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Working for the Cure: Challenging Pink Ribbon Activism

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A promotional pamphlet describing a weekend-long fundraising event that auspiciously works to *end* breast cancer features the image of a woman, bathed in sunlight, standing defiantly with arms stretched above her head. The pose is familiar to the post-cancer crowd—the top half of the warrior pose or a sun salutation—yoga positions that symbolise strength, preparedness and openness. Because the woman's head is wrapped tightly in a bandana, we take her to be a survivor. Because she is young, strong, healthy and hopeful, she represents the 'survivor-thriver' so frequently celebrated in the mass media. This image captures the ethos of pink ribbon activism—a compelling message of health, hope and cure that frames breast cancer discourse.

Breast cancer campaigns are a thriving form of health consumer activism in Canada and the US. This is indeed due to high incidences of breast cancer in these countries,¹ but also due to its high marketability as a women's issue, a community-builder, a forum for corporate responsibility and an affirmation of the social good that biomedical research offers. While feminist, corporate and biomedical interests have often been antagonistic, the breast cancer movement in its current formation brings these interests together in a shared goal of curing a serious and life-threatening disease. This historically unlikely alliance deserves investigation and evaluation.

Captured and branded in the highly recognisable image of the pink ribbon, the politics of breast cancer at the start of the twenty-first century is markedly hopeful (given the grim statistics) and surprisingly compliant with the medical establishment's defined health goals and approaches to addressing the breast cancer epidemic. This chapter examines and evaluates how the pink ribbon message has shaped and organised social response to breast cancer. The *work* in question is

'healthwork', a term found in the critical health literature denoting the active and purposeful work that people do to look after their health (Mykhalovskiy and McCoy, 2002). Healthwork analysis tends to focus on personal care practices such as taking medicines, dealing with health care practitioners, informal caregiving and health information seeking, that are then subject to examination of how those individual actions invite extended relations of governance and ruling (Mykhalovskiy et al., 2004). In this examination of breast cancer campaigns, the same analytic concern with governance is taken, but the health-related work is extended beyond personal care and self-surveillance to include the volunteer work done by many concerned citizens in their contributions of time, energy and money to support campaigns for the cure.

I argue that while the appropriation of the language and themes of the early women's health movement frames pink ribbon activism as a highly personal, emancipatory and socially responsible individual effort, this brand of breast cancer activism instead serves to fund a limited biomedical research agenda that is largely shielded from public scrutiny. This agenda has been universalised through endearing 'hero' narratives of personal struggle that inspire civic engagement by complicit consumers rather than critical activists. Pink ribbon activism problematically diverges from the demand made by the women's health movement for participation in setting the research agenda and determining treatment strategies. This neglect is troubling, given that breast cancer discourse is so fraught with contested knowledge claims regarding disease aetiology, prevention and treatment. While the pink ribbon message offers hope and optimism, it does so by suppressing many counterclaims, disputes and ambiguities surrounding the problem of breast cancer. Instead of soft 'pink', a more critical social response to breast cancer is needed in order to ensure women's informed participation in addressing this serious challenge to women's health.

Comparing pink ribbon activism and the goals of the women's health movement

Women's community health activism, including breast health education, public awareness, fundraising, pink purchasing and athletic events that fall under the rubric of 'pink ribbon activism', has its historical origins in the US-born women's health movement. Therefore, I begin this examination with a look at the movement's programmatic aims and goals and compare them to the current practices and objectives of pink ribbon campaign efforts.

The surprising feature of current breast cancer activism and community-based campaigns for the cure is that the women's health movement has traditionally challenged biomedical approaches. Women's health is widely understood to:

go beyond the traditional confines of medicine and medical issues to examine how various social, institutional, political, and economic arrangements influence women's health. For instance, domestic violence, labour practices, social assistance, and international development policies have been examined from a women's health perspective.

(Goldenberg, 2007, p. 440)

These studies have enlarged the epidemiological scope of the sources of poor health to indict globalisation, ill-conceived development policies and poverty as major hindrances to women's health around the world. Pink ribbon activism, in contrast, supports the medical model, often fundraising for biomedical cancer research and treatment centres. While women's health activism need not be adversarial towards the medical orthodoxy, feminist efforts have historically pushed against the mainstream and challenged conventional thinking in ways not found in the pink ribbon message.

The broad aim of the women's health movement was, in its grassroots beginnings, and still arguably is, to reclaim women's bodies from the oppressive institutions of medicine and to reframe women's knowledge and experiences of their bodies in ways not configured by sexism and androcentrism. Early breast cancer activism challenged many of the conventional prophylactic practices. In the 1970s and 1980s, for instance, feminist activists successfully campaigned against the most disfiguring form of breast cancer surgery, the Halsted radical mastectomy, which removed breast tissue, nearby lymph nodes and chest wall muscle, leaving women permanently disabled (King, 2006b). The women's health movement also put an end to the common surgical practice of proceeding directly from biopsy to mastectomy without ever rousing the patient from anaesthesia (Ehrenreich, 2001). Feminist groups also demonstrated the ineffectiveness of high dose chemotherapy, where bone marrow was removed prior to otherwise lethal doses of chemotherapy and later replaced (Ehrenreich, 2001). Women's health activists also influenced the research agenda, demanding answers to questions that women were asking. For example, was the breast-conserving lumpectomy comparably efficacious to the mastectomy? It was also the strong lobbying efforts

of women's health organisations in the early 1990s that successfully achieved government and health research organisations' recognition of breast cancer as a research priority, with a corresponding increase in research funding in response (Lerner, 2006). These combined efforts by women's health activists shifted some of the patriarchal norms surrounding breast cancer treatment.

