

HavreDe Hill
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Survivor Discourse: the National Breast Cancer Coalition (NBCC) Tactics

The survivor discourse of the mainstream U.S. breast cancer movement has capitalized on the victim/survivor dichotomy through badge-of-honor pink ribbons, personal testimonies reminiscent of war tales, athletic events promoting images of physical strength, and a myriad of pink products designed to re-feminize women after breast cancer. The National Breast Cancer Coalition (NBCC), dedicated to eradicating breast cancer, is one of the few organizations that have not employed the typical breast cancer survivor discourse in their mission. Beginning in 1991, the NBCC is a grassroots organization that targets legislators rather than individuals affected by breast cancer to change the outcome of the disease. Through political activism, lobbying efforts, and research, the NBCC is responsible for attaining the largest funds for breast cancer research. Research funding secured by the NBCC comes directly from the Department of Defense (DOD), making the U.S. government the largest contributor of breast cancer research funding. However, the current political climate and state of war have decreased monies allocated to DOD research programs, and as a result may have jeopardized the momentum of NBCC initiatives. NBCC is now utilizing the survivor discourse already commonly used in mainstream breast cancer initiatives to continue to support their mission and legislative priorities through a national campaign, "Stop Breast Cancer: Personal Stories, Public Action."

To begin, I will give an overview of the mainstream breast cancer movement's survivor discourse through four main components and reveal the tropes associated with it. Next, I will turn specifically to the NBCC and show how it began, evolved, and is distinct from the mainstream movement as a unique mode of activism. Then, I will analyze the survivor discourse of domestic violence and sexual abuse social movements in the context of the related victim/survivor dichotomy to reveal other possible unintended consequences applicable to the NBCC's recent campaign. Within the framework of survivor discourse from the mainstream U.S. breast cancer movement and domestic violence and sexual abuse social movements, I will open the curtain to introduce the NBCC's national campaign, "Stop Breast Cancer: Personal Stories, Public Action" and explore the survivor discourse it utilizes. I will assert that the NBCC is redefining victimization as a public problem, rather than an individual one, through the campaign by promoting a collective ideology of survivorhood.

Breast Cancer Survivor Discourse: Pink Business

The breast cancer movement we know today began in the early 1990s, after which an entire culture erupted to bring about support, awareness, and new corporate incentives to don pink ribbons. In fact, mainstream breast cancer culture may better be represented as "pink business," both economically and socially speaking¹. Prior to this, breast cancer was stigmatized and concealed in whispers, medically ignored in advancing research and commonly recognized as the woman's fault (Casamayou, 2001; Kasper & Ferguson, 2000; Kolker, 2004; Lerner, 2001;

¹ When I refer to mainstream breast cancer culture, I am referring specifically to the "pink business" that feminizes the disease and experience of women affected by breast cancer, reinforcing and supporting traditional patriarchal ideologies of womanhood.

Leopold, 1999). In the 1970s, a remarkable chorus of voices from prominent women such as Betty Ford, Happy Rockerfeller, Betty Rollins, and Rose Kushner who had battled the disease hit the public with personal stories of horrifying accounts of treatment procedures and realities of fears of the dreaded, whispered disease (Casamayou, 2001; Ehrenreich, 2001; Kasper & Ferguson, 2000; Kolker, 2004; Lerner, 2001; Leopold, 1999). Support organizations began to form and incidence rates garnered more attention. By the 1980s, women were outraged, and Congress began to slowly pick up the slack for ignoring this disease² (Casamayou, 2001; Kasper & Ferguson, 2000; Kolker, 2004; Lerner, 2001; Leopold, 1999). One lone ranger that testified on behalf of all women who had been diagnosed with breast cancer and those who had yet to be diagnosed was Rose Kushner, to whom much credit is due to furthering Congress's awareness of the disease and inspiring others to come forward (Casamayou, 2001; Ehrenreich, 2001; Kasper & Ferguson, 2000; Kolker, 2004; Lerner, 2001; Leopold, 1999). At the end of her life from breast cancer in 1990, a rare and particular political climate was emerging that would finally allow for all of Kushner's hard work to pay off and affect the changes she could only dream of (Casamayou, 2001). And like a bomb in 1993³, breast cancer exploded into mainstream consciousness and history was made. From then on, those who lived to tell the tale of their personal battles of breast cancer were publicly deemed survivors and breast cancer survivorship became a culture all its own. As it is known today, the four components of the breast cancer culture that capitalized on the dichotomy of the victim/survivor are pink ribbons, pink products, races and athletic events, and personal stories.

