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

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### **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 2010-2013, 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.

### **Keywords**

Canada; North America; cancer; cancer survivorship; biosociality; interviews; discourse analysis

*When I first heard that Rancie 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.*

### **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 & Everest, 2006; Kedrowski & Sarow, 2007; Kromm, Smith, & Singer, 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 & 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?

### **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 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 & 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 & 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 NBCC was one of the founding members of the NBCC (NBCC, 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 2008-2009 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 the 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' the breast cancer movement engendered amongst women diagnosed with the disease, with the rights and responsibilities of citizenship increasingly articulated in biological terms (Petryna, 2002; Rose & Novas, 2005). This led to a focus on the *rights* of breast cancer survivors to better treatment and support and more research into the causes and effects of the condition—a phenomenon Rose and Novas (2005) have terms 'rights bio-citizenship'. However, it also stimulated a sense of *responsibility* to participate in such research. The result was a large population of women with a perceived duty to participate in research and highly motivated to do so.

As a consequence of these distinct but intersecting factors, the bulk of the research conducted into cancer survivorship in North America (and elsewhere) has focused primarily on women with a history of breast cancer. Although Sulik (2011) suggests that both masculine and feminine models of cancer survivorship operate in North America – the former exemplified by Lance Armstrong and the LiveStrong Foundation and the latter by 'pink ribbon culture' – I would suggest that these models are not on equal footing. Studies purporting to discuss cancer survivorship in a broader fashion tend to rely disproportionately on women with a history of breast cancer – often without acknowledging this underlying bias. This research, in turn, has informed the creation of a burgeoning array of programs and services for the larger population of 'cancer survivors' to help them "experience, share, intervene in, and 'understand' their fate" (Rabinow, 1996, p. 244). The net result of these developments is that popular and biomedical conceptions of cancer survivorship have been influenced to an inordinate degree by *breast* cancer, such that the two appear to have become all but synonymous. As Moynihan (2002, p. 169) has observed, "Breast cancer, with all its apparent connotations, has become the exemplar of all other cancer journeys and protocols..."

Instead of treating this semiotic collapse of cancer/breast cancer as the *end* of the story (as some styles of discourse analysis are wont to do), I treat it as the *beginning*. In my view, it is essential to empirically investigate the ways that people have responded to these representations, rather than treating them simply as docile bodies constrained by hegemonic discourses (c.f. Lupton, 1997). How do people with a history of cancer engage with dominant discourses on cancer survivorship? Drawing on interviews with 32 Canadians with a history of cancer, it is this question that forms the focus of the remainder of this paper.

## **Methods**

The data I analyze in this article are drawn from a qualitative study aiming to explore the social, political and cultural context in which people who have lived through cancer make sense of the 'cancer survivor' identity and the ways in which dominant discourses on cancer mediate their experiences. Recruitment occurred through a variety of mechanisms, including: advertisements at the local cancer treatment agency, an alternative cancer treatment centre,

and a local newspaper. The facilitator of the cancer survivorship program at the provincial cancer treatment agency also distributed information about the study to clinicians and counselors handed out study advertisements at cancer support groups. Various community-based cancer support organizations also helped to distribute information about the study to their members (via newsletters, list serves, etc.). This latter mechanism was by far the most successful means of recruitment and a large minority of participants belonged to community-based support organizations.

The recruitment materials were aimed at adults over the age of 18 who had “completed primary treatment”. The study goals were very broadly framed and solicited participants interested in “taking part in a 1-2 hour interview where you will be asked questions about your everyday experiences as a cancer ‘survivor’, whether you identify with the term, and how you think society understand and treats people with a history of cancer”. Participants who expressed an interest in taking part in the study were screened for eligibility and given a consent document to read through; an interview was then scheduled. Ethics approval for the study was obtained from the University of British Columbia Behavioural Research Ethics Board.

In total, 38 participants took part in the study between 2010 and 2013, including 30 women and eight men; twenty-five participants were 45 or older. Despite considerable efforts to attract a diverse array of participants, the final study sample was relatively homogeneous. The majority of participants were working in (or retired comfortably from) professional or skilled jobs such as teaching, business and administration, although a sizeable minority (n=9) were receiving disability benefits, income assistance or were otherwise struggling financially at the time of interview. In light of the size of the local Chinese and Punjabi communities, efforts were made to recruit members of these populations: Chinese and Gurmukhi versions of the study advertisements were placed at local community centers and regional cancer treatment agencies and I employed both a Mandarin/Cantonese-speaking and a Gurmukhi-speaking research assistant to conduct interviews in participants’ native tongue. However, the majority of participants in the study were Anglo-Canadian (n=28). Moreover, although participants included people with a history of breast, ovarian, colorectal, lung, prostate, blood cancers, stomach, head and neck, cervical and testicular cancers, the most strongly represented cancer sites were ovarian cancer (n=11) and breast cancer (n=6) – this latter figure would have been substantially higher if I had opened up the study to all the breast cancer survivors who expressed an interest in taking part. The majority of those interviewed were disease-free at the time of interview, but a number (especially women diagnosed with ovarian cancer) were living with recurrent disease and six participants had metastatic cancer.

