WHAT IS A STORY OF BREAST CANCER?

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ABSTRACT: This paper explores questions of the permissible and the impermissible in breast cancer narratives. It deploys (inter alia) a theory of discourse and counterdiscourse to argue that the genre itself of the personal narrative performs a regulatory function in public discourse on cancer. The paper is inspired by an idea introduced into science studies by Schiebinger and Proctor—the idea of agnotology: the cultural production of ignorance. The paper argues that ignorance about cancer is maintained, in part, by the rehearsal of stories that have standard plots and features, and that suppress or displace other stories. The paper turns on examples of both conventional and unconventional stories. It focuses on Barbara Ehrenreich’s renegade cancer story and its public reception, and Wendy Mesley’s renegade cancer documentary and the public reception of that. The paper seeks to contribute to genre studies by analyzing instances of a genre of public discourse, and suggesting the nature of the social action performed by the genre itself.

KEYWORDS: genre, breast cancer, narrative, ignorance

In a widely posted call for proposals, leading to a conference at Stanford University, October 2005, historians of science Robert Proctor and Londa Schiebinger introduced into interdisciplinary science studies a new theoretical perspective and methodology: agnotology, the cultural production of ignorance. Proctor and Schiebinger’s idea was that we deploy resources of research and scholarship to investigate how we know what we know—but we don’t marshal the same resources to investigate how, and why, we don’t know what we don’t know. Proctor and Schiebinger invited scholars to “explore how ignorance is produced or maintained in diverse settings through . . . media neglect, corporate or governmental secrecy and suppression . . . and [other forms] of inherent or avoidable culturopolitical selectivity, inattention, and forgetfulness.”

With the invention of agnotology, Proctor and Schiebinger supplied a conceptual frame for questions I had long had about illness narratives in general, and breast cancer narratives in particular: What is the public function of breast cancer narratives? And what are the warrants for resisting, as I do, the narrative that has emerged as the standard story of the breast cancer “survivor”? This is my agnotology thesis: Personal breast cancer stories are one means of producing and maintaining ignorance about breast cancer. They do this, in part, generically. Stories typically, for example, begin at the moment of the discovery of a lump in the breast—arguing by the narrative arc itself that the cancer story begins with the appearance of unwanted tissue in an individual body. They are, conventionally, as G. Thomas Couser has noted, comedies: they have happy endings—if only because the narrator lives to tell her story. (This is the closing of a cancer narrative published recently in a magazine dedicated to “survivors”: “Cancer inspires me. I’ve been given a wake-up call that many people will never receive. I have been reminded that life is never a guarantee, and with that knowledge, I am happy to simply be alive” [DONALDSON, 2007, p.26].) They share a coda, and that coda, as Diane Price Herndl notes, is, “Be like me” (HERNDL, 2006, p. 232). Nearly thirty years after Susan

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1 In the United States, in 2005, over 270,000 women were diagnosed with breast cancer. That year, in the United States, over 40,000 women and 460 men died of the disease. While men do get breast cancer, we know that breast cancer is, in the first instance, a disease of women, more fraught, in fact, because of its femininity. With all due respect to men with breast cancer, I will talk about breast cancer as a women’s disease and breast cancer stories as women’s stories. The Canadian Cancer Society reports that, in Canada, less than 1% of breast cancers are in men (www.cancer.ca).
Sontag impugned the military metaphors in which cancer is publicly narrated, battle has become so entrenched as a description for the experience of cancer, it seems natural, not a metaphor at all. In a recent news story about a three year old who died of leukemia, the child is described as a “true fighter who never gave in to her disease or wavered from her determination” (SALINAS, 2006, p. S2). The description deposits on the child the anxieties of adults in the grip of a metaphor they’ve forgotten is a metaphor, betraying everyone’s lack of narrative imagination.

The standard breast cancer story does not emerge in a vacuum and it is not innocent. We know that people don’t fashion their narratives out of just the events of their lives; the narratives are structured using the narrative knowledge of a culture (see also POTTS, 2001). Then, because of the willingness of people to tell certain kinds of stories and receive them and repeat them and even ironize them, these stories suppress other stories. We know this is true, because once in a while we hear the sound of a renegade story failing.