In the 1980s the red ribbon for AIDS wrapped up anger, awareness, and support in one common symbol to combat stigma (Reifler, 1997). The breast cancer movement utilized the same symbol, but in pink, to bring about the same attention. Pink, in itself, is full of connotations that speak volumes of traditional femininity. Although the disease also affects men, it primarily affects women and the experience of the illness is socially constructed on the basis of the gender politics associated with breasts and female sexuality. To Ellen Reifler, the translation between the AIDS ribbon and the breast cancer ribbon is ineffective, "A red ribbon on a man is a shock, a demand that screams 'I will not be silenced'. A pink ribbon on a woman is a plea that sighs 'Please don't forget about me'" (1997, p. 25). However, it can be argued that the symbol of a pink ribbon on Congressmen's lapels made a profound statement after breast cancer became the U.S. government's darling of causes to support. As others have noted, the pink ribbon also did not translate into a controversial issue as AIDS did, and this made breast cancer an easily adoptable cause (Casamayou, 2001; Ehrenreich 2001). But now pink ribbons can even be seen on the sides and backs of vehicles with the new ribbon magnet craze. Are the issues surrounding breast cancer becoming too tightly wrapped up in pink ribbons and therefore limited in awareness because of current trends? What began as ribbon of activism has been turned into pink business.

If pink ribbons weren't enough, then pink products in support of breast cancer certainly made up for any lacking visibility. As Barbara Ehrenreich stated in the title of her published article in Harper's Magazine, "Welcome to Cancerland: A Mammogram Leads to a Cult of Pink

² In 1988, Congress passed the Medicare Catastrophic Coverage Act which covered mammography screening for women over age 65, but it was later repealed before it went in effect and then reintroduced in 1991 attached to H.R. 5835 (Casamayou, 2001).

³ The NBCC's congressional demand for \$3 million more for breast cancer research was met, setting a precedent for breast cancer research funding and attracted much public attention.

Kitsch” breast cancer culture has become cult-like (2001). In her personal account of breast cancer, Ehrenreich details the pink world into which she is catapulted after her diagnosis:

The ultra feminine theme of the breast-cancer “marketplace”—the prominence, for example, of cosmetics and jewelry—could be understood as a response to the treatments’ disastrous effects on one’s looks. But the infantilizing trope is a little harder to account for, and teddy bears are not its only manifestation (2001, p.46).

In her account, these pink products may be supporting patriarchal beauty ideals and/or infantilizing a woman’s experience, further gendering the disease. Ehrenreich also analyzes some of the large corporate sponsors that have signed on to the cause by promoting “pink products” for awareness. In fact, it became so popular for corporations to promote social causes that an entire new strategy was developed—cause-related marketing (CRM).

In an article from Marketing to Women, CRM is defined as, “the practice linking a company or its produce to a specific social issue to win women’s dollars”—a perfect opportunity for companies to capitalize on breast cancer (1997, p.1). A 1994 report about CRM campaigns from 1993 focused on 12 different companies that were supporting causes from domestic violence to AIDS through their products (Marketing to Women, 1994, p.3). It is no surprise that out of the eight different causes only breast cancer was represented by more than one company. In fact, breast cancer was spotlighted that year as the cause for Avon, Estee Lauder, Hanes Hosiery, and Ready-to-Wear Review. Since 1993, corporations have used their products, decorated in pink to sell awareness to women—Yoplait, ChapStick, Revlon, New Balance, Lee Denim, and many more. For survivors, the act of buying pink products may be in some way to gain symbolic ownership of their survivorhood status. It’s similar to being a part of an invite-only-club where members are privy to exhibit their status outside the club through logo embossed items. From candles to journals, tote bags and umbrellas, lipstick and nail polish you can decorate your home and body “for the cure.” But who benefits more from this marketing, the many women affected by breast cancer or the corporations selling the snake oil as pink tinted hope? With some pink products only an insignificant amount of proceeds go to the cause or no one is sure where the money goes, if any goes at all (Springen, 2004).

