

# The problem of standardized breast cancer narratives

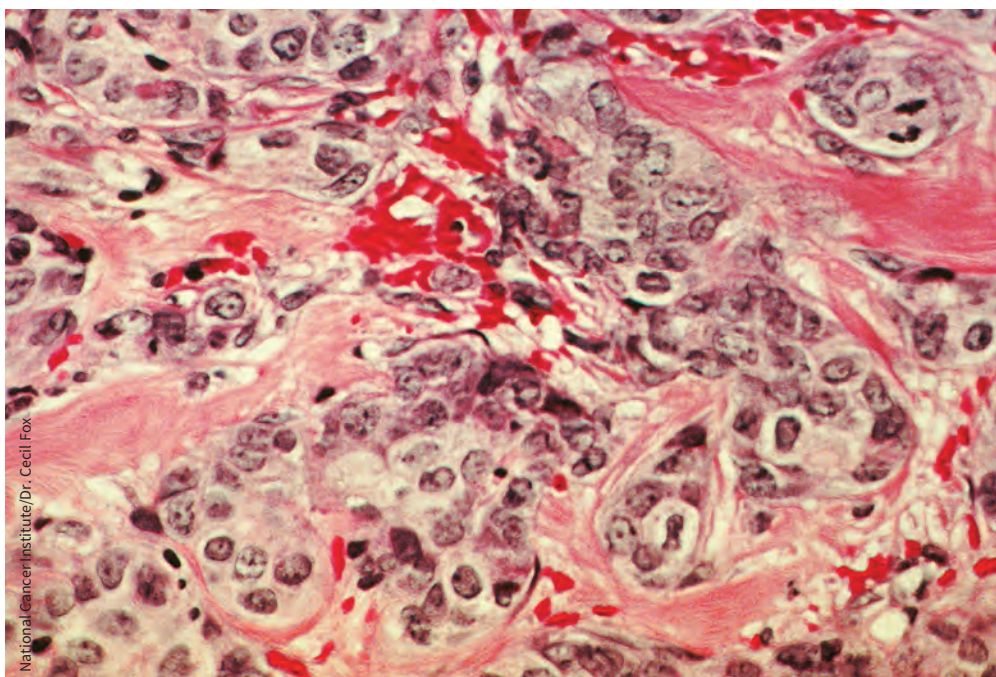
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The American Cancer Society’s “Tell Your Story” campaign solicits a particular type of cancer narrative when asking for “inspirational stories” to provide “hope” or “comfort and courage” for the many people whose lives are “touched” by cancer. It is a version of “the standard story of breast cancer,” which dominates public discourse of the disease.<sup>1</sup> There are, however, reasons to resist calls for hope and courage, if only because a diagnosis of breast cancer is fraught with the conflicting emotions of anxiety, anger and sadness.<sup>2</sup>

Notably, social critic Barbara Ehrenreich first publicly resisted the standard story of breast cancer when she wrote “Welcome to Cancerland,” a personal account published in *Harper’s Magazine*.<sup>3</sup> She questions the publicly acceptable feelings a patient with cancer can express, observing that “so pervasive is the perkiness of the breast-cancer world that unhappiness requires a kind of apology.” But cancer is not an intrinsically ennobling disease, and Ehrenreich describes how a cancer diagnosis did not make her more courageous or hopeful; instead, it only made her more “deeply angry.”

When the American Cancer Society asks on its website for “inspirational” cancer stories, what should be understood is that uplifting narratives with a happy ending are very welcome. Yet in making space only for cancer narratives with positive outcomes, other types of stories are effectively silenced. Unfortunately, not every person who receives a breast cancer diagnosis will experience successful treatment and recovery. *Canadian Cancer Statistics 2017* reports that 1 in 8 Canadian women is expected to develop breast



cancer within her lifetime and 1 in 31 is expected to die from the disease. In 2017, an estimated 26 300 new cases of breast cancer were diagnosed in Canada, with a projected mortality of 5000 deaths.<sup>4</sup>

Given that breast cancer narratives are too often standardized in such a way that they obscure pain and suffering, some critics have argued that these stories can do little more than contribute to “agnotology,” or “the cultural production of ignorance.”<sup>1</sup> Some critics would go so far as to suggest that personal stories of breast cancer should be limited, perhaps even prohibited, in the public discussion of the disease.