The movement's aims were not merely to change medical practices but to empower women as participants in their health care decision-making (see Bella, Chapter 2). The Boston Women's Health Book Collective produced the groundbreaking publication *Our Bodies, Ourselves* in 1973 (Boston Women's Health Book Collective, 1973) towards this end. Now with dozens of translated, updated and age- and disease-specific editions, this important text offers knowledge not available elsewhere in easily accessible language. By valuing women's self- and embodied-knowledge, the movement legitimated self-help efforts, sharing of stories and mutual support networks that now figure so prominently in breast cancer discourses. Indeed, feminism helped make the breast cancer sisterhood possible.

Some have remarked that the women's health movement may be a victim of its own success. The medical mainstream has largely acknowledged the importance of women's health. Against its adversarial beginnings as a contested category in medical nomenclature, women's health is now easily thought of as a medical specialty like any other. Women's health is now largely negotiated from within the institutional structures rather than from without. For instance, the Canadian Institutes of Health Research now includes the Institute of Gender and Health. Likewise, the US National Institutes of Health has an Office for Research on Women. These offices work to counter gender discrimination in medical research and practice, such as the over-representation of male trial subjects in clinical trials. This problem persists despite declarations made by medical associations encouraging change to this practice and various corrective policies having been put in place (Marshall, 2005). While effective in many ways, this professionalised and insider position for women's health activism dilutes some of the movement's original political aims and runs the risk of returning women's health research to biological and reductionist paradigms.

The 'mainstreaming' of women's health has also been noticed by corporations looking to increase their female consumer base. Women's health has become a widely profitable market, as seen by the astounding array of health, nutrition and wellness products and regimes aimed at women. Critics of consumer culture will question whether direct

health marketing to women constructs complicit consumers rather than empowering women through information, choice and quality goods and services. But this message may not be heard, as the original spirit of self-help and self-knowledge that once inspired covert cervical self-examinations using plastic speculums, mirrors and flashlights has been commandeered by health marketers. We see this in the incredible marketability of the breast cancer cause, discussed later in this chapter.

The current state of breast cancer consumer activism limits the focus on activism—the efforts to change standards and practices in the delivery of goods and services—and instead places emphasis on consumption. There exists an impressive and widely available market of breast cancer products emblazoned with the ubiquitous pink ribbon logo. Far more than a simple T-shirt and teddy bear campaign, breast cancer awareness products include pink running shoes, socks, outerwear, underwear, jewellery, hats, scarves, pins, food products, cookbooks, cosmetics, small appliances, children's toys, home décor items, gardening tools, stamps, stationary, envelopes, computer mouse pads, bank cheques, credit cards, license plates and more. There are scores of consumer products that feature limited-edition pink versions with partial proceeds from the sales going towards 'breast cancer research'. The marketing of breast cancer products is done with such sophistication that breast cancer campaigning seems to be an industry in itself, captured in the clever term, 'Pink Ribbon, Inc.' used by Samantha King (2006b). Barbara Ehrenreich (2001) similarly referred to this phenomenon as 'the cult of pink kitsch'.

These items increase in appearance and availability during the month of October, Breast Cancer Awareness Month in many countries. Numerous five kilometre charity runs and other community-based athletic activities typically take place. They prove to be so popular that 'run for the cure' is now a misnomer. The downtown streets of many towns and cities are so jammed with cheerful participants, dogs and strollers that one can typically do no more than stroll for the cure.

These community events are not traditional activist demonstrations, as participants walk, talk and laugh, rather than shout slogans and wave placards. Nonetheless, these public gatherings still valuably exhibit a feminist commitment to redefining the *meaning* of illness. Gone is the shame of breast cancer. When thousands of people take to the streets to run, walk or march in solidarity, the previous silence around breast cancer is broken. What was once euphemised in women's obituaries as 'the long illness' (Ehrenreich, 2001) is now a mobilising cause for community and celebration. Rather than suffer in silence, survivors now

wear distinct pink shirts at cure campaign events (King, 2006a). Breast cancer has come a long way to being the 'biggest disease on the cultural map' (Ehrenreich, 2001). Beating drums, blowing whistles, wearing costumes, singing and chanting in unison, the participants walking and running along city streets also endorse a message of 'healthy mind, healthy body'. Stress, poor diet, negative thinking and lack of exercise are widely thought to cause cancer. Laughter, positive thinking and exercise are presumably the antidote.² In this age of information access, the 'consciousness raising' awareness piece of feminist health activism seems to have been distilled down to a message of 'eat your vegetables, exercise, don't smoke, and get an annual mammogram'.