If corporations aren’t willing to go the mile for breast cancer, then the population of those affected, either directly or indirectly by the disease, may be, and this may be evident in the mainstream athletic events centered on breast cancer. The most well-known are the Susan G. Komen’s “Race for the Cure” and Avon’s 3-day “Walk for Breast Cancer.” These events, as well as others, draw together survivors and supporters, materializing faces and body counts in massive visible quantities to the public eye, once a year, to raise funds for breast cancer across the nation. They are characterized by a sea of pink t-shirt wearing survivors and supporters adorned with tags in honor or in memory of loved ones. The race becomes the symbolic journey of the fight against breast cancer with a clear, beginning and end, where victims can cross the finish line as survivors.

Maren Klawiter states in regard to the Race for the Cure®, “In the discourse of the Race, survival is a matter of individual choice and responsibility,” where “...breast cancer is a disease of universal, individual, ahistorical, resilient, reconstructable, heterofeminine, biologically female bodies” (1999, p. 113). The victim/survivor dichotomy is paralleled with that of the individual/community. Victims are individualized with memorial tags and photos, where as survivors gather for special recognition, are all present dressed in pink, and are able to congregate in certain designated tents that provide free services and refreshments. But again, I must ask at what cost survivorhood is granted? The Komen Foundation’s and Avon’s use of

monies raised by these events has been criticized for spending up to one third of funds, supposedly raised for research, on advertising and overhead to produce the events (Ehrenreich, 2001).

Public displays of survivorhood can also be seen on the shelves of local bookstores or libraries and in internet chat rooms or web postings. Personal stories are accounted for in numerous texts as novels, journals, narratives, and poetry. Books of hope are often shrouded in pink covers. Testimonies of triumph are co-opted by corporate sponsors. And chat rooms and web postings are full of survivor war tales that discourage any messages of fear or anger. Jami Bernard gives a how-to on coping in her brightly pink covered book Breast Cancer, There and Back: A Woman-to-Woman Guide. Jennie Nash's book The Victoria Secret Catalog Never Stops Coming, and other lessons I learned from breast cancer was sponsored by Ford for the Susan G. Komen Race for the Cure ® attendees in 2002 and adorned with a pink ribbon stamped with the blue-oval, corporate logo. Christina Applegate accompanied with the telling of her mom's story and dressed in pink, was the face for a Lee National Denim Day campaign also to benefit Komen in 2003 (Morgan & Shoop, 2003). Web logs explore the power of pink in public declarations of attendance at breast cancer events while chat rooms provide unlimited spirit and hope, prayers and inspiration to emphasize survivorhood (Ehrenreich, 2001; Bahar 2003). These very personal stories may detail the pain, frustration, and anguish of their breast cancer experiences, but not without also offering some kind of hope to the individual reader. In each, the protagonist begins her story as a victim and emerges from the rubble a survivor. These stories are testament to the personal journey of breast cancer and are most often illustrated in pink, may be co-opted by corporate sponsors, and may valorize the breast cancer experience.

The "pink business" of the breast cancer movement and current breast cancer culture shapes breast cancer in very specific ways. It highlights the dichotomy of the victim/survivor, creating and separating the Self from Other. It reinforces and perpetuates patriarchal feminine ideals by promoting infantilizing tropes, emphasizing a loss of femininity during breast cancer, and providing re-feminizing products (nail polish, lip stick, clothing, etc.) to paint, cover, and decorate the individual. It also caters to a white, middle-class, heterosexual beauty ideal. A person's identity becomes marked by their experience with pink badges of survivorhood. And it may also undermine the severity of the disease by reducing it to a ribbon of hope that can be bought and sold by corporate America. As Fran Visco stated, "Sometimes when there's the proliferation of symbols, people think it's getting the attention it needs" but what people don't realize is how many still die from this disease and the many more that are still affected⁴ (Springen, 2004). The criticism of those things in which I identify as "pink business" is not intended to devalue their importance, social significance, or personal relativity. It is, however, intended to reveal the unintended consequences and to understand how they shape the outcomes and responses to the epidemic. In the same way survivors and supporters move through the crowd of a race signifying their relationship to the disease, the actors of the production of "pink business" move through the mainstream breast cancer movement signifying their relationship to the cause.