On average, interviews lasted approximately 80 minutes and all were audio-recorded and transcribed. For the first half of the study, the interviews were conducted primarily in person, but in a bid to increase recruitment I opened up the study to phone interviews; in total, 14 participants chose to be interviewed by phone. All participants received a \$25 honorarium for participating in the study. Interviews were conducted using a semi-structured interview guide which included demographic questions and prompts relating to participants’ experience with cancer diagnosis and treatment, and life post-treatment. Transcripts were subject to repeated readings to search for commonalities and differences in the ways participants spoke about life with and beyond cancer. In the process of analyzing participants’ responses, it became apparent that breast cancer was an important reference point for many participants, even though the majority had not been diagnosed with this type of cancer. In response to the question “How do you think your experience compares to that of people who have had other types of cancer?”, breast cancer was the universal comparator participants used. Moreover, comparisons with breast cancer occurred spontaneously throughout a number of the interviews

when people talked about their experience of life with and beyond cancer (n=15). The data presented in this paper stem from an analysis of the ways participants in the study who had *not* been diagnosed with breast cancer as their primary malignancy (n=32) talked about the disease.

Data analysis was informed by critical discourse analysis approaches. Although a scholarly orientation more than a discrete research ‘method’, critical discourse analyses share an interest in the relationship between discursive practices and wider social and cultural structures, relationships and processes (Locke, 2004). I searched all transcripts and summaries for references to “breast cancer” and “pink” and subjected them to a line-by-line analysis to examine: 1) the *contexts* in which breast cancer (or ‘pink’ culture) was raised and 2) the *ways* it was invoked. I was interested in both the manifest and latent content of participants’ narratives – in both what was said and what was *not* said. For these reasons, I did not extract the excerpts relating to breast cancer from each transcript and analyze them separately, but instead examined them within the context of the individual interview transcript. The themes identified were iteratively developed as the analysis progressed through constant comparison of individual transcripts and cases. All names presented in the analysis are pseudonyms.

### **Pink envy and the ‘loudness’ of breast cancer**

When asked to consider how the general public view cancer, the majority of participants drew attention to the heightened visibility of breast cancer in relation to other malignancies. For example, in response to this question, Rachel, a woman in her late 60s with metastatic colon cancer, observed:

How the general public views cancer? I really don’t know. [It] Depends how much people—how informed people are. And I think it depends what’s in the media, really. Like, I feel breast cancer gets much more popularity than, for example, rectal—that’s what I call it now, colorectal cancer—does, and colorectal cancer really could be cut down drastically if people would go for the screening.

Others talked in more general terms about the visibility of “pink ribbons”. Jacqueline, a middle-aged woman initially treated for non-Hodgkin’s lymphoma but later diagnosed with metastatic breast cancer, expanded on this view:

Oh, the only thing I can see is breast cancer all over the place with the pink ribbon stuff. I wish that more people are surviving breast cancer [sic]. It’s such a loud cancer movement that that’s the one that I think that stands out for me. I think it’s—I think it’s viewed as pink ribbons.

Several participants drew explicit links between the ‘noisiness’ of breast cancer and the resources and funding the disease had attracted. According to Terri, who was in her mid-30s and living with metastatic neck cancer at the time of her interview:

Well, I think the biggest difference between breast cancer and more rare or less common cancers is that breast cancer is very popular in the media. Like, everybody’s wearing pink, everybody’s talking about it, it’s out there, there’s support out there. People—I guess maybe if I had breast cancer—people would have been banging on my doors to help me, or, like, support me like these support groups. But there wasn’t anything for me in my community. There was no real support in that way, I had to find it online.

For William, a man in his 40s treated for testicular cancer, the visibility of breast cancer meant that there was more of a sense of urgency in dealing with the disease, something that he felt was lacking for other high prevalence cancers: “Do I feel like there’s, you know, that there’s an urgency now in dealing with some other cancers, like prostate or, you know, some of the ones

that are, you know, perhaps, you know, less, less apt to be a great fundraising vehicle? Probably not, no". William's perspective on this topic was likely informed by his position in a cancer charity, but he was not alone in his view of breast cancer as a particularly attractive fundraising vehicle. According to Ciara, a middle-aged woman treated for colon cancer, breast cancer is "the sexy cancer" – undoubtedly a reference to both its corporate 'saleability' and the fact that it affects a highly sexualized body part (see Sulik, 2011 for further discussion).