Every illness needs a story: the hero narrative and what remains untold

While the campaigns for the cure are galvanised by grim statistics,³ the events are framed as celebrations of courage and survival. Even the sombre moments, such as candle-lit vigils commemorating those who 'lost the battle', are framed in optimistic hopes for the future: learn from our sisters and screen! Raise funds! Join the fight! The wide appeal of the pink ribbon message in fact relies on its linkage to the personal struggles of brave women. These messages, however, are problematic in their encouragement of complacency with respect to disease occurrences and available response strategies. While the illness narrative sub-genre importantly allows marginalised voices to be heard, and helps many find meaning and comfort in times of existential crisis, contemporary breast cancer memoirs have become formulaic scripts celebrating the hero/survivor ('the hero narrative'). Their repetition becomes coercive as heroics emerge as the preferred paradigm for understanding the experience of breast cancer and anti-hero counterdiscourses are marginalised and silenced.

The breast cancer narrative is part of the important feminist practice of 'giving women voice' in previously inaccessible venues and forums. The tradition of breast cancer narrative started with the important works of Betty Rollin's *First You Cry* (1976) and Audre Lorde's *Cancer Journals* (1980) which both provided a much needed counterdiscourse to the biomedical discourses that were available at the time. These deeply personal insights offered thick description, from a woman's point of view, thus broadening the breast cancer story to include the personal, interpersonal, existential and economic hardships endured by women with cancer.

When Lorde was rebuked by a nurse for not wearing a prosthesis in place of her missing breast, she reports being 'too outraged to speak then' (Lorde, 1980). Here she learned the harm of silence and then framed the problem of being seriously ill as a problem of finding voice. She wrote, 'I was going to die, if not sooner than later, whether or not I had ever spoken myself. My silences had not protected me. Your silence will not protect you' (Lorde, 1980, p. 20). With the commitment to 'breaking the silence'⁴ also comes the responsibility on the part of the storyteller: 'to witness the memory of what happened, and to set this memory right by providing a better example for others to follow' (Frank, 1995, p. 133). Lorde's moral responsibility stemmed from her prior activism and particularised politics of self. 'Because I am woman, because I am black, because I am a lesbian, because I am myself, a black woman warrior poet doing my work, I come to ask you, are you doing yours?' (Lorde, 1980, p. 21). Here we find an early rallying call for mobilising community among women around illness.

Breast cancer survivor stories have since become numerous. Women have stories to tell about the challenges and lessons learned from the breast cancer experience. One can find a myriad of blogs and blog entries recounting the breast cancer experience and dozens of books offering detailed personal narratives (see Segal, 2007). It is now common and even expected practice for celebrities to publicly share their breast cancer experiences, and these stories are generally thought to inspire, comfort and console other women similarly enduring the challenges of breast cancer.

In her cultural analysis of the cancer experience, Jackie Stacey (1997) outlines the conventional trajectory of the breast cancer narrative. The story is one of 'triumph over tragedy', where 'pitting life against death and drawing on all possible resources, the patient moves from victim to survivor and "triumphs over tragedy" that has unexpectedly threatened their life' (Stacey, 1997, p. 1). The story begins with the discovered lump or suspicious mammogram; the suspense while waiting for biopsy results; the diagnosis; the despair; the bumps along the road to recovery; the difficult treatment and side effects; the relief when it ended; the story concludes with the available closures like hair growing back, returning to work, and crossing the 2-year threshold (Stacey, 1997). The hero's successful struggle is often a story of transformation in which misfortune becomes a positive source of self-knowledge. The protagonist benefits from new-found wisdom:

Accepting the fragility of life itself, the cancer survivor sees things others are not brave enough to face (or so the story goes). Cancer offers the chance to reassess. It allows the person to pause and to re-evaluate their life: having cancer teaches us that life may be shorter than we thought and that it may be time to decide to live it differently. These are the kinds of wisdoms which are told and retold in books about cancer.

(Stacey, 1997, p. 1)

If, Stacey continues, the person with cancer dies, the story will be one of great loss and suffering, but will also celebrate her courage and dignity. Often written by friends or family of the deceased, these stories will recount pointlessly shortened lives and lost opportunities, and warn others to avoid similar fate. But those stories are 'rarely disaster stories, and one typically finds heroism in the tragedy, stoicism and a fighting spirit. They document the triumphs along the way, even in the event of death' (Stacey, 1997, p. 2).

The hero narrative has normative implications for those trying to find meaning and/or their own voices within the cancer experience. Segal's (2007) analysis of public rebuke of anti-hero breast cancer narratives demonstrates the fixed normativity of heroism within breast cancer discourse. The stories of author and social critic Barbara Ehrenreich (2001) and journalist Wendy Mesley (2006) are examples where the cancer experience makes these narrators angry and challenging rather than simply self-reflective or thankful. Ehrenreich was publicly scorned for having a 'bad attitude' and 'needing therapy', while Mesley was charged with 'fear-mongering'. While disagreement over alternative views can be expected, these personal attacks on celebrity 'agitators' set tacit limits on the stories that other women are allowed to tell. Different points of view should be encouraged, as the emancipatory purpose of giving women voice is not realised when women are handed a script.

