

The Sense of an Illness and Breast Cancer Culture

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L'influence du cancer du sein sur la pensée positive pose problème. Cette force culturelle dominante exige une stricte conformité à la bonne humeur, une perspective qui dénie la tristesse de plusieurs patientes atteintes du cancer du sein. Des témoins compatissants avec les malades devraient les aider à retrouver la santé.

In her account of her personal breast cancer experience, essayist Barbara Ehrenreich denounces the “cheerfulness of breast cancer culture [that] goes beyond mere absence of anger to what looks, all too often, like a positive embrace of the disease” (48; 27). As on many other topics in her professional life, Ehrenreich writes against the grain. Endless books, hundreds of websites, thousands of blogs and chat rooms from all corners of cyberspace relentlessly insist on the personally enriching opportunities that breast cancer offers (by implication, anyone with any other form of the disease is hopelessly disadvantaged). Breast cancer culture, moreover, is also heavily invested in guaranteeing fun; many opportunities for immediate gratification play alongside the possibilities for more profound inner transformations. Breast cancer culture offers enticing performative aspects: trying on new looks, experimenting with wigs and make up, indulging in all shades of pink. It encourages participation in

energetic hikes sporting silly hats, face paint, and t-shirts with trendy breast cancer slogans, and even camping out in style, with massages for the foot-weary, and cozy campfire sing-a-longs. It provides shopping therapy for endless cancer paraphernalia. It means cheering on cancer and feeling good about it.

To find a dissenting voice like Ehrenreich’s, especially in the early, confusing days of diagnosis and treatment, is a challenge.¹ Nonetheless, critiques of the breast cancer hype are growing. Recognizing the exclusionary nature of the breast cancer campaign, Toronto’s Princess Margaret Hospital renamed its “weekend to end breast cancer” walk to the “weekend to end women’s cancers,” but the 2010 advertising material promoting the changed event remained the same: crowds of happy, smiling participants who are clearly “putting the fun in fundraising” (“Weekend to End Women’s Cancers 2010 promotional material). The message is meant to empower: join the team, pump pink and all will be well. Samantha King’s 2006 study, *Pink Ribbons Inc, Breast Cancer and the Politics of Philanthropy*, critiques this consistently upbeat marketing of breast cancer which consumes huge sums of money, time and energy while reserving little, if any, place within its vast reach to seek the disease’s causes and advocate its prevention. Referring to a “tyranny

of cheer,” she “assesses the extent to which the market-driven, optimistic culture of survivorship is implicated in the exclusion of issues such as access to health care, poverty, and environmental racism from the agenda of the mainstream breast cancer movement and the political and medical institutions it is ostensibly seeking to change” (xxxiii). King sees this breast cancer culture of cheerfulness as limited and limiting and failing many women, but this failure extends well beyond inadequacies of physical care in the health and social systems to a wide range of emotional and psychological costs.

The breast cancer culture of cheer is unmistakably female. The reasons for this gendering are both cultural and biological. Breast cancer is directly related to a part of the female anatomy which, whether culturally valued or objectified, draws attention. While men, too, can get breast cancer, the disease overwhelmingly targets women. The incidence rate of breast cancer and the number of actual cases are widely disparate between males and females. The proportion of the female population diagnosed with breast cancer, moreover, is exceptionally high, higher than for other forms of cancer, including specifically female cancers. Other cancers may prove more deadly, but only certain types of skin cancers are more frequent among women.² The Canadian Can-

cer Society estimate of breast cancer cases for 2010 was 23,200 for women, and 180 for men. If the numbers associate breast cancer so strongly with women, is it possible that they also draw to the disease some of the social demands with which women have had traditionally to contend? A culture of cheer hints disturbingly at the nineteenth century's angelic and true ideal woman, who was expected to submit unquestioningly to adversity; to suppress rather than express justifiable anger.³ The culture of cheer may very well help some breast cancer patients, but for others, it is more damaging than healing; its dominant status in mainstream culture results in its invalidating experiences that deviate from it. In denying the emotions and perceptions of breast cancer patients who are unable to conform to its ideology, it intensifies their isolation and alienation at one of the most vulnerable times in their lives. Following a pattern familiar in women's history, the breast cancer culture of cheer operates as another mode of negating the full spectrum of female experience.

Diane Price Herndl locates in breast cancer autobiographies the same "relentlessly upbeat" (223) tone embraced by fundraisers and marketers.⁴ While in the range of works that she examines by women from different backgrounds some show "a greater acknowledgment of fear and despair," she finds the tone in all ultimately "celebratory" (224). Herndl's study addresses the act of "writing a new identity" after a breast cancer diagnosis, and the challenge in doing so of "creating an ethical narrative." The issue that Herndl addresses specifically for autobiographical writing is one that Ehrenreich's essay and King's critique probe for the breast cancer culture: "Overwhelmingly, writers of breast cancer autobiography construct narratives that attempt to paint a positive picture of recovery and healing," Herndl observes, and questions the extent to which "such narratives [are] unproblematically true?" (222). And if untrue, or only

partially true, what effect does this have on their audience, especially on other breast cancer patients who form a large percentage of their readership? What are the implications of half-truths around a potentially fatal disease?