As Kedrowski and Sarow (2007, p. 11) note, "the clamor for attention by various issue proponents make the policy debate noisy. Competition is fierce for a place on any of these agendas". For a variety of reasons outlined previously (effective political organizing, alliances between cancer charities, corporations, the state and the media), breast cancer advocates were able to capture the attention of media professionals, the public and policy elites early and sustain interest over time (King, 2006; Kedrowski & Sarow, 2007). Moreover, in the competition for funding with other cancers, breast cancer advocates were highly successful in marshalling arguments in support of their disease over other malignancies. For example, in response to criticisms that breast cancer was not neglected in comparison to lung cancer, NBCC co-founder Susan Love argued that lung cancer, unlike breast cancer, is caused by an agent or event that can be controlled, regulated, or banned by the government (cigarettes); however, the causes of breast cancer are unknown and therefore require more research. The success of the breast cancer movement in invoking the 'neglect' frame can be contrasted here to the less convincing attempts of prostate cancer advocates to frame their cancer as neglected in relation to breast cancer. In the words of Kedrowski and Sarow (2007, p. 183), "given the weight of history, men's health advocates cannot argue convincingly that their needs have been neglected or overlooked in favour of women's health issues...".

Although participants expressed varying degrees of resentment towards the high profile of breast cancer that have parallels to the sorts of framing common to prostate cancer advocacy, several saw this largely as a consequence of the prevalence of breast cancer; thus Terri differentiated breast cancer from "less common or more rare cancers". Similarly, towards the end of his interview Tom noted that he did not "begrudge" the attention given to breast cancer, which was more prevalent than his own disease. Like Chelsea discussing "pink envy" on her blog (see epigraph), other participants also talked about cancer in ways that emphasized the commonalities of 'the cancer experience', which they felt superseded the differences between the individual malignancies. As Janine, a middle-aged woman treated for ovarian cancer, observed in discussing the differences between breast and ovarian cancer: "the cancer might have a different name but I think the ravages it leaves behind are similar". Similarly, in response to the question of how his experience compared with people with other types of cancer, Jack, a man in his early 40s treated for Hodgkin's lymphoma, noted:

Well, I think there's probably a lot of similarities even though they're different types of cancers. A lot of the treatments are, from what I can gather, relatively the same, right, with chemotherapy at different levels of regimes, and all the same sort of losing your hair and, you know, 'Oh my God I've got cancer!'. And people kind of react differently all across the board, but it's a relatively shared kind of process, right.

According to Gillian, also in her early 40s and treated for stomach cancer:

I think cancer journeys are actually quite similar. You know there is so many [cancers], but I think they're very, very similar. You know, the type of cancer, the type of treatment—those will vary a little bit but, I think, you know, our fears, our, our—I think, I just think, I just think we all go through the same kind of stuff.

Such participants expressed the sort of overarching biosocial identity Mullan (1985) had in mind in his initial description of cancer survivorship, with the 'cancer survivor' a distinct category of

person forged through the shared experience of diagnosis, treatment and its physical and psychosocial “ravages”.

### **“Not breast cancer” as a distinct form of biosociality**

While there was a tendency to affirm the common elements of the cancer experience in a number of participants’ accounts, this was not universally true. In fact, it became evident in some interviews that breast cancer had become a frame that participants defined their experience *against*. This occurred most consistently amongst women diagnosed with ovarian cancer, the majority of whom were recruited through an ovarian cancer support group run by an advocacy organization. For many of the women interviewed from this group (although not all, as Janine’s comments make clear), breast cancer was the referent they used when talking about their experiences of ovarian cancer.

In many cases, these contrasts were elicited when women were asked to consider how their experience compared with that of people diagnosed with other types of cancer. For example, in response to this question, Mary, a middle-aged woman, noted:

With some of the cancers, no, not all of them but let’s say breast cancer now, their cure rate is, like, unreal. They get in remission and they stay in remission. The course of ovarian cancer is not that. There are some people that do: they have treatment for very high-grade cancer and they never have a remission. The more logical, the more often thing that happens is it recurs and it recurs and it recurs... a lot of times survivorship is kind of like “I had cancer, I’ve beaten it and I’m on”. That’s not us [ovarian cancer survivors].

This tendency to set up the experience of ‘the breast cancer survivor’ in opposition to ‘the ovarian cancer survivor’ was evident in a number of accounts. Thus, in response to the same question, Margaret, another middle-aged woman, observed:

Some of it feels as if they’re [different cancers are] similar, but some of it is different, yeah. Because I feel like breast cancer has so much publicity, so much support, you know. And any time when it’s a female, when you talk about cancer, everybody assumes its breast cancer. *Everybody*. And they go “Oh yeah, the breast cancer survivor, they’re so good”, and then, you know, “I don’t have breast cancer”. And they go “Oh, okay”, you know, it’s that thing. So I feel like, yeah, the breast cancer, for the women, has a lot more support, a lot more resources and there’s a lot more compassion for them, whereas when you talk about ovarian [cancer] they go “uh-oh!”. You know, they don’t quite know what to say or what to do, right?