Yet criticising the highly reproduced generic cancer narrative still invites some discomfort. Not only do these stories build on an important feminist activist history, but they also offer helpful resources for many women trying to come to terms with a cancer diagnosis and to live through the difficult negotiations surrounding treatment and their personal lives. Illness narratives are an important genre, as illness presents as 'an occasion for autobiography' (Frank, 2000) and memoirs of illness can offer therapeutic value (Kleinman, 1988) and present 'openings to ethical ways of living' (Frank, 2000). In trying to make sense of the 'why me?' of the cancer diagnosis, narrative is a helpful genre because it offers

a way of ordering events, assigning roles and providing coherence to a confusing situation (Frank, 1995; Stacey, 1997; Salander and Moynihan, Chapter 8, this volume). When put under duress, people seek explanatory frameworks and willingly cling to the narratives offered to them (Frank, personal conversation, 15 April 2009). Yet that insistent need suggests that the narrative itself may get taken up without sufficient critical consideration.

I join Segal (2007) and Pezzullo (2003) in suggesting that, 30 years later, breast cancer narratives themselves require a counterdiscourse. In their repetition of the formulaic 'hero' narratives, breast cancer narratives have become normative and can be coercive. While the early narratives were rallying cries for women and women's health activism, the genre of breast cancer narratives that followed might have out-served its original emancipatory purpose. The narrative has become so scripted that at least two other important issues are left out. The first is the suppression of the anti-hero narrative, and the second is those features of the cancer story that betray the narrative arc. In addition to marginalising certain themes and content, the hero narrative also promotes an uncritical acceptance of biomedical discourse, as medical science and its practitioners can also be scripted with similar valour.

Beginning with the former, consider that 'stories of progress and rationality are tempting, but perpetuate the illusion of life as a steady upward learning curve in which all crises have a profound meaning' (Stacey, 1997, p. 15). Such mythologies encourage the reader to believe that suffering makes us wiser and serve to heroise those who suffer most. In *Undeclared* (2006), survivor Marsha Hunt wrote: 'Cancer's been a wonderful experience for me . . . One of the best experiences I've had' (Hunt, 2006, quoted in Segal, 2007, p. 14). Another survivor tells us, 'Cancer inspires me. I've been given a wake-up call that many people will never receive' (Donaldson, 2007, quoted in Segal, 2007, p. 4). However, certain health imperatives accompany that critical self-accounting inspired by life-threatening disease: be strong, be grateful. The reader is challenged to be a hero, to 'be like me' (Herndl, 2006, quoted in Segal, 2007, p. 4).

Many will embrace the hero metaphor for the comfort it provides. The hero's cohesive storyline denies the absences and gaps in the cancer story that can come from the futility of pain, the arbitrariness of disease or the pointlessness of suffering (Stacey, 1997). By erasing potential ambiguity or lack of meaning, these stories offer the reader truths about life with illness. The hero story also offers 'fantasies of power and control through the narrative rationalisation of progress and improvement' (Stacey, 1997, p. 15). Against the flattened feelings of pointlessness that

long-term illness can invoke, the suffering cancer patient can fit her understanding into a familiar structure of good triumphing over evil.

And indeed, this narrative offering clearly marks a positive step. Women who are in a position to take advantage of the optimism and camaraderie of survivor culture are likely to find resources to aid in their recovery. The isolating emptiness is not a better alternative. It is because the cancer diagnosis re-scripts the life story with 'ruthless editorial authority' (Stacey, 1997) that the cancer narrative is so important. Illness narratives pursue such questions as:

How should my life be imagined in such an unexpected context?
Can the self be reinvented to cope with the shock? What kind of
body hides the evidence of cancer so effectively? What kind of disease
disguises itself so skilfully?

(Stacey, 1997, p. 5)

Unfortunately, the new image of breast cancer promoted through pink ribbon activism brings with it a slew of other problems. The cheerfulness and consumer-oriented character of breast cancer survivor culture can be enormously alienating to women who do not have the networks of social support or financial means to participate in it and it may also unintentionally denigrate those who have 'failed' to survive (King, 2006a). Ehrenreich (2001) has argued that through the well-intended efforts of breast cancer survivor culture, the disease has been problematically transformed into a rite of passage rather than an injustice against which we must struggle. The political consequences of this reframing of breast cancer activism will be discussed shortly.

For all the benefit that the hero narrative can offer, it falters at the points where the cancer experience betrays the narrative. In his own cancer story, sociologist Arthur Frank writes,

I myself am no Phoenix [rising from the ashes]. Whenever one of my own medical tests requires 'further investigation', the skin that covers over the memories of my first cancer bursts . . . the pain of having cancer bears down on me again with all its terrible weight. Each time I learn how close to the surface those memories remain.

(Frank, 1995, p. 136)

Frank (1995) recognises that metaphors, and the narratives that reproduce them, are potent ways of understanding illness, but he warns

against the generic metaphors offered as storylines for others' self-stories.

