

## **Breast vs. the Rest: a Response to Koczwara and Ward**

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### **Introduction**

In their commentary on my article “The breast-cancer-ization of cancer survivorship” (Bell, 2014), Koczwara and Ward make three main points. First, they argue that many of the dynamics I identify are also evident in the accounts of women with breast cancer themselves; second, they disclose additional factors that help to explain the prominence of breast cancer in the cultural and medical imaginary; finally, they provide some suggestions regarding the ways that we might move beyond the kinds of binaries I discuss in my article (between, to put it crudely, “breast and the rest”). I don't have a problem with any of these points, although in relation to the first, I think they've misunderstood my arguments a little and in relation to the third, I'm not sure their proposed solution will resolve the current polarity. But I'm getting ahead of myself. In what follows, I'd like to address these three points in a little more detail in order to clarify my own position and to elaborate on the issues Koczwara and Ward raise.

### **Point 1: women with breast cancer are victimized by the prevailing discourses on (breast) cancer too**

In their commentary, Koczwara and Ward note that: “For every patient with cancer other than breast cancer, who feels marginalised, there are patients with breast cancer who do not identify with the sanitised image of breast cancer either”. I couldn't agree more. I'm

certainly not intending to suggest that people with breast cancer are better off than people diagnosed with any other type of cancer. Women with breast cancer are just as negatively impacted by the “relentless brightsiding” (Enrenreich, 2009) of the disease as anyone else—and a number of people have written evocative and persuasive pieces on just this topic, many of which I cite in the paper. I also completely agree that ‘hierarchies of suffering’ operate amongst women *with* breast cancer as well as *between* cancers. In fact, my initial work on this concept developed out of fieldwork conducted at a support group for women with metastatic cancer, the majority of whom had breast cancer as their primary diagnosis (see Bell & Ristovski-Slijepcevic, 2011). However, in the paper I purposely chose *not* to focus on how women diagnosed with breast cancer have responded to the prevailing discourses precisely because others have discussed this topic at length. As I state in the conclusion:

The resultant cultural and biomedical model of the ‘cancer survivor’ – her attributes, her needs and her orientation to the future – has problematic effects for breast cancer ‘survivors’ themselves. However, its effects on people with other types of cancer may be equally significant, *albeit considerably less studied* (Bell, 2014, p. 63, emphasis added).

In fact, at certain points Koczwara and Ward seem to misread my arguments slightly—based, I suspect, on an occasional tendency to conflate the views expressed by participants with my own. For example, I don’t argue that “the ‘breast cancer experience’ provides ‘a lens for people diagnosed with other cancers’ which may be empowering...”. Frankly, I don’t think the image of the ‘she-ro’ (Sulik, 2011) is particularly empowering for *anyone*—or at least not for long. While the story of the ‘new and improved breast cancer survivor’ might initially be inspiring for some, too quickly it becomes coercive. As Judy Segal (2012, p. 293) wryly observes, this cancer-story

coda, with its “I’m so great” and “be like me” message, is the narrative equivalent of the proverbial ‘mean girl’.

I also don’t argue that “some aspects of [breast] cancer like mastectomy may in fact be more challenging”. This is a view that some participants subscribed to (e.g., Sarah, Suzanne, Anneke and Caitlin), but it was one I questioned, noting the ways in which “certain forms of suffering became more visible and effectively ‘trumped’ others” (Bell, 2014, p. 62). Different cancer treatments entail their own challenges. Is 63-year-old Hector, who mourns the loss of his ability to have “a real honest to good crap!” following his colon cancer treatment and resultant colostomy (see Ristovski-Slijepcevic, under review) any better off than a 55-year-old woman with a mastectomy? One procedure affects a highly stigmatized part of the body, the other a highly sexualized one. Both can be hidden, although carry a risk of exposure. Both may complicate sexual intimacies. Although I suspect these kinds of assessments of who has it ‘better’ or ‘worse’ are to a certain extent unavoidable, I agree that they can be pernicious—*especially* when they map onto prevailing discourses about ‘goodness’ and ‘badness’ and ‘worthiness’ and ‘culpability’, which are themselves invariably gendered, classed and racialized.

