the groups that participants are allowed to interact with while at a Race. While this doesn’t feel problematic at the time, in comparison, it led me to wonder who was controlling the messages more – Komen or their impressive sponsors?

_Balancing perspectives_

The bottom line is that we need both Komen and the NBCC. The unfortunate truth is that we still don’t know enough about this disease to be able to prevent it or cure it and who is to say that striving for one is more or less valid than striving for the other? Certainly it is important to approach this disease from both sides and hope to find successes that will diminish the pain of breast cancer at any stage: pre or post diagnosis. I am certain that either organization would recognize and celebrate advancements in breast cancer care regardless of the source. This is after all not a competition between Komen and the NBCC, but a common mission of both organizations and their members.
Breast cancer politics are not simple. After the Komen Foundation sparked my initial interest in breast cancer campaigns, I found that I was forced to re-evaluate the frameworks from which I understood this disease several times. Initially, the emotional experience of running in a Race for the Cure resulted in a feeling of loyalty towards this organization and its cause. I was reluctant to trust the National Breast Cancer Coalition when I stumbled upon it as it conflicted with many of the messages I had received through Komen. After some more thorough research however, I found myself turning on Komen and siding with the NBCC. Since then, I have reflected, researched, and participated in both organizations events and written a great deal about both and I find that I have reconciled my feelings about Komen. I may not always like Komens methods or partnerships when it comes to promoting breast cancer awareness, but I do appreciate this organization for the role it has played in helping to continue the work of early activists in making this disease something that women are free to talk about today. As for the NBCC, I will always remain loyal to their mission and their members: I learned more about fighting for what you believe in than I ever thought I would. While I find that I am more personally satisfied with my NBCC involvement, I would certainly not discourage anyone from participating in a Komen event.

Conclusions

Following a study of this magnitude, it is important to ask what value the conclusions have for the researcher, the field, and the subject under study. I think that this work has great value for all parties. Personally, this work has led to a deeper interest in the history of women’s health care in the United States and the current consequences of
past decisions. I find myself wondering what other diseases and ailments found no logical home in the early days of the AMA and how current health care reflects these decisions. I also want to know more about the women who fought for greater knowledge and control over their bodies: the Women’s Field Army, and the Boston Women’s Health Book Collective especially. These organizations are monumentally important in the story of the women’s health movement and especially breast cancer awareness and activism. Finally, as a result of this work, I find myself telling the stories I have learned along the way and continuing the tradition of activism practiced by the NBCC.

Just as this work has changed my thinking, it also has the potential to change the way that others think by providing a theoretical contribution to the field of communication in three different ways: by answering a call, extending existing theory, and privileging communication contexts.

Theoretical Implications

First, this work answers a call in the health narrative literature to study cultural dimensions of health communication, or narratives constructed from and by the social community, to use the phrasing consistent with this work. Many scholars, (Brown, 1995; Kline, 2003; Lupton, 1994; Sharf & Vanderford, 2003; Van Maanen et al., 1988) have noted this gap in the literature and also noted the difficulty in such an undertaking. Sharf and Vanderford (2003) argue that health communication scholarship that stems from the social construction approach, such as this work, should conform to a list of recommended guidelines. Among these guidelines they list: “contextualize discourse, identify contrasting perspectives, incorporate cultural sensitivity, reveal what is rhetorical, be alert
to the clinical implications of personal narrative, and recognize the tension between emancipation and appropriation of voice” (p. 29). The very nature and design of this comparative ethnographic study of the two largest non-profit breast cancer organizations clearly attempts to honor these recommendations and advance the social construction approach to health communication scholarship. In asking how public narratives of breast cancer are performed and tracing that narrative through science, history, and the literal site of current performances, this study demonstrates how a narrative is a product of social construction and how it may be analyzed as such. The interpretations and conclusions drawn from the three guiding research questions offer a bridge from existing scholarship on breast cancer communication to future studies that might extend from this work to ask additional questions about the state of awareness and advocacy in the United States.

Second, this dissertation contributes to the study of communication by advancing existing narrative theory. In the process of analyzing the ethnographic thick descriptions and addressing the research questions, it became apparent that the narrative theories of Goffman and Frank could be merged and a natural connection drawn between the ways we have traditionally examined public and private narratives. Goffman’s dramatistic metaphor revealed the ways that the Komen Foundation and the NBCC perform a unified narrative as a group. Rather than limiting analysis to Goffman’s theories, which are more naturally suited to a public or collaborative narrative performance, it made sense to extend the analysis to Frank’s taxonomy of narrative types, which have typically been reserved for narratives performed or told by individuals. Frank’s three narrative types:
restitution, chaos, and quest, proved to be an ideal compliment to Goffman and essential for understanding how these narratives are performed, their emergence from cultural and historical traditions, and the ways that they influence the current state of breast cancer awareness in the US. Both theoretical perspectives benefit from this pairing: Goffman’s metaphor provides a valuable tool for leading a researcher to unexpected connections between theories and perspectives and may be thought of as an analytical bridge for future work. Additionally, Frank’s narrative types have proved useful in analyzing narratives in a new context: social rather than individual. This extension of Frank’s work is interesting, because he initially wrote about the “wounded storyteller.” Given this extension, it would seem that these storytellers not only band together to perform a unified narrative, but they also seek out and perpetuate the narratives that provide the most salient personal meaning. As the participants of the Race for the Cure and NBCC Conference collaborate to perform a single narrative, it makes sense in this study to examine them with the categories that Frank has identified. For future research, it would be interesting to examine other collaborative narratives to determine if Frank’s categories might be generally applied, or if new categories emerge.