Frank alerts us not only to the anti-hero narrative that does not get told but also of the failure of cancer 'survival' to fit into the narrative structure. The difficulty occurs because the hero story requires finality or closure. To be a survivor is to overcome adversity. Yet because there is no cure, the cancer story is never complete. While treatments end, and, as years go by, the chance of recurrence minimises, the former patient remains in remission—a postponement, but not finality. Frank uses the term 'remission society' to describe the people who are 'effectively well but could never be considered cured' (Frank, 1995, p. 8; see Frank, 2002). We learn from Frank that the failure of survivor stories is similar to the ineffectiveness of the Phoenix metaphor in capturing the complexity of the cancer experience:

they can present the burning process as too clean and the transformation as too complete, and they can implicitly depreciate those who fail to rise out of their own ashes... while the phoenix remembers nothing of its former life, the victim of some trauma... does remember.

(Frank 1995, p. 135)

In the end the renewal is never complete.

Survivor stories make for compelling literature: they combine the 'masculine' heroics of adventure narratives with the 'feminine' suffering and sacrifice of melodramas. They offer victims and villains, and dramatically 'pit the hero against the disease in a life-and-death battle. The hero usually has truth, goodness and the pursuit of knowledge on his or her side' (Stacey, 1997, p. 11). That same narrative structure of brave struggle against a sinister disease opponent⁵ found in the personal stories of women is reproduced in biomedical representations of the disease, thereby encouraging complacency with respect to the standards of medical practice. Indeed, *Globe and Mail* columnist Margaret Wentze's censure of Mesley's anti-hero auto-documentary (2006) assailed Mesley for 'having done cancer research a huge disservice' (Wentze, 2006) in her investigative journalism; suggesting, it seems, that personal breast cancer stories *ought* to support the medical model.

In the biomedical accounts, scientific progress becomes the hero. Medical research *will* produce the cure for cancer. *This* is the reason people are running, walking and cycling. In this story, the heroes of medicine are the victors who can save women from the horrors of their

bodies (see Leopold, 2000). Cancer is commonly characterised as the 'cells in chaos', or chromosomal 'anarchy' (see, for example, Angier, 1991; Duesberg, 2007). Through the progress of scientific discovery and knowledge, the fantasy of ultimate control is offered (see, for example, Janeka, 2007). With enough time and money, the public is told, the chaos will be brought under control and cures will be found (Stacey, 1997). Genomics and personalised medicine are conveyed in the media as a tantalising promise despite disappointing findings regarding the explanatory power of the human genome (Wellcome Trust, 2004) and the limited predictive basis of genes for the onset of common diseases like cancer and diabetes (Wade, 2009). The hero narrative instructs us to trust the doctors, as they know what is best for the female body that has become a battleground between good science and bad disease. We stand the best chance if we do as we are told: engage in the healthful behaviours advised by the medical experts, watch for early signs of breast cancer and report to our physicians immediately. It is worth reflecting on how the long suppressed 'voice' given to women tells stories where the masculine hero narrative of science plays out. Women's embodied knowledge, argued so fiercely by the early women's health movement to be missing from dominant health discourses about women's diseases, serves little purpose in this story, as women's participation is limited to side-line efforts like self-surveillance and fundraising for the large cancer foundations and hospitals.

The commercialisation of breast cancer activism: from personal responsibility to social action

The encounter with breast cancer invites both personal and social struggle. In this section, I demonstrate that once action shifts from individual reflection to social action, options are largely limited to an unquestioning support of the medical model. Despite various sites of contested knowledge with respect to disease aetiology, prevention and treatment, pink ribbon campaigns marvellously organise and direct many highly motivated individuals to participate in cause-related activities and campaigns that promote decisive verdicts on how breast cancer is best addressed personally and socially.

The cleansing finality and added optimism of the problematic hero narrative is magnified by corporate interest in the disease and the lucrative marketing opportunities that breast cancer offers. Businesses looking to sell more products to female consumers have been quick to latch on to changing attitudes towards breast cancer, and the pink

ribbon industry that has emerged as a result is deeply dependent upon a positive image of the disease. Sickness and death do not sell nearly as well as images of survivors who are uniformly youthful, feminine, attractive and optimistic.

Corporations are not alone in promoting an overly optimistic account of the struggle against the disease. Large non-profit cancer foundations such as the Canadian Breast Cancer Foundation, the Canadian Cancer Society and the American Cancer Society have used similar tactics in promoting the cause. King (2006a) recounts attending glamorous fundraising events featuring celebrity guests and pink-ribboned designer swag, where one could come away with the impression that breast cancer is a disease from which people no longer die. The breast cancer foundations have discovered that upbeat messages result in more devoted individual fundraisers and more generous corporate sponsors (King 2006a).

But the message—'there's hope!'—needs to be more than reassuring; it also needs to motivate civic action. The public are told that the war against breast cancer cannot be won without community support and involvement. Many people understandably want to contribute and become involved in that captivating message of hope, cure and survival. Here the ethic of personal responsibility, described by Bella (Chapter 2) to be a wilful compliance by individuals to follow health promotion prescriptions under the guise of 'patient empowerment', compels many to take action. First, there is the responsibility that one can take for one's own and one's family's health: 'Eat your vegetables, don't smoke, exercise, and get your yearly mammograms' are regularly pitched as the formula for protection against breast cancer. The second step is community involvement, and the major breast cancer foundations provide ample opportunity for the concerned public to work towards finding the cure.