I offer this thesis reluctantly. When breast cancer narratives first began to appear, they provided a much-needed counterdiscourse to the sort of thin, surgical, biomedical discourse that was available for the disease. Betty Rollin’s First You Cry, published in 1977, is still advertised as “the inspiring, true story about how one woman transformed the most terrifying ordeal of her life into a new beginning”; the book was one means of installing breast cancer, and the person with breast cancer, into public life. Three years later, feminist activist and poet Audre Lorde published her Cancer Journals, offering a deeply personal and at the same time political view of breast cancer. Lorde wrote, she said, “to break [the] silence and bridge some of the differences between us, for it is not difference which immobilizes us, but silence. And there are so many silences to be broken” (LORDE, 1980, p. 22). So I should explain how I came to believe that, thirty years on, breast cancer narratives themselves require a counterdiscourse (see also PEZZULLO, 2003): they have become repetitive, prescriptive, and coercive; certainly, they have been coopted–by business and industry in general, and by pharmaceutical companies in particular, who, for example, advertise anti-cancer drugs directly to consumers, using the very terms of the narrative itself: “The opponent, breast cancer recurrence. In defense, Arimidex” (ARIMIDEX ad, 2006, p. 17; see also GENENTCH ad, 2006, below).

In 2003, I wrote a book chapter called, “The Epideictic Rhetoric of Pathography” (SEGAL, 2005). In it, I suggested that illness narratives constitute what Aristotle called an epideictic rhetoric: a rhetoric of praise and blame. Illness narrative literature, I argued, not only documents and catalogues illness experience; it also reflects and reinscribes a hierarchy of values for such experience: humour is good; despair is bad; surviving is noble; dying, by implication, isn’t. And so on. In doing this values work, pathographical accounts sponsor a situation in which some illness stories are more familiar than others, more welcome, more permissible–and, finally, more speakable. One of the cases I used to illustrate my point was the (by now better known) case of Barbara Ehrenreich.

Barbara Ehrenreich was diagnosed with breast cancer in the late 1990’s, and she wrote about her experience in an essay called, “Welcome to Cancerland,” published in Harper’s Magazine in 2001. In “Welcome to Cancerland,” Ehrenreich describes her cancer diagnosis and treatment, as well as her anger, her despair, and her research. She also writes about sharing her cancer story online with other women with breast cancer—and, importantly, about how her online postings were received. The breast cancer story Ehrenreich had posted was not cheerful at all; she had shared a list of “heartfelt complaints about debilitating treatments, recalcitrant insurance companies, environmental carcinogens, and . . . ‘sappy pink ribbons’” (2001, p. 50). And she had called for a political response to breast cancer, one that takes up, for example, the
problem that the very industries that produce environmental carcinogens make profits at the other end with breast cancer diagnostics and treatments.²

Ehrenreich reports in “Welcome to Cancerland” that her online posts were met with a “chorus of rebukes.” Those who didn’t rebuke her, she says, pitied her. One respondent advised her to “run, not walk, to some counseling.” Another respondent wrote, “I really dislike saying you have a bad attitude towards all of this, but you do, and it’s not going to help you in the least” (quoted in EHRENREICH, 2001, p. 50).

The breast cancer story Ehrenreich told failed by refusing to be the standard story; she didn’t say what she was expected to say, and what she did say could not be tolerated. Ehrenreich’s Harper’s article, written some time later, was her opportunity to reflect, for a wider public, on her experience with both cancer and cancer online support groups. But the Harper’s article was also met with a chorus of rebukes. Several readers sent letters to the editor, and most of them berated Ehrenreich for her attitude. From one letter: “There is life after breast cancer, and there is nothing shallow about wanting life” (YANDLE, 2002, p. 4).

My concern, when I elaborated the Ehrenreich example four years ago was that a standard breast cancer story had already emerged. And I suspected that the story by its replication represented a kind of narrative regulation. My thinking about breast cancer narratives, and my collection of them since, has led me to wonder about the public appetite for homogeneous breast cancer narratives—the story told and retold, now about Melissa Etheridge, now about Sheryl Crow . . . now about Marsha Hunt (the mother of Mick Jagger’s first child), who writes, “Cancer’s been a wonderful experience for me. . . . One of the best experiences I’ve had” (quoted in LIPPMAN, 2006, p. D16). That is, since I first wrote about Ehrenreich, my attention has turned to the public function of breast cancer narratives, the reception of dissonant narratives—and what has become now an agnotology claim.