The History of NBCC's Breast Cancer Activism

Feminist breast-cancer activists, who in the early nineties were organizing their own mass outdoor events—demonstrations, not races—to demand increased federal funding for research, tend to keep their distance from

⁴ Breast cancer kills approximately 40,000 annually (2004, Springen).

these huge, corporate-sponsored, pink gatherings (Ehrenreich, 2001, p. 51).

The NBCC stands apart from the mainstream breast cancer movement. It is a grassroots organization currently comprised of over 600 other organizations and represents 70,000 individuals—patients, health care professionals, and supporters of breast cancer (NBCC, 2005). Their mission to eradicate breast cancer is employed through three main goals of promoting research, improving access to health care, and increasing the influence of consumer advocates (NBCC, 2005). A variety of NBCC supported research continues to be done through clinical trials, evaluating the relationship between breast cancer and the environment, better breast cancer care, and “think tanks” for new innovative ideas on all aspects of breast cancer (NBCC, 2005). They are currently ranked as one of the 25 most influential groups in health policy out of 171 interest groups, and the only grassroots advocacy organization even on the list (NBCC, 2005). They are also well-known for obtaining the most public funding for breast cancer research from the DOD, which has fostered consumer activism through peer-review of research initiatives and design⁵. Through advocacy and action they aim to empower the individual and demand public accountability for disparities in health care based on policy neglect and inequitable biases⁶.

The actions taken in the beginning of the NBCC, May 1991, were crucial to its success in being recognized by Congress and awarded increased research funding. In October 1991, with little resources the NBCC launched its first national campaign: “Do the Write Thing”. The purpose was to collect 175,000 letters in reference to breast cancer incidences and to be delivered to Congress to represent the amount of expected diagnoses made that year. After only six weeks, 600,000 letters were collected and brought to Capitol Hill. The original goal of 175,000 letters was delivered to the President and the rest distributed to members of Congress. Unfortunately, they were not as well received as hoped and it became clear, “President Bush’s support for increases in public funding was at best luke-warm” (Casamayou, 2001, p. 120).

Nonetheless, some members of Congress took notice, and in 1992 the NBCC came back to Congress demanding a \$300 million dollar increase in breast cancer research funding⁷. Being an election year, the NBCC also paid close attention to who most supported policy initiatives that complimented their own agenda. Bill Clinton supported women’s issues and universal health care, both positives in the direction of advancing NBCC goals (Casamayou, 2001).

After Clinton won the presidential election, the NBCC successfully completed another campaign, “Campaign ’93—2.6 Million Signatures” an amount representing the number of women living with breast cancer in the U.S. during that year. President Clinton personally received all of the petitions. With Presidential support and more seats than ever before occupied by women in Congress, the demand for \$300 million more was met. Because it would be unethical to take funding from another area of medical research and budgets were stringently capped, money had to be found elsewhere to meet the demand.

Senator Harkin (D-IA), who had lost two sisters to the disease, found the key—why not use the extra funding set aside for the Cold War in the DOD budget? But because breast cancer

⁵ Consumer advocacy refers to patient consumption of the health care system through the diagnosis, treatment, and maintenance of breast cancer care.

⁶ Although their mission is specific to breast cancer, they do support applicable broader health care initiatives.

⁷ The amount was formulated in response to the NBCC research task force’s evaluations of under funded, potential research.

was not an issue of defense, necessarily, it could not be granted from defense funds⁸. However, Harkin found a loophole; the U.S. Army Medical Research and Material Command (USAMRMC) was already doing breast cancer research. And so, he submitted an amendment to increase the \$25 million funding to \$210 million, and it eventually passed⁹. As stated by Kolker in her research on the breast cancer movement, "...by fiscal year 1993 federal breast cancer funding had increased from \$89 million in fiscal year 1991 to \$433 million in fiscal year 1993, a phenomenal success" (2004, p. 24).

