



The breast-cancer-ization of cancer survivorship: Implications for experiences of the disease



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ARTICLE INFO

Article history:

Received 8 October 2013

Received in revised form

22 February 2014

Accepted 27 March 2014

Available online 28 March 2014

Keywords:

Canada

North America

Cancer

Cancer survivorship

Biosociality

Interviews

Discourse analysis

ABSTRACT

Numerous observers have commented on the cultural prominence of breast cancer in North America. However, although popular and biomedical conceptions of cancer survivorship have been influenced to an inordinate degree by breast cancer, few researchers have examined the impact of dominant discourses on people diagnosed with other forms of cancer. Drawing on interviews with 32 Canadian men and women with a history of cancer conducted between 2010 and 2013, I demonstrate that breast cancer became central to their *own* experiences of cancer, providing an important lens through which to understand the effects of the disease. The effects of these comparisons were diverse, leading some participants to want to differentiate themselves from this implicit norm, leading others to downplay the seriousness of their own forms of suffering, and amplifying a sense of shame and stigma in yet others.

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When I first heard that Rancic came public with her breast cancer battle, I rolled my eyes. When will a celebrity come out about a less popular cancer? Then I automatically regretted my bratty feelings and felt sympathy for Giuliana. Cancer is cancer. And, as we know, cancer, well, it sucks ~ Chelsea, 'Adventures with my enemy Melanoma' blog, 19 October 2011.

1. Introduction

In 2001, Barbara Ehrenreich observed that breast cancer had become "...the biggest disease on the cultural map, bigger than AIDS, cystic fibrosis, or spinal injury, bigger even than those more prolific killers of women – heart disease, lung cancer and stroke" (p. 45). In the dozen years since the publication of her controversial essay, breast cancer's star has not noticeably diminished. This dominance makes itself felt in a variety of ways, from the visibility of breast cancer in the media (Seale, 2002; Clarke and Everest, 2006; Kedrowski and Sarow, 2007; Kromm et al., 2007), to the abundance of research into the experience of breast cancer 'survivorship' in comparison to other cancer sites (Moynihan, 2002; Aziz, 2007; Rowland, 2007). For these reasons,

bloggers have now begun to talk of 'pink envy' and 'breast cancer envy' – terms that convey (only half jokingly, one suspects) the growing sense of resentment many people diagnosed with non-mammary-related cancers have begun to feel regarding the heightened profile of breast cancer (see Chelsea, 2011; LinnieGayl, 2011).

To date, although a variety of compelling critiques have been mounted of the cultural prominence of breast cancer and the hegemonic narratives regarding the disease, for the most part, these critiques have focused on the impacts of dominant discourses on women diagnosed with breast cancer (e.g., Ehrenreich, 2001; Jain, 2007; Sinding and Gray, 2005; King, 2006; Segal, 2007; Kaiser, 2008; Sulik, 2011). However, as Segal (2012) makes clear, although the 'new and improved breast cancer survivor' seems to constitute the archetypal figure in these narratives, the triumphal cancer story operates well beyond the confines of breast cancer (see also Stacey, 1997; Seale, 2001; Little et al., 2002; Bell, 2012). In this article I examine the impacts of the cultural dominance of breast cancer in North America – and the semiotic collapse of cancer/breast cancer it appears to have engendered – for people diagnosed with *other* malignancies. If breast cancer has become the paradigm for understanding cancer 'survivorship' (life with and beyond cancer) more broadly, what effects has this had on people diagnosed with the disparate collection of diseases encapsulated under the cancer label?

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1.1. Cancer survivorship, biosociality and breast cancer's rise to dominance

In many respects, the history of the concept of cancer survivorship illustrates the emergence of cancer as a distinct form of 'biosociality'. Rabinow (1996) introduced the term to describe the new forms of collectivization organized in the context of growing knowledge about genetic diseases and risks, which saw people asserting the commonality of a shared genetic status and the new 'truths' it inscribes. Although researchers have examined biosociality primarily in relation to the transformations in identity engendered through new forms of genetic knowledge (e.g., Gibbon and Novas, 2008), the concept has also been used more loosely to signify the ways in which practices of science, public health and medicine enable the formation of new subjects and collectivities based on shared illness or 'somatic' identities (Rose, 2007; Klawiter, 2008). It is precisely this shared somatic identity that the initial conceptualization of the 'cancer survivor' articulated.

Mullan (1985) laid out the parameters of the concept in a commentary published in the *New England Journal of Medicine*. A young physician with a history of cancer, Mullan argued that there was one path for people diagnosed with the disease: that of survival, dominated by dealing with the physical and psychological effects of diagnosis and treatment. Although cancer is actually a collection of more than 100 distinct diseases with radically different effects, treatments and outcomes, Mullan's concept asserted a common ground between people superseding their type of malignancy (and treatments and likelihood of survival), along with other forms of difference, such as those based on gender, age and ethnicity. This discourse on the 'cancer survivor' thus served to articulate a new category of person – one with a unique biomedical and psychosocial profile (Bell, 2012).