We all cope as best we can when faced with dire happenings, which includes the diagnosis of a life-threatening illness; if the breast cancer culture of cheer offers hope, action, or indeed even serves as a distraction, and raises unprecedented cancer research funds to boot, then it is serving multiple purposes, and a cynical view of it seems misplaced. To its credit, the culture of cheer does not ignore those who have died from the disease; memorial moments are part of the ritual at most events and embracing the culture provides a means of coping with the loss of loved ones for many. The cheerfulness culture is not disabling for everyone. But uncontested, breast cancer optimism becomes another source of psychological oppression intensifying the oppression that the disease itself brings. Breast cancer cheerfulness grows, in large part, out of the time beyond diagnosis, and treatment, when patients look back with some degree of regained normalcy. And yet, the culture of cheer assumes to speak with authority for all aspects of the breast cancer experience. It demands conformity and compliance. It generalizes on to those newly diagnosed as well as those dying from the disease the perspective of the recovering and the recovered, and of those who experience breast cancer second hand and need the cheerfulness culture to carry on. This culture facilitates a social norm of expected and acceptable behavior for breast cancer patients that begins to inform all cancer care. In the stressful practice of oncology, a cheerful, upbeat patient is much more manageable, less time-consuming, and much less emotionally and psychologically draining than a distraught, angry or even sad one. The culture of cheer creates a standard against which all

responses to the disease are measured and even minor deviations quickly begin to signal another, additional pathology.

As Herndl found, the number of breast cancer autobiographies is huge, ranging from works by creative and professional writers to those who have never written before. The compulsion to tell is a complicated one. It suggests the trauma of the breast cancer experience, the need to re-tell and re-visit, and perhaps in the culture of cheer ultimately to re-fashion, even reverse, the sense of a wounded self. The compulsion to tell reflects the overwhelming need to come to some kind of understanding about how this could have happened. How could anyone, with a risk factor of two in a thousand for this dreaded disease, end up with a tumor that requires surgery, chemotherapy and radiation, the outcome of which is only a faint hope that the disease has not spread and that the cancer will not recur. As writer Carol Shields put it, "I haven't begun to absorb the reality of it. I still wake in the morning in a state of disbelief. I have breast cancer. Impossible" (16).

But ultimately the compulsion to tell speaks to our deep need as human beings to have someone bear witness to both the joys and sorrows of our lives.⁵ We need to tell but also to be heard. Witnessing affirms our feelings and experiences whatever they may be. The sadness of breast cancer stories also requires an audience. Sadness is not necessarily the same as despair and defeat. The mainstream breast cancer movement could do much good by acknowledging more fully the profound sorrow of the breast cancer experience; the fear, dismay and suffering of diagnosis and treatment; the need for a deep and unaccommodating mourning for the self and for what life has wrought; and a calmer but no less passionate cry about what is coming next.

In *Illness as Metaphor*, Susan Sontag talks about humankind's dual citizenship in the "kingdom of the well and ... the kingdom of the sick."

The “night-side of life,” she dubs the latter (3). It is a lonely, desolate place no matter how many others might be milling around, partly perhaps because it assumes the perspective of the perpetual looker-on, separated by a somber distance from the familiar and vibrant. In the kingdom of the sick we are de-centered, sidelined from the action and energy that drive the world. Sontag’s talk of “kingdoms” seems to invoke T. S. Eliot’s deathlike kingdoms inhabited by his “hollow men” with their implied, disturbing connections between injured bodies and broken minds (75-80 *passim*).

The words, “you have breast cancer,” are strange, distant, bewildering, yet their simplicity is unequivocal; their clarity, authoritative. The diagnosis of a potentially death-threatening disease thrusts us into the midst of the solitary, confusing kingdom of the sick where no one wants to be. Concealed beginnings and unknown destinations make the journey there and back impossible to map, indeed, throw into numbing doubt the possibility of return.

Perhaps the greatest difficulty for the ill remains the uncertainty; medical progress these days makes excellent prognoses a reality, even for serious illnesses, offering hope for substantive recovery, but doubts still linger, slip in amidst the hope, and whisper defeat. There is the slow pace, and long waiting for endless medical appointments, as well as the small, mostly indiscernible signs of improvement. The loss of control, the difficult treatments, the unpredictable setbacks offer no easy comfort to the sick. They bring not only the specter of mortality, but the fear that the world we have known and loved is lost to us forever. In its place rears the haunting presence of a curtailed, lobbed-off life, with an endless array of physically and spiritually debilitating compromises; they bring before us, too vividly by far, the threat of a half-lived existence so different from the fullness that we were experiencing perhaps only the day, even the hour before, and so distant from our hopes and dreams for the

possibility of future accomplishments and fulfillments.