With funding secured from the DOD, the NBCC has been able to continuously obtain medical research funding and further their initiatives—promoting research, improving access to health care, and increasing the influence of consumer advocates. They have an annual conference and lobby day that educates advocates on the current breast cancer research and NBCC legislative priorities, ending in a peaceful march on Capitol Hill and scheduled meetings with respective state representatives of participants. They have created Project LEAD (Leadership, Education, and Advocacy Development) ®—a program to train activists on the science of breast cancer in order to participate on peer-review panels for research. Through "Beyond the Headlines," the NBCC carefully analyzes media reports and portrayals of breast cancer that are released to the public to debunk myths, health scares, and empty "cure" promises. Among some of the legislative accomplishments since 1991 are the Breast Cervical Cancer Treatment Act (2000), Access to Cancer Therapies Act (2003), the Native American Breast and Cervical Cancer Treatment Technical Amendment Act (2002), Medicare Coverage of Routine Care Costs During Clinical Trial Participation (2000), and the Protection Against Genetic Discrimination for Federal Employees (2000) (NBCC, 2005). Other educational programs include the "Clinical Trial Initiative" to encourage insurance coverage of, access to, and participation in clinical trials; the "Environmental Initiative" to focus on links between breast cancer and the environment; and the "Quality Care Initiative" designed to set standards of quality care for patients and practitioners.

The NBCC presents breast cancer as a public health problem in which women are not victims of their biology but rather neglectful public policy and gender inequity (Casamayou, 2001; Kasper & Ferguson, 2000; Kolker, 2004; Lerner, 2001; Leopold, 1999). While other organizations focus on detection, diagnosis, and treatment, the NBCC focuses on prevention, causal attributes, and access to health care to be achieved through increased research funding, research implementation, and policy changes. On a poster at a Capitol Hill rally, a breast cancer advocate from the NBCC reminds Congress to "FORGET the PINK! USE the INK: Support Access to Quality Care" (NBCC, 2005). You cannot buy "pink-kitsch" from their website or events. And they do not offer individual support or promote individual stories of the victim/survivor to further their cause in the same way other mainstream breast cancer organizations do; however, that is not to say that members haven't identified their status in Congressional testimonies. I am also not claiming that the NBCC hasn't utilized some of the very same tactics that the rest of the mainstream breast cancer movement has. They owe part of their success to the media and have strategically used it to their advantage, but they differ in the ways in which they utilize it. The NBCC uses testimony to appeal for public action and not

⁸ Fran Visco, the president of the NBCC testified to Congress in 1992 that women had "declared war on breast cancer" and they had better find a way to fund it (Casamayou, 2001, p. 125).

⁹ "This amount was to be spent over a two-year period and was subsequently reinforced with an additional funding of \$115 million in the DOD budget (Casamayou, 2001, p. 150).

public sympathy. They hold press conferences to emphasize “Not Just Pink Ribbons.¹⁰” Instead of promoting races, they publish position statements. They also try to adequately represent men and, more specifically, all women across the lines of age, race/ethnicity, class, sexual orientation, health status, etc. The NBCC may be mainstream breast cancer *activism*, but it stands apart from the mainstream breast cancer movement’s pink culture (see Fig.1).

<u>National Breast Cancer Coalition (NBCC)</u>	<u>Susan G. Komen Foundation</u>
Mission: “to eradicate breast cancer through <i>action</i> and <i>advocacy</i> ” <i>screening</i>	Mission: “to eradicate breast cancer through <i>research, education, and treatment</i> ”
Research Funding: obtained through political activism and lobbying	Research Funding: Race for the Cure ®
No pink business	Yes pink business (website “Marketplace”)
Not a support group	Yes on-line support chat rooms
No individual public appeal to sympathy	Yes individual appeal to sympathy

Fig. 1

Other Survivor Discourses within Women’s Social Movements

To further examine the effects of survivor discourse I will explore how it has been used in the social movements of domestic violence against women and sexual abuse of women. First, I will look at how the dichotomy of the victim/survivor is produced, the political implications surrounding it, and how it relates to the transformation of the individual and collective identity. Then, I will look at the unintended consequences of these survivor discourses.