Third, this research seeks to make a contribution to the way that communication scholars study health narratives. This study examined narratives as essentially context-driven communication and traced the narrative through those contexts in order to understand how science, history, and the site of performance co-create the narrative that exists today. Narratives do not exist in a vacuum, and must not be studied as such. Atkinson (1997) and Sharf (2001) have both warned against the practice of placing the
individual health narrative on a pedestal and glorifying it rather than examining it. Narratives can be wonderfully compelling, but the stories that precede, influence, and shape them are often equally so. This study demonstrates that when context is privileged as much, if not more so, than the original narrative, we can discover much deeper truths about the narratives that we live by. Echoing Walter Fischer’s definition of *homo narrans*, Sharf and Vanderford (2003) claim, “the most common way of communicating our personally constructed ideas of the realities we experience is through the social sharing of narratives” (p. 14). If this is so, then as narrative scholars, we must follow the trail of narrative diffusion and reveal the roots of our ideas and realities if we are ever to fully understand how we communicate about them.

**Practical Implications**

This research also offers a number of practical implications for the US breast cancer community. First and foremost, I think the most important point I can make is that breast cancer is still a disease without a cure. The thousands of women who face this disease every year, and the family, friends, and caregivers who relentless fight and campaign for a future free from breast cancer should be commended – whatever organization they choose to work with, their fight is a voluntary effort to change the current narrative and this work is invaluable. In the continuation of this fight, there are a variety of ways that research like mine may provide assistance:

First, this study presents a guide to the current status of breast cancer awareness in the US. The ethnographic data documents breast cancer awareness and activism as it happens and sheds light on the process. Anyone interested in understanding either
Komen’s campaign or the NBCC’s conference could use this data to make these events experience-near quite easily. I can see this as being quite valuable for small or young organizations who wish to study how larger breast cancer non-profits have achieved such success. Organizations focused on other health concerns could also find value in a focused case study of two highly accomplished non-profits and the divergent strategies that led to their individual success.

Second, throughout the process of writing this dissertation, I have worked very hard to be inclusive rather than exclusive. What I mean by this is that I have tried to acknowledge and honor the work of all survivors, fighters, activists, and participants no matter which organization they work for. That being said, I have also worked hard to be as critical of outcomes and consequences as I am respectful of the effort. This has not been an easy task. It would have been much simpler to point fingers and make judgments, but because the way we experience and respond to an illness like breast cancer is such a personal and emotional effort, I didn’t want to alienate potential readers by suggesting that their choices are in some way wrong. Personally, I cannot choose: the NBCC is doing the sort of work that I think needs to happen to change the current state of breast cancer in the US, but it is hard to dismiss Komen entirely as there is great value in the sort of personal victories that they celebrate and endorse. My purpose in explaining all of this is to highlight it as a practical strength of this study: I would hope that anyone reading it, regardless of what sort of activism or awareness they might prefer, would be able to find value in the discussion and comparison rather than personal offense in my
words. This is a document to foster learning, understanding, and most of all communication.

The third practical strength that I feel this dissertation offers is that it serves as a mirror for Komen and the NBCC. Very rarely do organizations have the opportunity to view their efforts through the eyes of a participant, and the ethnographic thick descriptions offer that chance. I also think that they could learn a thing or two from my analysis of their events. I would like for Komen to recognize their enormous potential to turn awareness into advocacy. I’d like the NBCC to continue to empower, educate, and enable activists, but to also consider the founding inspiration of Rose Kushner and ask if more could be accomplished by working together? Could the NBCC ever find common ground with an organization like Komen and collaborate towards untold success?

Limitations and Final Thoughts

Like all research projects, the conclusions that I have drawn in this dissertation are bound by the context of my study, and as a result have certain limitations. It is important to remember that this is first and foremost an ethnography. Ethnographic research provides a snapshot of a culture at a particular point in time: I attended one NBCC Conference and Lobby Day and two Race for the Cure events. As recurring events, there are always opportunities to revisit these sites and revise the narratives that are performed from year to year. While I have made every effort to couch these events within a rich cultural, historical, and theoretical context, I cannot deny that culture is ever evolving and that what I have recorded may not be a perfect reflection of the current reality. And I cannot guarantee that another researcher would record these events as I
have and analyze them towards the same conclusions. This is the nature of ethnographic research: it is an intensely personal way of knowing and I am not always able to share everything that I feel and know to be true through the words that I write. Knowing this, I have made every effort to describe these events as thoroughly as I can and have turned to additional resources like field notes, recordings, and event documents to aid me in my telling.

My personal perspective as a participant-observer ethnographer also places boundaries on this study. I have witnessed these events and recorded them as a participant might. I chose to focus on the narrative performances of Komen and the NBCC from the perspective of an average participant because I was interested in the messages that these organizations communicate to the general public. Further studies can definitely be conducted from other perspectives: I would expect the experience of a breast cancer survivor would yield far different observations at either event. I would also think that an examination conducted from within either organization would also result in some compelling research. I hope to either conduct or read about such research endeavors in the future.

Since beginning this project, I have moved from Ohio to Texas and the race-number from my first Race for the Cure, along with the NBCC pink bulldozer magnet that once held it to my refrigerator have been lost. I’m sure they will resurface in some misplaced box at some point in the future and I’ll have to decide if they are still worthy of such prominent placement in my kitchen and in my life. I’ve learned so much and changed my thinking in so many ways since I first received that number and the magnet
that now they seem to represent past thinking more than future ambitions. My research on breast cancer awareness is not over and I no longer need a number and a magnet to be inspired to ask more questions and pursue more answers. As with most research, the more answers we find, the more questions we discover need answers – and I have many questions.
References


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