This is what the standard story looks like, this abbreviated version of it from the front page of a recent issue of a free Vancouver newspaper: “For Sharon Moyer, dealing with breast cancer is all about making choices . . . When she was diagnosed last December, she began learning as much as she could about the disease . . . . Her philosophy includes using humour to keep a positive attitude . . . . Her goal was to put a smile on the face of every person in the [cancer] ward. Luckily, her partner Geoff shares her sense of humour. [Cancer] has been a learning process for him too” (FERRIE, 2006, p. 1). The standard story, of personal struggle and personal victory—and personal responsibility—is not only a story in itself; it is also a trope in another story, a story of progress. It is being used currently on the back cover of Harper’s, to promote the interests of a pharmaceutical company. From the ad (which is in the form of handwritten letter): “Several years ago my husband died in a car accident. Our daughter, Julia, was then only three years old . . . . A year and a half later I was diagnosed with a very aggressive form of cancer. After some research, I entered a clinical trial using one of Genetech’s therapies . . . . Now I feel like one of the lucky ones. Thank you, Genetech” (GENENTECH, 2006).

In fact, I have been an accidental participant in my own research. About a year and a half ago, I was taping a local radio phone-in show on the topic of breast cancer. When the talk

² On the very day of submission of this essay (28 April 2007), the Globe and Mail reported the finding that good exposure to sunlight is responsible for lower cancer rates in certain parts of the world. That is, the reason cancer rates are higher in northern countries is not the presence of more environmental carcinogens in the north, but rather the relative absence of sunshine. Cancer is, in part, a Vitamin D deficiency condition. It will be interesting to see what sorts of public claims follow this finding. The news has little bearing on my thesis about breast cancer narratives (although most such narratives encourage feelings of personal responsibility, and I am personally already feeling guilty for not taking Vitamin D supplements – and for staying out of the sun, as the dermatologists advised).
turned to reports that some women had “beaten the disease” because they’d focused on their children, whom they steadfastly refused to leave behind . . . I couldn’t stand it any more. I didn’t phone in, but I emailed the host to say that I objected to the implication of this line of reasoning that women who had died of breast cancer hadn’t loved their children enough to save their own lives. The host emailed me back in a commercial break. “I wish you had phoned the show,” she said. “Then we might have helped you have a better attitude.”

In March of 2006, the Canadian Broadcasting Corporation aired a television documentary by journalist Wendy Mesley, called, Chasing the Cancer Answer. The documentary told a story rooted in Mesley’s own experience with breast cancer, but it was, in the first instance, a commentary on what we know and don’t know about the causes of cancer. Mesley maintained that the “eat your vegetables, get your exercise, and have your mammograms” approach to cancer, focused as it is on protection in individual cases, dwarfs another approach to cancer, focused on community prevention, a story in which we are, all of us, containers for environmental carcinogens. Campaigns “for the cure,” Mesley said, distract us from campaigns “against the cause.” What’s interesting about Mesley’s report is not only what it argued but, again, how it was received. The documentary was described in Canada’s national newspaper, by columnist Margaret Wente, as “stunningly simplistic,” “full of misleading information and fear-mongering.”

In fact, Margaret Wente accused Wendy Mesley of a kind of “drive-by” journalism in part because Mesley embarrassed the CEO of the Canadian Cancer Society by asking her directly why more pressure has not been put on manufacturers to keep known carcinogens out of household products or to keep those products off of store shelves. (“I can’t answer that question” was the response.) But Mesley offended the cancer establishment not only because she asked an unprepared administrator an apparently unfriendly question, but also because she had, generically, the wrong kind of story to tell: In the 1970’s, we rejected the cancer story in which the ill person was the patient, at the mercy of her physicians who rewrote her story in the language of biomedicine and told it for her. We trained ourselves to require a story in which the person with cancer is instead an agent: a well-informed, responsible, embattled, “survivor.” In Mesley’s story, though, Mesley herself isn’t patient or agent: she is instead the scene on which an ambient cancer has played itself out (see the pentad in BURKE, 1969).