In Jennifer L. Dunn’s research on the survivor discourse of battered women, she identifies how the image of the victim is socially constructed to claim a social problem. Inadvertently, the victim comes with “stigmatizing attributes” and is then in need of “repair work” (Dunn, 2005, p. 1). The repair work is the act of mobilizing social change, by which one presumably becomes a survivor. As Dunn points out, “To the extent that victims are presented as trapped, and survivors, conversely, are shown as making choices, they are constructed in ways that place them at opposite poles of an agency continuum” (2005, p. 2). The idea of having or lacking agency then creates the problem of what constitutes agency and how agency is obtained. A “true” victim would be void of personal responsibility for her situation and would be “innocent” by all means (Dunn, 2005, p. 3). In the case of a battered woman, this would render her completely incapable of leaving or changing her situation. The dichotomy presented here doesn’t take into account the varying experiences of battered women and the degrees to which a woman is victimized and can claim survivorship. In fact, the dichotomy goes to show how battered women can be further victimized by such extremes in socially constructed identities. Dunn points out that, “Activists, including researchers and clinicians, construct images of battered women for popular and policy-makers’ consumption,” in order to “...emphasize their

¹⁰ “Not Just Pink Ribbons” was a press conference held in October 2, 2002 calling for “action behind the symbol” to kick start Breast Cancer Awareness Month.

agency as well as their victimization” (2005, 21). The individual is then co-opted by a social movement and agency becomes legitimized through social constructs of the victim/survivor.

The question of legitimacy is also central to Sexual abuse survivor discourse. In her evaluation of sexual abuse, Nancy Naples states,

Survivor discourse is often posed in contrast to expert discourse, which is legitimated through a distinction between different forms of knowledge production, one that derives from personal experience and emotional pain versus one grounded in more systematic and presumably objective truth claims (2003, p. 1159).

This analysis informs the different types of knowledge in survivor discourse and places emotions apart from “scientific or academic” knowledge. However, Naples also states that survivor discourse can be oppositional or even transformed into expert discourse, giving validity and agency to survivor discourse in its different forms (2003). In the case of sexual abuse, survivor discourse may have inadequately represented dynamics of identity politics, leaving out or “glossing over” differences in experiences along lines of race, gender, class, sexuality, culture, location, and personal history (Naples, 2003). These dynamics are important and embedded deeply in personal experience and should be chosen by the survivor to identify if going public with a personal story (Naples, 2003).

Claiming the status of either victim or survivor, individually or collectively, translates differently by who is authorized agency from the testimony. In a collective, individual identities can be ignored, creating a monolithic victim/survivor identity and a hierarchy of classifications by which standards are set for individuals to receive services and/or funds (Dunn, 2005). To claim either victim or survivor status individually may mark a person’s identity solely on the basis of their “issue” rather than their personhood, or limit a person who has reached the status of survivor from seeking future assistance down the road for fear of reclaiming victimhood. This dichotomy poses unintended consequences for both the individual and the collective. However, a combination of the two may present desired results, where victims and survivors are not dichotomized, collectively and/or individually, and instead are able to mutually exist in mainstream social constructions where individual agency is understood on a continuum (Dunn, 2005). In other words, the victim is the survivor and the survivor the victim; they cannot be separated or understood apart from each other.

The unintended consequences of the victim/survivor dichotomy created through survivor discourses of the domestic violence and sexual abuse social movements may further victimize individuals. Stigmatization implies that a person is broken, needing to be repaired, and can lead to the invalidation of agency or the lack there of. The question of agency ultimately also questions personal authority. Social movements may co-opt “ideal” testimonies that inevitably marginalize others’ experiences. Social constructions of a monolithic victim/survivor identity may mandate services and resources. Once a survivor status is claimed, it may also discourage an individual to seek help if there is recurring trauma. The process by which one is to recover has become medicalized and institutionalized. And last but not least, there has also been a tendency to “blame the victim” when a person doesn’t adhere to expected victim/survivor behavior.