Most of the health and lifestyle messages about breast cancer are not meant simply to inform, but also to evaluate and govern people (Segal, 2007). 'Health-conscious' lifestyle choices are preferred over others, and women ought to have children, do it while they are relatively young, and breastfeed them (Yadlon, 1997). Despite scientific studies failing to show that a low-fat diet and regular exercise can reduce cancer (Hunter et al., 1996; Kim et al., 2006; Smith-Warner et al., 2001),⁶ we still routinely encounter breast health diets and risk-reducing fitness plans that are endorsed by the Canadian Cancer Society and others. There is also no evidence that a positive attitude has a bearing on breast cancer occurrence and outcomes (Allegmang, 2002), and experts disagree

about the benefits of breast self-examination (Baxter, 2001) and regular mammography on women under 50 (Ringash, 2001; for a history of mammography use and controversies, see chapter 2 of Batt, 1996).⁷ Despite these negative and uncertain findings, the mainstream message still champions without hesitation the benefits of positive attitude, healthy lifestyle, breast examination and mammograms.⁸

What these guidelines *qua* imperatives amount to is a message of individual responsibility. With each highly publicised media report of the latest breast health promoting activity, come the burdens and responsibilities that new-found health knowledge demands. If you have not committed to cancer-reducing activities, the cancer may be your fault. Even though we hear the stories of young, health-conscious mothers being diagnosed with breast cancer, that seems to only add some fascination to the narrative—how unfair and tragic for her as the 'why me?' question becomes harder to answer. But these cases have not led to serious questioning of whether our causal account is indeed correct. If incorrect, our prevention strategies and activist efforts may be similarly misguided.

The aetiology of breast cancer resides within the genetic-environmental matrix. Most expert resources on breast cancer cite genetic inheritance as the primary cause; the heterodoxy cites environmental cause. While the current tendency to cite 'genetic-environmental interaction' (NIEHS, 2007) seems to quiet this disagreement, the concept is in fact so broad in its possibilities that it does not provide decisive support for any one prevention strategy over other reasonable contenders, nor does it explain to many breast cancer patients why this happened to them. For example, the National Institute of Environmental Health Sciences (NIEHS) provides this broad claim about the cause(s) of breast cancer:

Although scientists have identified many risk factors that increase a woman's chances of developing breast cancer, they do not yet know how these risk factors work together to cause normal cells to become cancerous. Most experts agree that *breast cancer is caused by a combination of genetic, hormonal and environmental factors.*

(NIEHS, 2007, p. 1, emphasis added)

This statement indicates that the specific causes of breast cancer are still unknown.

Almost every knowledge claim about breast cancer is disputed by a more than inconsequential minority view (for a review of the breast

cancer debates, see Sherwin, 2004). Women seeking information in order to prevent breast cancer, understand why they got it, or avoid its reoccurrence will likely be surprised, if not confused, when they come across alternative views on the aetiology, prevention and treatment of breast cancer. One might expect the conflict of information to lead to frustration and disengagement, but the popularity and success of pink ribbon activities and events suggests otherwise. Without a good starting point for understanding the disease, one can easily find oneself following health and prevention recommendations blindly. This health promoting strategy is far from ideal. Furthermore, because there is always more that we could do or could have done by way of lifestyle, positive attitude or stress reduction, the potential for victim blaming (see Nettleton and Bunton, 1995; Veinot, Chapter 3) arises, whether self-inflicted or determined by others.

This focus on individual responsibility for one's health links breast cancer discourse back once again to narrative genre, as personalised stories entrench and naturalise the focus on the individual and make stories that are not individually focused harder to tell (Segal, 2007). Segal cites Ehrenreich's (2001) and King's (2006b) observation that many breast cancer chat groups and internet message boards discourage contributors from raising questions about environmental carcinogens, pharmaceutical company profits and what Ehrenreich called the 'Cancer Industrial Complex' (Segal, 2007). While gently explained and justified by the webpage-moderators as a desire to focus on healing through personal stories, these efforts exert a conservative influence on breast cancer discourse by making some stories more permissible and understandable than others (Segal, 2007). Those marginalised stories raise questions about the practices and priorities of the cancer cure industry at large and propose a shift in responsibility from individuals to governments and industry to initiate large-scale community prevention efforts.

The presence of doubt and dissent can seriously compromise many organisational efforts to campaign for the cure, and thus there is at least motive to silence alternative views. Returning to the genetic-environmental debate over what causes cancer, the campaigns for the cure and the cancer foundations that organise them are quiet on the environmental causes of breast cancer. Even though only a small (but not insubstantial) number regards breast cancer to be primarily environmental (see Eisenstein 2001; Rothman 1998; Steingraber 1998, 2000), it is generally accepted that some cancers are caused by environmental toxicants. While Marin County and other San Francisco Bay Area activists⁹ will strongly reject the sceptical estimate of 2 per cent

(Steingraber, 2000), even this conservative number suggests the need for a shift in cancer research priorities. Sandra Steingraber has commented that if we take that minimal number to be accurate:

two percent means that 10,940 people in the United States die each year from environmentally caused cancers. This is more than the number of women who die each year from hereditary breast cancer—an issue that has launched multi-million dollar research initiatives. This is more than the number of children and teenagers killed each year by firearms—an issue that is considered a matter of national shame. It is more than three times the number of non-smokers estimated to die each year of lung cancer caused by exposure to secondhand smoke—a problem so serious it warranted sweeping changes in laws governing air quality in public spaces.