I do not share this perspective. In highlighting the work that breast cancer narratives can do — for those writing them and those reading them — it becomes

evident that restrictive cultural politics engender standardized stories, while personal narratives always have the potential to be both deeply emotive and well informed. Narrative, in providing the very opposite of scant description where experiential knowledge is concerned, can provide a window into the complex, often painful and distressing world of patient experience. What I’d like to call for then is a steadfast reflection on the types of narratives upheld as good examples of patient experience. I’m not alone in calling for this type of reconsideration, as prominent scholars in medical humanities have debated the various uses and abuses of the narrative turn.

For example, Angela Woods aims to reignite the debate on the role of narrative within the medical humanities.<sup>5</sup>

Although narrative is granted a privileged place within mainstream medical humanities scholarship, Woods identifies 7 narrative tropes left too often unexamined, including the common assumption that all people are somehow “naturally narrative.” Said another way: we all have a story we can tell. Taken as a whole, Woods’ provocation is not a call to “do away with narrative,” but for a more critical engagement with how narrative is used within humanities approaches to medicine and health care. Rather than position herself “against narrative,” Woods argues against standardized stories, as well as standardized branches of scholarship, too often valorized by biomedicine in search of common truths about patient experience.

Delese Wear and Julie M. Aultman caution that not all medical students are intrinsically willing to engage with narrative and especially with stories by those deemed “unruly subjects.”<sup>6</sup> For medical students with the kinds of unearned privilege that intersectional analysis might easily reveal, disruptive narratives of illness can fundamentally challenge assumptions of who patients are and how they should properly act. Wear and Aultman stress that in some instances, personal narratives of illness do not always impart the kinds of lessons in empathy and compassion that a medical humanities education might intend.

Therefore, these authors point to the need to resist focusing only on personal experiences as represented in narrative form and to discuss instead how inequality can be symptomatic of structural forces rather than individual choices. With this perspective in mind, a medical humanities education can highlight how clinical medicine functions through discourses, practices and narratives. It has the potential to produce certain kinds of patients through the institution of biomedicine.

Still, illness narratives are taught in a medical education context in part because of the powerful affective dimensions of patient experience these stories can con-

vey. In fact, narrative is taught because it is deemed to function unlike any other type of teaching tool. Although the teaching and study of illness narratives is not a simple shortcut to empathy, personal stories do have the capacity to reach even the most resistant reader. But how?

For me, what makes a disruptive narrative of breast cancer compelling is that these stories question the norms circulating through breast cancer culture and even dare to talk back to institutions such as biomedicine. In my research, I have focused on the limitations of standardized narratives, but I can attest that for some patients, such stories are meaningful. However, as Stella Bolaki says, the ongoing discussion about the limits of narrative can be understood as divisive, even negative, even when it provides “new energy and impetus for conversation.”<sup>7</sup> Such a discussion illustrates that although certain stories may prove difficult to engage with, they serve a critical role in illuminating issues that transcend the standardized narration of the self as patient.

Illness narratives do not always function to solidify knowledge in the ways they might in biomedicine. In fact, patients often remark on how misleading disease descriptions are, not because they are incorrect, but because they are woefully incomplete. Narrative then is embraced in a medical humanities context with the hope it might provide a remedy. But as Ann Jurecic emphasizes, published personal accounts of illness present a particular challenge to criticism. Literary scholars too often display outright disdain and decide in advance that autobiographical writing on illness fails both as testimony and as literature.<sup>8</sup> She rightly argues that “a suspicious critical position is not necessarily wrong, but it is incomplete.”

How then should we evaluate, study and teach narratives of illness, breast cancer in particular?

It is my contention that disruptive breast cancer narratives explicitly offer

experiential insights into breast cancer as a disease and a culture from patients who are affected by but not necessarily equipped with biomedical knowledge. But the “disruptive” aspects of these stories can surface only if the multiple ways of telling a breast cancer narrative are encouraged in public discourse rather than shut down. Disruptive narratives on breast cancer are formed in relation with and in response to standardized storytelling about cancer; still, disruptive breast cancer narratives are heterogeneous in perspective, theme and tone. Contained within disruptive narratives on breast cancer are questions of how to perform patienthood and survivorship. In fact, these disruptive narratives test the limits of narrative and the ways in which emotion, gender and sexuality in relation to breast cancer diagnosis and treatment all become necessarily complicated, relational and questioning.

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