“Stop Breast Cancer: Personal Stories, Public Action” Campaign

As previously stated, the particular political climate in which the NBCC emerged from played a unique role in its success. However, the political tides have turned, and the U.S.

currently is in the second term of the George W. Bush administration. Along with it, have come war and uncertain terms as far as defense issues are concerned. Therefore, DOD funding has inevitably decreased and the economy as a whole declined. The NBCC is now focusing its legislative priorities on ensuring access to quality health care for all. “While our mission is to end breast cancer, we recognize that we cannot effectively prevent, diagnose, treat or cure this disease without a system that delivers quality health care for everyone. Clearly, conquering breast cancer and other diseases is dependent on scientific research as well as improvements to the overall health care system and access for all individuals” (NBCC, 2005). This initiative is being supported by the current campaign, “Stop Breast Cancer: Personal Stories, Public Action”. This campaign is intended to culminate in the distribution of the compiled data obtained from the personal stories to members of Congress, stressing the importance of recognizing the disparities in health care and encouraging action to remedy the situation. The NBCC is tactful and forceful in always reminding politicians that they are supported by constituents, some of whom have probably been directly or indirectly affected by breast cancer. But, this campaign is also translatable to the larger health care crisis, and as such is not specific to breast cancer, and is intended to be applicable to guarantee equal access for all.

The campaign’s materials can be obtained on-line or by contacting the NBCC. In a neat packet by mail, the package consists of the campaign overview, tips on “How to Host a House Party,” “NBCCF Talking Points,” the official NBCC position statement on “Principles for Achieving Guaranteed Access to Quality Health Care for All”, “Why Are We Asking For Your Stories,” sample story forms, actual story forms with a privacy statement, “Questions to Consider,” “NBCCF At A Glance Leaflets,” campaign volunteer postcards, and a shorter version of the main principles for the health care initiative. The campaign is not a fundraiser. The purpose is to collect individual stories of disparities in accessing health care. Volunteers are instructed to host house parties or gatherings to encourage people to tell their stories, as it is not as simple as signing a petition or a pre-fabricated letter of support like other NBCC campaigns. It is not specific to breast cancer patients—expanding not only the NBCC supporter base but also the NBCC’s commitment to the public. In this way, the NBCC is assuming that the experiences in accessing health care have been negative for the majority of people and they are advocating for policy change to reflect the varied disparities among individuals and illnesses. For the remainder of the discussion regarding the campaign, I will focus on three aspects of the campaign hand-outs that socially construct the health care problem, the patient, and the response by analyzing the “Questions to Consider,” the story form to be filled out by participants, and the sample story form with an example fictional entry.

On the “Questions to Consider” hand-out, 18 questions prompt participants to think about their experiences with problems in accessing health care. Some of these questions are directly linked to socio-economic status, physical ability, cultural affiliations/beliefs, language barriers, and ability to understand the information given. Others focus on the insurer and/or health care provider with questions regarding general respect, privacy, information and options made available to patients, encouragement of questions and second opinions, standards and protocols of care, reconciliation of any problems, and acknowledgment of suggestions for improving care. These questions do not prompt participants to identify their medical diagnoses or to reveal otherwise private medical information. The overall tone is to understand the standpoint of the patient accessing the care and the response of the medical provider and insurer to meet their needs.

Taking the “Questions to Consider” into account, the actual story form leaves space for the participant to explain their negative experiences with the health care system and asks the individual to identify some specific personal information. The first bit of information asks for the state in which the participant lives in. The information boxes ask about employment status at the time the form was filled out, current insurance status, amount of treatment covered by insurance, if any, and an explanation in the case of partial or no treatment coverage from insurance. The privacy statement assures that all information will be kept confidential unless otherwise authorized by the participant to be used publicly. It also informs the individual that “Some of the stories will be highlighted in media, print materials, and forums.” The contact information provided will be used only to ask for permission to use personal stories.

The sample story form is completely filled out to give the participants an idea of what the NBCC is asking for in response to the question prompts. The sample participant is a 36 year-old mother of two diagnosed with breast cancer. She also speaks on behalf of her mother, who was also diagnosed with breast cancer. The prognosis of her breast cancer is not specific, but it can be assumed that there may be a genetic mutation involved being that both mother and daughter is diagnosed with breast cancer¹¹. The daughter has insurance and the mother does not. The coverage the daughter has is limited, and she expresses that they are both in debt from medical bills being turned over to collection agencies. She makes special reference to not being eligible for government assisted health care,

You hear about the system wanting to help low income women and their children get coverage, but what about women like me? Women who have health coverage, but the company will hardly pay for anything. Women like us seem to fall through the cracks.