(Steingraber, 2000, p. 31)

Furthermore, Steingraber adds, 'none of those 10,940 Americans will die quick painless deaths. They will be amputated, irradiated, and dosed with chemotherapy' (Steingraber, 2000, p. 31). Despite these staggering numbers, Pezzullo has added, cancer activists continue to encounter significant obstacles when attempting to bring environmentally related carcinogens into the foreground of US public dialogue (Pezzullo, 2003). This is also the case in Canada. In the CBC documentary, 'Chasing the Cancer Answer', Wendy Mesley stunned a chief executive from the Canadian Cancer Society, the organisation that sponsors most national awareness and cure campaigns, by asking her why more pressure has not been put on manufacturers to keep known carcinogens out of household products or to keep those products off of the store shelves (Mesley, 2006). Caught on camera, the executive gawked awkwardly and then answered 'I can't answer that question' in an uncertain voice. The American Cancer Society has been similarly criticised by environmental groups for downplaying environmental causes of cancer and not taking a stance on any environmental legislation (Pezzullo, 2003).

Amidst the messages of hope and triumph, breast cancer marketing campaigns seem to erase from public consciousness the fact that incidence rates remain stubbornly high and newly diagnosed women face essentially the same treatment options that they did 40 years ago: surgery, radiation, chemotherapy. Mortality rates have been declining slightly since the early 1990s, but this offers little comfort to the nearly 25,000 Canadian women who will be diagnosed with breast cancer in 2009 (see note 1). The only recent new options for the prevention of

breast cancer are pharmaceuticals like tamoxifen, which, while thought by most to be effective in reducing the risk of breast cancer recurrence, also brings with it serious side effects including increased risk for uterine cancer, and drastic surgical interventions like prophylactic mastectomies (King, 2006a).

Yet people will often point to the good work that breast cancer campaigns perform in raising 'awareness' and may argue that regardless of the corny accompanying messages, pink ribbon products and five kilometre runs raise large amounts of money for a good cause. But this position raises its own set of questions: What exactly are we being asked to gain awareness of? And how is the money being spent? For those campaigns and events that venture into specifics, awareness usually means preaching the benefits of early detection through mammograms. Although this approach might prompt people to discover if they already have breast cancer, this selective awareness leaves the aftermath of that diagnosis in the hands of the individual (as was the previous responsibility to fend off the disease), and ignores those tougher questions about what could have prevented this and so many other cancer incidences. These campaigns also promote ignorance regarding the limitations of mammography as a tool in the fight against breast cancer. Mammography is not a preventive technology, as its proponents often claim. It does not keep people from getting cancer and its effectiveness in reducing mortality rates by earlier detection has not been confirmed. While they may help with early detection (albeit with numerous false readings), mammograms expose sensitive breast tissue to radiation, which may, over time, cause tumours to grow (Weisman, 2000). Some researchers say the small decreases in breast cancer deaths in recent years are better explained by the widespread use of tamoxifen and other new chemotherapy treatments than by mammography (King, 2006a, 2006b).

Some might argue that an institution, flawed as it may be, that gives women hope, should not be criticised. Indeed, the participants who organise, raise funds and participate in athletic events often do this with joy and pride. Testimonials from participants of the *Weekend to End Breast Cancer*, a nation-wide event where each participant raises a minimum of \$2000 in sponsorship contributions in order to walk 60 kilometres over 2 days, frequently speak of feeling hopeful, and enjoying the community, friendship, fun and support. In a video commemorating the 2007 Edmonton Weekend, one participant fights back tears and comments, 'you will never ever ever be prouder of yourself than you are on a day like today'. Another says, 'you come through this

experience with a sense of "I can do anything"' (Edmonton WEBC, 2008). However, when considering the time, energy and physical exertion requested of the participants in the various races for the cure, it is important to be sure that people's goodwill is not being exploited. When further considering the large sums of money raised through that collective labour,¹⁰ the need for transparency regarding how those funds are distributed becomes evident. Public discussion is warranted over what health strategies get promoted and which get suppressed.

There is a lot of fear and uncertainty surrounding breast cancer. While women surely need hope, this should not and need not come at the expense of reliable information. To suggest otherwise is paternalistic and out of sync with current norms of patient autonomy and informed decision-making (for a discussion of paternalism in health care, see Salander and Moynihan, Chapter 8, this volume). Women do not need neatly packaged messages that misinform about progress being made or provide decisive prevention and screening programmes that are contestable. What is needed is reliable information so that women can make informed decisions.

The term 'pinkwashing' has recently been applied in the context of critiques of the commercialisation of breast cancer activism to suggest that pink-ribboned activism is ineffective. The term 'pinkwashing' was lifted from the environmentalism lingo, where 'greenwashing' refers to the phenomenon of disingenuous environmental appearances. Because of the commercial caché of 'being green', consumers often have difficulty discriminating between talk about being green and actual action being taken to stop environmentally destructive practices (Pezzullo, 2003). This is seen in the ironic claims made by some mining and gas companies who promote themselves as 'green' industries. 'Pinkwashing' has been used in the context of campaigns for the cure and awareness campaigns for undermining the very efforts that they purport to support. The Avon Cosmetics company, for example, sponsored the largest US breast cancer fundraising event, the *Race for the Cure*, for many years, while still manufacturing cosmetics containing toxic chemicals that are known or suspected carcinogens (King, 2000b).