Solace in stringent difficulties never comes easily. At these times, a culture of cheer is inadequate. One of the old stand-by panaceas for misfortune—the thought that affliction, of whatever kind, builds character—is not entirely convincing. Its close cousin, the prospect that we can benefit from misfortune to change and improve our lives, is one that the breast cancer culture finds particularly appealing, but it appears even more doubtful. Perhaps this is true for those who face extreme adversity for the first time; or those who, for whatever reason, have been living unexamined lives in which the priorities and values that make us fully human have gone awry. But for the rest of us, for most of us, affliction speaks loudly and forcefully the language of loss and depletion. The larger global perspective too suggests that these consolations stand on shaky ground. The wretched of our earth have shown us often enough that misery only breeds more misery. “Fear, envy and despair” formed Satan’s triumvirate in his fall and they continue to lurk always, to some degree, in misfortune and affliction, regardless of how these manifest themselves (John Milton, *Paradise Lost*, Book IV, “Argument”). Spiritual growth and blessedness do not spring from the hard ground of poverty or death-threatening disease. Wretchedness does nothing to improve humanity. For all their trials, the starving, the sick, the oppressed are not better people. They are only more miserable, and ultimately more vulnerable to violence and destruction both in themselves and in others. What does help is global aid, a practical form of bearing witness to the needs of others.

The compassionate response to human need is a powerful solace. Acknowledging the sorrows and suffering of breast cancer patients diminishes the gap between Sontag’s two kingdoms. Most breast cancer patients are forced to go public because the disease changes their appearance.

The social acceptance of the need to mourn for a lost self instead of joining the culture of cheer as reluctant masqueraders would help many to move forward in coping with the physical and mental brutality of the disease. Family, friends, colleagues and neighbors, whose acts of kindness recognize the needs of the sick, are already doing this. These individual groups also reflect a breast cancer culture, one that, in bearing witness to this particular time of pain and sorrow, opens up the possibility of looking beyond it, not from the perspective of hyped cheer, but through the resources of the human spirit found in both the self and in the compassion and sympathy of others.

The acknowledgment of suffering, moreover, need not be all cheerless. Even in the midst of sorrow, the human spirit retains the capacity to recognize genuine humor and engage with irony. The many kindnesses of family and friends are intensely gratifying, but also provide moments of startling insight into the self, into what we may mean to others, into past kindnesses to others returned with generous interest. It is a kind of Tom Sawyer-like experience. In the adventures named after Twain’s boy hero, Tom and his friends run away to become pirates; they only run as far as a nearby island, and soon discover that the townspeople are searching the river for their bodies. Tom sneaks back home one night to learn more, and overhears his Aunt Polly’s heartfelt eulogizing of him. Moved to tears, he quickly succumbs to “a nobler opinion of himself than ever before” (Chapter 15, 417). This is a joyous moment, one worth coming alive for again.

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¹bcaction.org is the website for a helpful, activist organization

²The Canadian Cancer society website, under Breast cancer statistics, states: "Breast cancer is the most common cancer among Canadian women (excluding non-melanoma skin cancer)."

³The cult of true womanhood was first identified by Barbara Welter. The true woman's transatlantic counterpart is the angel in the house, which is also the title of a poem by Coventry Patmore (1854); literary examples of the type populate the Victorian novel.

⁴Herndl's designation of these narratives as "autobiographies" is problematic since, as she acknowledges, they deal with diagnosis and recovery, and hence, are autobiographies of the cancer rather than of the author. As the ambivalence around the term "survivor" suggests, many breast cancer patients reject being identified by the disease. Herndl's study addresses issues of identity thus explaining in part at least her choice of the term.

⁵Cathy Caruth's work on trauma and, to a lesser degree, Herndl's interpretations of Kelly Oliver's theories on witnessing are suggestive for an understanding of the reactions and responses to being diagnosed with a potentially fatal disease, and the subsequent need to tell about it.

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The Breeze, Resting

Late summer wind, encouraging
the phlox
The breeze rests
and summer music fills the air.

Age, and the threat of tomorrow,
diminishes somewhat
Perhaps this,
another time only, not the end.

We know much has not
been part of our experience
We nod and smile in an amiable way,
sometimes, but the challenge remains.

Music sublime paints the scene
of late day
And sunlight on flowers
illuminates all for now.

The flowers nodding, smiling for a time.

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