**Point 2: there are additional factors that explain the visibility of breast cancer**

There are undoubtedly many factors beyond those I discussed in the paper that contribute to the heightened visibility and appeal of breast cancer. As Koczwara and Ward observe, currently in the USA, breast cancer is more likely to affect those of higher socio-economic status. To this I would add that it’s also more likely to affect *white* women, who are (not incidentally) substantially more likely to *survive* it than women of color (Jemal et al., 2008). However, to be clear, for I feel there is a potential for misunderstanding my argument, I don’t think such women actually have a responsibility

to 'give back' after treatment is completed. My point was that the over-representation of women with breast cancer in research is not just due to the fact that more funding dollars are devoted to breast cancer, but also that women themselves are more willing to take part in research because of the new forms of 'rights bio-citizenship' (Rose and Novas, 2005) the breast cancer movement engendered.

Koczwara and Ward's assertion that the biology of breast cancer provided an 'accidental' boost to the efficacy of available treatments sounds plausible, along with their observation that the pharmaceutical industry focuses on investments that deliver higher yields. Lochlann Jain (2013) has recently discussed the ways in which market forces disincline private industry from working on sub-categories of cancer. As she observes, "Ironically, what makes for good science makes for poor economics; subsets shrink markets, thus reducing the chances that companies will develop more specific treatments" (p. 10). I also completely agree that the status of breast cancer is connected with the "sanitised, more palatable version of cancer that our society is comfortable to see"; Gayle Sulik (2011) addresses this at length in her recent book.

### **Point 3: Moving beyond the prevailing binaries**

I appreciate Koczwara and Ward's efforts to provide suggestions for a way out of the current polarity (something I'm notoriously bad at myself). That said, I'm not sure that the solution they have devised will resolve things. They argue that one way to deal with different cancer advocacy groups jostling for attention is "to move away from individual cancer affiliations and recognize the commonality of their goals". Isn't this what organizations like the American Cancer Society, the Canadian Cancer Society and Cancer Council Australia already aim to accomplish? But one of the dangers of this approach is that the highest prevalence cancers will have the strongest representation,

leading us right back where we started. A brief look at the American Cancer Society's currently funded projects is instructive, as breast cancer research receives the lion's share of funding (more than double any other cancer).

The approach advocated also presumes that cancer advocacy groups share core goals. However, the history of cancer advocacy casts doubt on this assumption. The splits within the North American breast cancer movement I discussed in the paper are symptomatic of the larger problem: different advocacy organizations have different agendas and interests. For example, Lung Cancer Canada arguably has more in common with the Canadian Lung Association than it does with other cancer advocacy groups, because lung conditions such as coronary obstructive pulmonary disease confront a similar, and fairly distinctive, set of issues (e.g., smoking-related stigma, physician nihilism, delays in care-seeking).

Thus, that different cancer advocacy organizations would emerge to promote particular interests and agendas is unsurprising. After all, there is no 'singular' experience of cancer; experiences are fundamentally crosscut by gender, ethnicity, sexuality, age and socio-economic status, as well as disease site and its presumed causes. A further complicating factor is that the term 'cancer' covers a variety of diseases with radically different etiologies, effects, treatments and outcomes. As Jain (2013, p. 2) notes:

Too wily to be tethered to a solid noun, the conundrums of cancer match its craftiness. Despite news articles promising a cure... scientists continue to furiously debate how cancer arises, whether it should be studied as one disease or hundreds... The word's tangibility dissolves into sheer bafflement, for doctors and patients alike, over what, exactly, it describes.

However, I do agree with Koczwara and Ward that cancer charities should strongly guard against (if they can possibly help it) the invocation of rights-based arguments to further their agendas. As I noted in the paper, rights are categorical; thus, “the invocation of the rights of one group often comes at the expense of another” (Bell, 2014, p. 61). I also agree that the term cancer ‘survivor’ causes more problems than it solves (see Bell & Ristovski-Slijepcevic, 2013) and that there needs to be a place for *other* stories about cancer(s) beyond the hegemonic breast-cancer-ized narrative. I end with a quote from Segal (2012, p. 313) who nails the central problem:

We, each of us, when we face a diagnosis of serious illness—heart disease, neurodegenerative disease, any cancer—need to get oriented to the new place in which we find ourselves. The stories we might tell of the experience, if we wish to tell a story at all, do need to be honored, even if they are—especially if they are—the ones no one really expected to hear.

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