For Margaret, the ovarian cancer/breast cancer binary was a necessarily defensive move – a consequence of assumptions that a woman diagnosed with cancer *must* have breast cancer.

Comparisons with breast cancer also occurred when women were discussing the concept of the cancer ‘survivor’ more broadly. Participants from the ovarian cancer support group tended to dislike the concept of the cancer ‘survivor’, highlighting its lack of fit with their own experience. In these accounts it became clear that women saw the concept of ‘the survivor’ as synonymous with breast cancer. Thus, in her critique of the term, Sally, a woman in her mid-40s, pointed out that people dealing with MS weren’t considered to be survivors, so why was cancer so special? For Sally, the answer to this question lay in breast cancer and the “bloody pink ribbon” campaign. The equation between the concept of the cancer survivor and the breast cancer survivor became more strongly pronounced in an exchange with Anneke, a middle-aged woman:

I: So [do] you think different people have different ideas of survivorship?

Anneke: Yeah, I think of women with breast cancer, which is a little bit more common to be cured. You know, when they say “I’m a cancer survivor”, and, you know, their life has kind of returned and

we'd [women diagnosed with ovarian cancer] say we're survivors, you know, until it takes us out and we're not survivors.

I: Yeah.

Anneke: Yeah, it's a little bit different.

I: With ovarian cancer?

Anneke: It is, yeah, yeah.

Evident in women's accounts was the clear sense that breast cancer survivorship had set the terms for the concept of cancer survivorship more broadly, leading to a vision of life with and beyond cancer that failed to resonate with their own experiences in dealing with ovarian cancer. Indeed, this issue appeared to have motivated many of the women to participate in the study and seems to reflect the emergence of ovarian cancer as a distinct form of biosociality, albeit one defined largely in terms of its *difference* from breast cancer. That the majority of participants expressing this view belonged to a support group is likely no coincidence in light of the role that such groups appear to play in facilitating the formation of biosocial identities (cf. Rabinow 1996). Previous research has also highlighted the ways in which cancer support groups may solidify particular narratives about cancer (Mathews, 2000; Bell, 2009) and the consistency in women's accounts suggests that this phenomenon was much discussed in the group. They thus saw research as an important means of rectifying the imbalance in representations of cancer (especially the bias towards breast cancer survivors). This kind of activism has certain parallels with the prostate cancer movement, albeit without the gendered, anti-feminist politics that characterize the latter (see King, 2006; Kedrowski & Sarow, 2007).

### **Breast cancer and the 'good'/'bad' cancer binary**

Although difference from breast cancer became a way of asserting a distinct biosocial identity, for some participants it was clear such comparisons served to inhibit its formation. This was a consistent theme in the comments of people diagnosed with highly stigmatized forms of cancer.

Anna, a woman in her mid-30s, was the sole participant in the study diagnosed with cervical cancer. Early in the interview, she highlighted the stigma attached to cervical cancer as a disease associated with sexual promiscuity:

Anna: I was in a relationship when I found out [about the cancer]. Not a sexual relationship, it was non-physical intimacy. But I was in a long-term relationship with a man and when I told him that I had cervical cancer he said, "Well, that's because of all the sex you had when you were younger".

I: Oh my God!

Anna: And I was like—I'm not with him anymore, thank God—I said "You've lost it, you know". And so then I started doing research on HPV... I found out it's not just, you don't even have to have sex to be, to have, you know, cervical cancer.

Anna's comment speaks to the ways that HPV vaccination appears to be reinscribing much older associations between cervical cancer and promiscuity (see Casper & Carpenter, 2008 for further discussion); however, it was also clear that Anna felt the stigma attached her disease had lessened its worth in the eyes of the public. Thus, when asked her about cervical cancer in comparison to other cancers, Anna responded:

I feel that from my own personal experience, cervical cancer is not looked at as serious, and not worthy of research and help, because it's just cervical. But I think it's an incredibly intimate cancer, which makes it just—*just as personal as breast cancer* because it affects your sexuality, your vagina, your ovaries...

That breast cancer was the implicit referent she used when highlighting the perception of cervical cancer as less serious or worthy of research and support became evident in her invocation of the former to highlight the seriousness of the latter.