In 1986 Mullan joined with other American cancer survivors and health professionals to create the National Coalition of Cancer Survivorship (NCCS): a survivor-led advocacy organization. Importantly, although ostensibly a US organization, the NCCS was also influential in Canada, and Canadians numbered amongst its general and board membership (Batt, 2011). The advocacy efforts of the NCCS were instrumental in the development of an Office of Cancer Survivorship within the National Cancer Institute (NCI) in 1996, a move that dramatically increased the profile of cancer survivorship and the allocation of earmarked NCI funding (Bell and Ristovski-Slijepcevic, 2013). The cancer survivorship movement continued to gain momentum throughout the late 1990s and into the twenty-first century, assisted by the efforts of high profile celebrity survivors such as Lance Armstrong and his LiveStrong Foundation. However, the 1990s also saw the consolidation of the breast cancer movement, which emerged independently of the cancer survivorship movement, although there were certain areas of overlap and convergence.

As Klawiter (2008) has documented, the U.S. breast cancer movement actually consisted of three distinct but overlapping 'cultures of action': cancer detection and screening advocacy, women's health advocacy, and activism around cancer prevention in the context of environmental activism. Breast cancer was not the predominant focus of these movements; instead this focus congealed over time, especially at the national level. For example, four of the seven founding members of the National Breast Cancer Coalition (NBCC) were feminist cancer organizations, not breast cancer organizations, and none of the initial feminist cancer anthologies privileged the perspectives of women with breast cancer above and beyond those of women with other types of cancer (Klawiter, 2008, p. 282). As should be evident, cancer 'survivorship' was not a specific focus of the movement, although the NCCS was one of the founding members of the NBCC (NCCS, 2013). However,

despite the varied goals of the organizations comprising the 'breast cancer movement', breast cancer soon became the rallying point for the movement at a national level, with the NBCC's activities solidifying around the need to address the inadequacy of scientific research on breast cancer; the lack of medical progress in preventing, diagnosing and treating the disease; and the absence of the voices of breast cancer survivors at the policy level (Klawiter, 2008, pp. xx–xxi). As an advocacy organization, the NBCC was a resounding success: in its first year of lobbying (1991) it secured a \$43 million increase in federal funding for breast cancer research, followed by an additional \$300 million increase the following year (Klawiter, 2008, p. xxi). As Batt (1994, 2011) has documented, the breast cancer movement in Canada had a similarly fractured history, as the various feminist organizations, cancer charities and lobby groups that constituted the movement had different body politics, identities and strategies (around the acceptability of partnering with industry, for example).

Although the breast cancer movement in North America continued to solidify along distinct lines, three factors appear to have ensured the centrality of breast cancer to the cancer survivorship movement. First, given the high prevalence of breast cancer, it was inevitable that this population would become an important focus of the burgeoning field of cancer survivorship. However, the prevalence of breast cancer alone does not explain the profile of the disease. For example, according to Surveillance, Epidemiology and End Results (SEER) data estimates, in 2009 there were 2,747,000 U.S. women with a history of breast cancer; this figure is only marginally higher than estimates for men with a history of prostate cancer (2,500,000) and other high prevalence cancers such as colorectal cancer (1,140,000) also have a substantially lower profile. In Canada, between 2008 and 2009 the prevalence of prostate cancer was actually higher than the prevalence of breast cancer (21% versus 18.9%); at 12.5%, the prevalence of colorectal cancer was not far behind (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013).

More important than the prevalence of breast cancer was the prominence accorded to the disease, which is a second key factor in the growing convergence between discourses on cancer survivorship and breast cancer survivorship. Largely as a result of the efforts of organizations like the Susan G. Komen Foundation, beginning in the 1990s breast cancer awareness became the cause célèbre of corporate North America, with a variety of corporations sponsoring breast cancer awareness campaigns, charity events, non-profit organizations and/or adding 'pink ribbon' items to their existing product lines (Batt, 1994; King, 2006; Klawiter, 2008. Sulik, 2011). While most of the corporations sponsoring breast cancer fundraisers used it primarily as a way of enhancing their corporate images, the corporatization of the breast cancer movement dramatically increased the profile of the disease in relation to other cancers. This increase in the visibility of breast cancer was echoed by a growing body of biomedical and psychosocial research focused on the experiences, attributes and needs of the 'breast cancer survivor'.

There is no doubt that the volume of research into breast cancer survivorship can be partially explained by the comparative abundance of dedicated funding for the disease. Women with a history of cancer also became the predominant focus of research into cancer survivorship more broadly – although this trend is more noticeable in the US than in Canada. For example, in the 2003 fiscal year, 44% of studies on cancer survivorship funded by the NCI were unique to or included samples of breast cancer survivors (Rowland, 2007) and breast cancer receives far more funding from the NCI than any other cancer (King, 2006). However, I would suggest that the bias towards research into breast cancer survivorship must also be understood in terms of the new forms of 'biological citizenship'

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