It has even been proposed that the commercialisation of the breast cancer cause has overshadowed the search for a cure (King, 2006a). The money raised by pink ribbon products comprises a tiny percentage of total funding for research, and corporations benefit from conveying an image of corporate responsibility without donating significant profits to breast cancer research. Non-mainstream breast cancer activists insist

that many of the large pink ribbon events spend a third or more of their earnings on overhead and advertising (Leopold, 2000; Think Before You Pink, 2007). Perhaps because people are made to feel good about ethical purchasing, consumers who are genuinely concerned about breast cancer are not engaging in effective consumer activism, such as urging corporations to direct their largesse towards preventative and curative science. Breast Cancer Action, the organisation that first introduced the term 'pinkwashing', reminds the public that the most effective way to support the cause is to give directly to those organisations whose work they support rather than filtering it through the commercial efforts (Breast Cancer Action, 2009).

Conclusion

The pink ribbon promotes a message of health and hope that is undeniably appealing but largely uncritical. By capitalising on the rhetoric of women's health activism, the glory of survivor stories and slick marketing, it inspires many to pursue prescribed patient empowerment strategies and 'take charge' of their health both at the individual and community level. These individual responses are problematic in light of competing knowledge claims and open-ended demands on people's time, energy and commitment to health. The community responses are consistently missing critical engagement with those health promoting strategies. It was no small feat that early women's health activists created channels for participation in setting research and treatment agendas. Within the women's movement, woman-centred care has been seen as impossible if communities of women did not have a role in defining their own health care needs and goals. This important position must be retained. Everyone wants to put an end to breast cancer, and it hardly warrants mention that running, walking and campaigning for the cure will not *end* breast cancer. These activities raise awareness and funds that can then be put to use. Activists must concern themselves with and involve themselves with the details and not allow 'campaigns for the cure' to serve corporate interests under a pink wash of corporate responsibility rather than the needs of women.

Notes

1. In 2009, an estimated 22,700 Canadian women will be diagnosed with breast cancer and 5400 will die of it (Canadian Cancer Society). In the US, it is estimated that 192,370 women will be diagnosed with and 40,170 women will die of breast cancer in 2009 (SEER).

2. Even though medical research has not established any connection, the cultural imaginary of the 'cancer personality' is deeply and historically rooted (see Baines, 2008).
3. One in eight women in industrialised countries will be diagnosed in their lifetime and endure debilitating treatment (SEER; Canadian Cancer Society). Caught early, the prognosis is good, however the chance of recurrence and repeated treatment will remain high.
4. Lorde was, of course, breaking several silences. Along with telling a personal story and a woman's story, her politics lead her to question many feminine norms (like hiding the mastectomy with prosthetic devices) placed on breast cancer patients. She also challenged the meaning of her illness—for instance, she likened her one-breastedness to tribal warriors who remove one breast in order to sharpen their use of bow and arrow in combat.
5. This structure goes against Susan Sontag's (1978) well-known misgivings about using war metaphors in cancer narratives.
6. While the association between the incidence of breast cancer and high-fat diets has been supported in ecological and case-controlled studies, prospective studies and Smith-Warner et al.'s (2001) pooled analysis of prospective studies do not support this association.
7. A systematic review conducted by the Canadian Task Force of the trial data on mammography for women aged 40–49 with average risk of breast cancer found that 'although the trials constitute level I evidence, at present their conflicting results, methodologic differences and, most importantly, uncertainty about the risk: benefit ratio of screening mammography preclude the assignment of a "good" or "fair" rating to the recommendations drawn from them' (Ringash, 2001, p. 469).
8. It took 6 years after the publication of negative findings regarding breast self-examination by the Canadian Task Force on Preventive Health Care (Baxter, 2001), and its ensuing media frenzy for the Canadian Cancer Society to adjust its guidelines regarding breast self-examination.
9. Marin County, California is an affluent geographic region with extremely high incidences of cancer. The San Francisco Bay Area has a strong breast cancer activist community that endorses the heterodox view that these regional incidence rate are due to environmental toxicants unique to the area (Klawiter, 1999). They reject the conclusions drawn by several epidemiological studies suggesting that the high rates of breast cancer stem from the socio-demographics of the region. Affluence is associated with numerous breast cancer risk factors, such as delayed childbirth and nulliparity (see Clarke et al., 2002).
10. A 14 June 2009 media release from the Princess Margaret Hospital Foundation in Toronto reports that the second annual 200 km Ride to Conquer Cancer generated \$14.5 million in funds from its 3530 participants across Canada (Princess Margaret Hospital Foundation, 2009). Toronto's fifth annual Weekend to End Breast Cancer, a 2-day 60 km walk held in September 2007, was similarly successful, with 5521 walkers raising \$17.3 million in funds to benefit research and patient care at Princess Margaret Hospital (Princess Margaret Hospital Foundation, 2007).

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