She states that she would like to have reconstructive surgery,

Additionally, I feel I’m in desperate need of reconstructive surgery. I am a 36 year old mother of two children. Losing one of my breasts at this age is NOT on my agenda. How can I be attractive to my husband with only one breast and one deformed side of my chest, all because medical insurance companies don’t feel like reconstructive surgery is medically necessary.”

She also states that her mother has other health problems that she is unable to address because of her lack of insurance.

My mother cannot address those issues or follow-up with her doctor about the cancer because she has no insurance. I’m quite angry that she has to live like this. It’s not available to her. What can we do? What can we do? What can I do to help her—to help me too!

The woman used as a sample represents a young, married, heterosexual mother of probably what would be considered the low-end of middle class socio-economic status. She is also checked-off as unemployed in the information box, and lives in Maryland. This construction is complex and utilizes the “worst case scenario” of a young woman with two children robbed of her femininity and sexuality. This tactic is an appeal to sympathy; however, it is still only intended for the participant to see and is not complete with a face.

This campaign is designed to reflect the disparities in access to health care regardless of the status of having breast cancer, and encourages the participants’ specific identity markers be

¹¹ A genetic mutation implies that mother and daughter have a specific type of pathology that may be considered a pre-existing condition under insurance clauses. The NBCC may have included this because it is an important and parallel initiative that may further health care disparities on the basis of genetic discrimination.

revealed. It differs from other personal accounts in that it is very specific in the scope of the story it is asking for and is limited to reveal the problem, not necessarily the person. The assumption of a negative experience in health care focuses on one of the NBCC's main concerns from its inception: the individual is victimized by a failed system, policy neglect, and bias based on inequity. The option to become a survivor of this victimization is not relevant to these stories or the campaign's mission.

Conclusion

“Stop Breast Cancer: Personal Stories, Public Action,” the recent campaign by the NBCC, stands apart from mainstream breast cancer advocacy; it does not adhere to “pink business,” it is a strategic gesture to affect political policy for access to health care, it does not construct an image of a monolithic victim/survivor, and it does not engage in mutual support for others or provide a personal testimony of triumph. There are no effects of stigmatization, and it avoids marginalization by the deconstruction of “ideal” victim/survivor identities. It does appeal to sympathy, and it does highlight individual aspects of personhood to explore disparities on the basis of identity politics. But it complicates the idea of the individual and the collective power dynamics by unconventionally giving agency to both. The individual chooses to tell her/his story with the understanding that stories and data will be compiled, but the personal information remains confidential. Even more radical, this special interest group is opening up this opportunity to others who normally would be excluded from campaigns specific to breast cancer. They are merging into broader health care issues to advance their agenda for breast cancer initiatives, and are redefining victimization as a public problem rather than an individual one. The campaign asserts that until there is equal access to health care for all, the NBCC's research on clinical trials, environmental causal factors, improvements to breast cancer care are moot if women don't have access to the system that will implement the beneficial results.

The NBCC's recent campaign, “Stop Breast Cancer: Personal Stories, Public Action” avoids the tropes of disjuncting the victim/survivor by allowing the victim “survivor agency” in telling her/his story without further victimizing her/him by promoting a generalized idea of survivorhood. The NBCC has no way to benefit directly from the campaign, as it is not intended to support funding or research initiatives but instead to affect public policy for all. By not blaming the victim, there is no room for judgment to be passed upon the individual on the basis of personal choice or responsibility, and it doesn't have the opportunity to exploit the individual without the individual's consent. The campaign is not exclusive to anybody or any illness, and it can only foster a generalization of the disparities in access to the health care system, not the individual participants.

The NBCC has been successful in obtaining research funding, empowering consumers through educational programs, and affecting public policy. The NBCC may also inform other social movements by its strategies and tactics from the current campaign, “Stop Breast Cancer: Personal Stories, Public Action” by looking at the problematic structure of institutions rather than focusing on individuals. “By locating survivor discourse in the material as well as the discursive context, we can develop more effective strategies for a broad-based and politically oppositional survivors' movement” (Naples, 2003, p. 1178). The NBCC unravels the victim/survivor dichotomy of pink ribbons, secures research funding without patronizing pink products, races further for the cure in research initiatives, and is a testimony to effective breast cancer activism.

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