Similarities were evident in the accounts of the three participants in the study diagnosed with lung cancer. Echoing lung cancer patients interviewed in previous qualitative research (e.g., Chapple, Ziebland & McPherson, 2004), each highlighted the especially stigmatized nature of lung cancer as a seemingly self-inflicted disease. Betsy spoke at length about this topic, indicating her initial hesitation to disclose her diagnosis to others because of her fears about judgment and condemnation. In her words, “It makes me angry. It makes me sad because maybe it’s—people don’t understand. They understand breast cancer, ovarian cancer, prostate [cancer]. There’s a lot more sympathy for those cancers, and yet according to my doctor, lung cancer is the biggest in the world, but it isn’t talked about”. For Betsy, while the “stigma” connected with her cancer mobilized her to want to speak up, she noted that for many other people diagnosed with the disease, it had the opposite effect, serving to silence them. This observation is borne out by previous research, which suggests that people with lung cancer are far more likely to internalize a sense of guilt and shame for getting cancer than people diagnosed with either breast or prostate cancer (LoConte et al., 2008).

The other two participants diagnosed with lung cancer, who were also both middle-aged, pointed specifically to breast cancer as a means of silencing lung cancer. For Pete, the lack of coverage of lung cancer in the media stemmed from the fact that: “it’s all about breast cancer”. Jenny, a woman from Hong Kong who migrated to Vancouver in the 1980s, explicitly highlighted the ways in which people with lung cancer might feel less deserving in the fight for recognition of their disease *in relation to* people with breast cancer, noting that smokers didn’t want to fight for a voice alongside of people who fighting about breast cancer, because of the prevalence of breast cancer – “there’s all the breast cancer!” – and because people who smoked thought, “well, probably I’m guilty because I did smoke”.

The contrasts Jenny drew between lung cancer and breast cancer have been articulated in earlier research, with a participant in Chapple et al.’s (2004) UK-based study observing the different responses patients with symptoms of lung versus breast cancer usually engender:

The first time you go to the doctor’s with a bad cough and coughing up phlegm in the mornings the doctor will almost certainly say to you, “Do you smoke?” and once you’ve said yes, you’re sent packing with a bottle of cough medicine. If you went to the doctor’s with a small lump the size of a pea on your breast you’d be straight into the hospital but you can be coughing up phlegm for years and nobody will offer you a hospital appointment... you are just pushed to the back of the queue.

As Sulik (2011) points out, ‘pink ribbon’ culture evokes ideas of feminine purity and virtue, with breast cancer represented as “the disease of innocence” (p. 95). Clearly evident in participants’ accounts is an awareness of the ways in which breast cancer has come to exemplify the ‘good’, ‘deserving’, ‘blameless’ cancer, with lung cancer constructed as its binary opposite. Indeed, as the comments of Susan Love about the neglect of breast cancer in relation to lung cancer illustrate, it is clear that discourses on the rights of breast cancer survivors to support and funding have sometimes inadvertently strengthened these binary oppositions between ‘good’ breast cancer and ‘bad’ lung cancer. As Johnson has argued, “Because rights are categorical, they often come in contradictory pairs” (cited in Keane, 2003, p. 230). Thus, the invocation of the rights of one group often comes at the expense of another.

### **Breast cancer and hierarchies of suffering**

These sorts of comparisons with breast cancer that were so integral to participants' experiences of their disease also occasionally caused some participants to consider their own experiences as less serious or in need of attention or support. For example, in response to questioning about how her experience differed from that of people diagnosed with other types of cancer, Sarah, a middle-aged woman with leukemia, stated:

Mine has been an easy experience. I didn't need surgery, and that's huge, anybody that's had that. And any chemo that they gave me was not—not corrosive, or didn't do any damage to other parts of my body, whereas I had a friend who, she got welts all over her feet and she's still having neuropathy in her feet, and of course the people with mastectomies and so on. So a blood cancer is a gentler cancer, I guess. So that part, yeah, so anybody that I've known with cancer, if you got to have a cancer, this [lymphocytic leukemia] is an easier one.

That breast cancer was a key referent became evident in her allusion to “people with mastectomies”.

This focus on breast cancer surgery as a unique source of suffering was reiterated in the accounts of other participants diagnosed with ovarian cancer. In response to the same question, Suzanne, a woman in her early 40s, similarly highlighted the particularly difficult nature of breast cancer in comparison to her own disease:

I think they [breast cancer survivors] have actually more to deal with than I do because they have to be on hormone suppressant drugs... not to mention, you know, depending on the type of surgery. If they had a lumpectomy versus a mastectomy, they're having the same body image. You know, I might—I've lost organs that nobody can see. I've essentially been, you know, for lack of a better word, I've been castrated or spayed or whatever way you want to look at it. I don't have any female organs anymore. I think that psychological impact of those kind of, you know, female cancers with their sex characteristics is just, I have to say, it's devastating. I think with breast cancer, women, I think—at least I can kind of put it away a little bit, but they'll look at their breasts every day. So I think it's that outwardly sex characteristics, to lose those, I think, might be harder.