As I’ve been suggesting, the available structures for storying illness can act to make and keep us ignorant about cancer. The conventions features of the personal narrative are so well-established that even those authors who try to write against the standard story often, in the end, just write it again. I want to illustrate this point by turning briefly to a pair of recent books that strain at the genre of pathography. They are breast cancer graphic memoirs (in the tradition of Art Spiegelman’s graphic novel about the Holocaust, Maus), and both display the sort of story/structure paradox you would expect to find in (what have been called) “trauma comics.”

Miriam Engelberg’s Cancer Made Me a Shallower Person seems at first to defy the conventions of breast cancer narratives: it’s funny and irreverent and self-deprecating. But examined closely, Engelberg’s book reveals many of the features of the standard breast cancer story. The memoir (which begins with a mammogram showing calcification) is entirely self-centered, for one thing–no other character really enters the picture at all–and it’s self-congratulatory to this extent: it can’t help but praise itself for its own sense of humour, for humour is claimed in memoir as a moral choice. The book turns out to be prescriptive too, only it’s prescriptive for an audience that has become ironic about breast cancer narratives. In one frame, the narrator calls to mind, comically, the figure of the noble person with cancer. Breast cancer patient Jenny says, “Now I enjoy each precious minute of life - It’s been a gift”; Brain tumor patient Bob says, “Despite intense pain, I’m determined more than ever to continue by activist work” (ENGELBERG, 2006, p. 2). Engelberg wants to deny that cancer demands
nobility (her book, after all, is called, “Cancer Made Me a Shallower Person”), but the momentum of the standard story is too great; the field for interpretation, too fixed. Finally, she writes a “be like me” story too, only the triumph she claims is the refusal to be swept away in the rhetoric of triumphalism. (In the end, her book is marketed as the memoir of a courageous person who never loses her sense of humour.)

Cancer Vixen by Marisa Marchetto has commanded more critical attention, because this is the Sex and the City of cancer narratives, and Monolos feature importantly. But, despite the genre-breaking claims made by reviews of the book (Glamour Magazine says, “This is not an expected woe-is-me tale”), Cancer Vixen is utterly conventional in the story it tells. It starts with diagnosis, proceeds through treatment, and ends tentatively, with the threat of recurrence. In one of the closing frames, the hooded figure of “death” says, if cancer recurs, “You’re in for the fight of your life.” Our heroine responds, “Ditto” (MARCHETTO, 2006, p. 208). This is another story of individual struggle, except that, because Marchetto is employed, talented, wealthy, beautiful, thin, and engaged to be married to the love of her life, the struggle has more high points than might be typical. The story itself poses no serious question that a doctor who knew a lot about treatment options and prognoses couldn’t answer best.

Which brings me to my conclusion. What are the questions about breast cancer to which personal narratives are the answers? The obvious question they answer is, “What is it like to have breast cancer?” But the narratives, cumulatively, constitute an answer to different question: “How shall one be ill?” This is an enormously important question in a culture (a North American culture with an aging population)—and at a time—in which so many people live with ongoing conditions (in what sociologist Arthur Frank called, “the remission society” [Frank, 1995, p. 8]): many of us don’t just get sick and get well again and are done. The trouble is that serious engagement with the question has been preempted by the fact it seems already to have been answered. A review of Marchetto’s book for the Breast Cancer Research Foundation “salute[s] women like [Marchetto] who not only have the courage to battle breast cancer, but are able to do it with . . . unflagging optimism, creativity, and humour.

That, I think, is a disappointing answer to the question of how we should be ill. We ought, in any case, to be asking more and different questions. Why is the number of cases of breast cancer increasing? What are the risks and benefits of cancer screening? What are the relations among carcinogen-producing industries, pharmaceutical marketing, and the network of cancer support groups? As long as the personal narrative dominates public discourse on breast cancer, those questions will be suppressed, even silenced, and a degree of ignorance will be maintained.

References

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