Despite highlighting the trauma of her own “castration” and the difficulties caused by treatment-induced menopause, for Suzanne, women with breast cancer had it “harder” because they were confronted with the visible effects of their surgery everyday in the mirror. Anneke made similar observations, noting that unlike women who had lost a breast, women treated for ovarian cancer were not “disfigured”. Similarly, Caitlin, who was in her mid-30s, characterized breast reconstruction as “such a visible, visible thing, especially for them and their partners”; she, on the other hand, had nothing physical except a small scar “that you would be able to tell that I'm, that I'm missing something inside of me”.

Although women's accounts alluded to the particular cultural significance attached to breasts as a key signifier of femininity, they also speak to the implicit “hierarchies of suffering” (Bell & Ristovski-Slijepcevic, 2011) participants developed in their valuations of their cancer experience – where certain forms of suffering became more visible and effectively ‘trumped’ others. However, not all participants ascribed to these hierarchies, and some explicitly highlighted the ways in which their own experiences had been elided. For Dolores, a woman in her early 40s with stage IV non-Hodgkin's lymphoma, the relative invisibility of her injuries in comparison to breast cancer surgery meant that her own suffering was not reduced, but merely less visible to the world. In her words, “Some people they have breast cancer, they lose their breasts at around 50. I've lost, like, you might as well have taken out, you know, so much of me, like, [you] might as well cut off an arm or a leg or something. But you can't see it, nobody sees it”.

Anna expressed a similar degree of anger about the relative invisibility of her own suffering as someone diagnosed with cervical cancer. When I asked about her views on the term ‘survivor’, she responded:

To be honest with you, I think it really only applies to women who have been through much worse than I have been through... They [society at large] don’t—they don’t think that a woman who have all the—you know, their, their outward appearance hasn’t changed—we don’t have the right to call ourselves survivors, and that pisses me off so much.

Although Anna did not explicitly refer to breast cancer in this part of the conversation, in light of her earlier comparisons between breast and cervical cancer and her reference to “women”, this appears to be the population she was primarily referring to.

## Discussion

Participants’ accounts speak to the ways in which the concept of cancer survivorship has been become, for want of a better term, ‘breast-cancer-ized’. Although many participants readily highlighted the prominence of breast cancer in popular and biomedical discourses, it is clear that these discourses also fundamentally informed their individual experience of cancer; breast cancer became a lens through which their experiences were filtered. In other words, for most participants their experience of cancer was inherently *relational*, with breast cancer the underlying norm and their own experience defined in relation to it. In semiotic terms, most malignancies thus appeared to be imbued with a kind of negative value. Negative value is the term used to express when a sign is defined by what it is *not*, rather than what it is: “What characterizes each most exactly is being whatever the others are not” (de Saussure, 1983, p. 115).

The effects of these sorts of comparisons were complex. For some participants, this experience of difference appeared to stimulate the emergence of an alternate, politicized form of biosociality focused on the need for greater recognition of the *distinctiveness* of their form of cancer from breast cancer. This was particularly evident amongst women who belonged to a local ovarian cancer support group. It was also apparent to some degree amongst the participants diagnosed with cervical and lung cancer; however, as their accounts made clear, such comparisons could also serve to inhibit the formation of a biosocial identity. Although combating stigma is often central to the formation of rights bio-citizenship (Rose & Novas, 2005), the relationship between stigma and the formation of a politicized biosocial identity is certainly not inevitable. As Kedrowski and Sarow (2007) note, reluctance to discuss a cancer diagnosis because of fears about discrimination may serve to impede political action rather than stimulate it. This may be because in the context of cancer an implicit value hierarchy of ‘good’ and ‘bad’ cancers appears to exist, with breast cancer the standard against which other cancers are measured and found wanting – especially those suspected to stem from a faulty lifestyle. In other words, comparisons with breast cancer may serve to both inhibit and facilitate the formation of a distinctive biosocial identity.

Interestingly, these hierarchies seemed to extend beyond the individual malignancies themselves to the forms of suffering they generated. Noteworthy was the existence of a tacit hierarchy of suffering in some participants’ accounts in which certain types of experience unique to breast cancer (e.g., mastectomy), became far more visible – both literally and figuratively – sources of suffering than experiences like the removal of internal organs, or repeated bouts of chemotherapy in the context of chronic disease. However, it is clear that these hierarchies of suffering were not just internally driven; instead, they seemed to reflect broader cultural valuations of the legitimacy of different forms of suffering. These accounts suggest that the specter of the “she-ro” – the heroic, generic breast cancer survivor (Sulik, 2011) – may haunt *all*

those diagnosed with cancer, not just women diagnosed with breast cancer.

Obviously there is the need for the usual caveats about the importance of further research to people's experiences of life with and beyond cancer as the findings are unlikely to be representative of this population as a whole, especially given that the majority of study participants were white, middle-class women. However, it is worth noting that many of the arguments presented in this paper have implications for the ability of qualitative health researchers to conduct research into people's experiences of life with and beyond cancer. If, as I have argued here, a desire to participate in research is partially determined by the extent to which the target populations have taken on a politicized, biosocial identity in relation to (breast) cancer, it is inevitable that the resultant research will primarily attract people who conceptualize their experience in such terms. This makes it very difficult to move beyond the populations already extensively researched, namely breast cancer survivors, or, more specifically, white, middle-class ones.

### **Conclusion**

In this article, I have argued that the concept of cancer survivorship has become inextricably entangled with breast cancer survivorship. In some respects, this is an accident of history. Although the breast cancer movement emerged independently of the cancer survivorship movement, the influence of the former (or various segments of it) enabled breast cancer to become the cause célèbre of corporate North America, resulting in an extraordinary degree of cultural visibility for 'pink ribbon culture' (Sulik, 2011). The subsequent willingness of white, middle-class women with a history of breast cancer to participate in research as part of their perceived duties as 'good' biological citizens also led to a proliferation of research into the experience of breast cancer survivorship. This research, in turn, was taken as emblematic of the experience of cancer survivorship more broadly. 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 (Sinding & Gray, 2005; King, 2006; Kaiser, 2008; Segal, 2008, 2012; Sulik, 2011). However, its effects on people with other types of cancer may be equally significant, albeit considerably less studied.

Study participants were well aware of the prominence – and dominance – of breast cancer in the popular and biomedical imaginary. However, their accounts suggested that breast cancer was equally central to their *own* experiences of cancer, providing an important lens through which to understand the effects of the disease. The consequences of this 'breast-cancer-ization' 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. Although further research is clearly needed, in my view, fellow health researchers conducting research on cancer in North America need to be more cognizant of the potential effects of this phenomenon on both people's experience of cancer survivorship and their willingness to take part in research on this topic.

### **Acknowledgements**

This study was funded by an operating grant from the Social Sciences and Humanities Research Council titled "Between Life and Death: the Contradictions of Cancer Survivorship". The arguments presented in this paper were influenced by discussions that occurred at the 'Cancer Cultures' conference held at University College London in November 2012 and I have also benefited from conversations with Svetlana Ristovski-Slijepcevic and Maggie Woo, who helped conduct the interviews drawn on in this paper. Svetlana also provided helpful feedback on an earlier draft of this paper. I would also like to acknowledge the invaluable assistance provided by Tracy Kolwich and Angela Bedard in helping to recruit study participants.

## References

- Bell, K. (2009). 'If it almost kills you that means it's working': Cultural models of chemotherapy expressed in a cancer support group. *Social Science & Medicine*, 68(1), 169-176.
- Bell, K. (2012). Remaking the self: Trauma, teachable moments and the biopolitics of cancer survivorship. *Culture, Medicine & Psychiatry*, 36(4), 584-600.
- Bell, K. & Ristovski-Slijepcevic, S. (2011). Metastatic cancer and mothering: Being a mother in the face of a contracted future. *Medical Anthropology*, 30(6), 629-649.
- Bell, K. & Ristovski-Slijepcevic, S. (2013). Cancer survivorship: Why labels matter. *Journal of Clinical Oncology*, 31(4), 409-411.
- Aziz, N.M. (2007). Cancer survivorship research: State of knowledge, challenges and opportunities. *Acta Oncologica*, 46, 417-432.
- Batt, S. (1994). *Patient no more: the politics of breast cancer*. Charlottetown, Canada: Gynergy Books.
- Batt, S. (2011). Messages of hope: Cancer optimism in three times. Paper presented at *Critically Interrogating Cancer Survivorship: Social Science and Humanities Perspectives Workshop*, Vancouver, Canada.
- Canadian Cancer Society's Advisory Committee on Cancer Statistics (2013) *Canadian cancer statistics 2013*. Toronto, Canada: Canadian Cancer Society.
- Casper, M.J., & Carpenter, L.M. (2008). Sex, drugs, and politics: the HPV vaccine for cervical cancer. *Sociology of Health & Illness*, 30(6), 886-899.
- Chapple, A., Ziebland, S., & McPherson, A. (2004). Stigma, shame, and blame experienced by patients with lung cancer: qualitative study. *British Medical Journal*, doi:10.1136/bmj.381111.639734.7C
- Chelsea (2011). Pink envy. *Adventures with my enemy Melanoma*.  
<http://adventurewithmelanoma.blogspot.ca/2011/10/pink-envy.html> (accessed 05.11.13)
- Clarke, J.N., & Everest, M.M. (2006). Cancer in the mass print media: Fear, uncertainty and the medical model. *Social Science & Medicine*, 62, 2591-2600.
- Ehrenreich, B. (2001). Welcome to Cancerland. *Harper's Magazine*, November, 43-53.
- Gibbon, S. & Novas, C. (2008). *Biosocialities, genetics and the social sciences: Making biologies and identities*. London: Routledge.
- Jain, L.S. (2007). Cancer butch. *Cultural Anthropology*, 22(4), 501-538.
- Keane, H. (2003). Critiques of harm reduction, morality and the promise of human rights. *International Journal of Drug Policy*, 14, 227-232.
- Kaiser, K. (2008). The meaning of the survivor identity for women with breast cancer. *Social Science and Medicine*, 67, 79-87.
- Kedrowski, K.M., & Sarow, M.S. (2007) *Cancer activism: Gender, media, and public policy*. Chicago, IL: University of Illinois Press.
- King, S. (2006). *Pink ribbons, inc.: Breast cancer and the politics of philanthropy*. Minneapolis, MN: University of Minnesota Press.
- Klawiter, M. (2008). *The biopolitics of breast cancer: Changing cultures of disease and activism*. Minneapolis, MN: University of Minnesota Press.
- Kromm, E.E., Smith, K.C., & Singer, R.F. (2007). Survivors on cancer: the portrayal of survivors in print news. *Journal of Cancer Survivorship*, 1(4), 298-305.
- LinnieGayl (2011). Think pink, but don't forget the other colors. *AAR After Hours*.  
<http://www.likesbooks.com/aarafterhours/?p=3969> (accessed 05.11.13)
- Little, M., Paul, K., Jordens, K.F.C., & Sayers, E-J. (2002). Survivorship and discourses of identity. *Psycho-Oncology*, 11, 170-178.

- LoConte, N.K., Else-Quest, N.M., Eickhoff, E., Hyde, H., & Schiller, J.H. (2008). Assessment of guilt and shame in patients with non–small-cell lung cancer compared with patients with breast and prostate cancer. *Clinical Lung Cancer*, 9(3), 171-178.
- Locke, T. (2004). *Critical discourse analysis*. London: Continuum International.
- López, E.D.S., Eng, E., Randall-David, E., & Robinson, N. (2005). Quality-of-life concerns of African American breast cancer survivors within rural North Carolina: Blending the techniques of photovoice and grounded theory. *Qualitative Health Research*, 51(1), 99-115.
- Lupton, D. (1997). Foucault and the medicalisation critique. In A. Petersen & R. Bunton (Eds.), *Foucault, Health and Medicine* (pp. 94-110). London: Routledge.
- Mathews, H.F. (2000). Negotiating cultural consensus in a breast cancer self-help group. *Medical Anthropology Quarterly*, 14(3), 394-413.
- Moynihán, C. (2002). Men, women, gender and cancer. *European Journal of Cancer Care*, 11, 166-172.
- Mullan, F. (1985). Seasons of survival: Reflections of a physician with cancer. *New England Journal of Medicine*, 313(4), 270-273.
- NCCS (2013). Timeline of achievements. *National Coalition for Cancer Survivorship*. <http://www.canceradvocacy.org/about-us/what-weve-done/> (accessed 05.05.13).
- Petryna, A. (2003). *Life exposed: Biological citizens after Chernobyl*. Princeton, NJ: Princeton University Press.
- Rabinow, P. (1996). *Essays on the anthropology of reason*. Princeton, NJ: Princeton University Press.
- Rose, N. (2007) *The politics of life itself: Biomedicine, power, and subjectivity in the twenty-first century*. Princeton, NJ: Princeton University Press.
- Rose, N., & Novas, C. (2005). Biological citizenship. In A. Ong & S.J. Collier (Eds.), *Global assemblages: Technology, politics, and ethics as anthropological problems* (pp. 439-463). Malden, MA: Blackwell Publishing.
- Rowland, J.H. (2007). Survivorship research: Past, present, and future. In P.A. Ganz (Ed.), *Cancer survivorship: Today and tomorrow* (pp. 28-42). New York: Springer.
- de Saussure, F. (1983). *Course in general linguistics*. Chicago: Open Court Publishing.
- Seale, C. (2001). Sporting cancer: Struggle language in news reports of people with cancer. *Sociology of Health and Illness*, 23(3), 308–329.
- Seale, C. (2002). Cancer heroics: a study of news reports with particular reference to gender. *Sociology*, 36(1), 107-126.
- Segal, J.Z. (2007). Breast cancer narratives as public rhetoric: genre itself and the maintenance of ignorance. *Linguistics & the Human Sciences*, 3(1), 3-23.
- Segal, J.Z. (2012). Cancer experience and its narration: an accidental study. *Literature & Medicine*, 30(2), 292-318.
- Sinding, C., & Gray, R. (2005). Active aging—spunky survivorship? Discourses and experiences of the years beyond breast cancer. *Journal of Aging Studies*, 19, 147-161.
- Stacey, J. (1997). *Teratologies: a cultural study of cancer*. London, UK: Routledge.
- Sulik, G.A. (2011). *Pink ribbon blues: How breast cancer culture undermines women's health*. Oxford: Oxford University Press.